

**LIVED EXPERIENCES OF MALTESE PARENTS
OF YOUNG CHILDREN BORN WITH
BIOLOGICAL RISKS
FOR
INTELLECTUAL DISABILITY**

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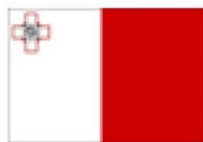
I, Elayne Azzopardi, hereby declare that this work is solely the product of my own research.

Signed

Date.....



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Dedication

I would like to dedicate this work to my husband, Ernest Anthony. Thank you for everything.

Lived Experiences of Maltese Parents of Young Children Born with Biological Risks for Intellectual Disability

Abstract

Parents of children born with risks for intellectual disability (ID) report emotional upheaval and greater support needs compared to those raising a typically developing child. Exploring these parents' needs and experiences is critical for the provision of early intervention and/or paediatric services that benefit the whole family. Consequently, this study aimed to explore the experiences and needs of Maltese parents of young children born with biological risks for ID, during the first five years of life. It adopted a cross-sectional qualitative design, using Interpretative Phenomenological Analysis (Smith et al., 2009). Four groups of parents, (N=37) depending on their children's age (0;6, 2;0, 3;6 and 5;0 years) were interviewed using a semi-structured interview guide. Six super-ordinate themes were identified: 'experiencing is true understanding', 'family functioning', 'info-emotional cycle', 'micro-system sociological framework', 'service-needs-resource cycle' and 'experiential challenges'. Socio-cultural influences have affected parents' interpretations of their experiences and needs. Moreover, parents reported that raising an 'at risk' child had an impact on their daily life as a family, as a couple and on their individual lifeworld. Maltese parents felt that their needs were not given their due importance by policymakers and professionals. This warrants the incorporation of parents' needs, together with the needs perceived for their child, in the provision of early intervention and/or paediatric services in Malta. This study also identified parents' experiential differences as the child grows, highlighting the need for regular re-evaluation of parents' needs. Recommendations for changes in Maltese family policy, service provision and education of professionals were proposed to reduce parents' stresses.

Key words: biological risks for ID, 'at risk' children, parent's experiences, parents' needs, early intervention, Maltese cultural influences, IPA.

Contents

| | |
|-------------------------------------------------------------------------------|-----------|
| Chapter 1 Introduction..... | 1 |
| 1.1 The Maltese context | 1 |
| 1.2 Personal perspective | 2 |
| 1.3 The importance of the child’s early years | 3 |
| 1.4 Rationale for the study | 4 |
| 1.5 Aims and objectives | 5 |
| 1.6 Overview of chapters..... | 6 |
| | |
| Chapter 2 Literature Review | 7 |
| 2.1 Introduction | 7 |
| 2.2 Biological risk factors for later intellectual disability | 7 |
| 2.3 Experiences and needs of parents of children born with risk factors | 13 |
| 2.3.1 At risk birth experiences | 14 |
| 2.3.2 Emotional experiences continuum..... | 16 |
| 2.3.2.1 Stress perceptions..... | 17 |
| 2.3.2.2 Co-existence of positive and negative emotional well-being | 22 |
| 2.3.2.3 Positive perceptions | 24 |
| 2.3.3 Coping styles..... | 26 |
| 2.3.4 Family functioning and management | 28 |
| 2.3.5 Support needs..... | 32 |
| 2.3.5.1 Informal support..... | 32 |
| 2.3.5.2 Formal support | 36 |
| 2.3.6 Information and communication needs..... | 40 |
| 2.3.7 Financial needs | 43 |
| 2.3.8 Changes over time | 45 |
| 2.4 The Maltese culture | 47 |
| 2.4.1 The Maltese family | 48 |
| 2.4.2 Experiences of Maltese parents | 50 |
| 2.4.3 Paediatric services in Malta | 52 |
| 2.5 Conclusion..... | 55 |
| | |
| Chapter 3 Theoretical framework..... | 56 |
| 3.1 Introduction | 56 |
| 3.2 Bio-ecological model and developmental niche..... | 56 |
| 3.3 Family systems theory | 59 |
| 3.4 Early intervention model | 60 |
| 3.5 Family-centred principles | 62 |
| 3.6 Relationship of models with the current study | 63 |
| 3.7 Conclusion..... | 66 |

| | |
|--------------------------------------------------------------------------------|------------|
| Chapter 4 Methodology | 67 |
| 4.1 Introduction | 67 |
| 4.2 Research questions | 67 |
| 4.3 Operational definitions | 67 |
| 4.4 Research approach..... | 69 |
| 4.4.1 Philosophical background of research approach | 70 |
| 4.4.2 Rationale for research approach | 73 |
| 4.4.3 Interpretative Phenomenological Analysis methodology | 74 |
| 4.4.4 Rationale for Interpretative Phenomenological Analysis methodology | 76 |
| 4.5 Research design | 77 |
| 4.6 Sample | 78 |
| 4.6.1 Inclusion criteria | 79 |
| 4.6.2 Rationale for age groups | 80 |
| 4.7 Ethical considerations and permissions..... | 82 |
| 4.8 Data collection procedure | 84 |
| 4.8.1 Participants' recruitment..... | 85 |
| 4.8.2 Data collection process | 85 |
| 4.8.3 The interview schedule | 86 |
| 4.8.4 Transcription..... | 87 |
| 4.9 Data management and analysis | 88 |
| 4.9.1 NVIVO8 software..... | 89 |
| 4.9.2 Analytical procedure..... | 89 |
| 4.10 Pilot study..... | 93 |
| 4.11 Reflexivity | 93 |
| 4.11.1 Creating a reflective routine prior data collection | 94 |
| 4.11.2 Reflexivity during data collection..... | 94 |
| 4.11.3 Reflections during analysis process | 96 |
| 4.12 Assessing the quality of the study | 96 |
| 4.12.1 Sensitivity to context | 97 |
| 4.12.2 Commitment and rigour..... | 98 |
| 4.12.3 Transparency and coherence..... | 100 |
| 4.12.4 Impact and importance..... | 101 |
| 4.13 Conclusion..... | 102 |
| | |
| Chapter 5 Results and Analysis | 103 |
| 5.1 Introduction | 103 |
| 5.2. Demographic background of participants | 103 |
| 5.3 Parenting a child born with risks for intellectual disability..... | 106 |
| 5.4 Experiencing is true understanding | 107 |
| 5.4.1 Self-protection barrier theme | 107 |
| 5.4.1.1 Rollercoaster of emotions sub-theme..... | 108 |
| 5.4.1.2 Lack of empathy sub-theme | 112 |
| 5.4.2 Identification with similar others theme | 114 |
| 5.4.2.1 Emotional comfort sub-theme..... | 114 |
| 5.4.2.2. Sharing of information sub-theme | 116 |

| | |
|------------------------------------------------------------------|-----|
| 5.4.3 Life-world transformations theme | 118 |
| 5.4.3.1 Couple transformations sub-theme | 118 |
| 5.4.3.2 Individual transformations sub-theme | 121 |
| 5.5 Family functioning | 123 |
| 5.5.1 Extended family theme | 124 |
| 5.5.1.1 Practical support sub-theme | 124 |
| 5.5.1.2 Emotional wellbeing sub-theme..... | 126 |
| 5.5.2 Parenthood theme | 128 |
| 5.5.2.1 Parenting with a difference sub-theme..... | 129 |
| 5.5.2.2 Child-centred perspective sub-theme..... | 133 |
| 5.5.2.3. Future concerns sub-theme | 135 |
| 5.5.2.4 Older/younger siblings sub-theme | 136 |
| 5.5.3. Parents as couples theme | 138 |
| 5.5.3.1 Coping strategies sub-theme | 138 |
| 5.5.3.2 Gender roles sub-theme..... | 140 |
| 5.6 Micro-system sociological framework..... | 143 |
| 5.6.1. Person perspective theme..... | 143 |
| 5.6.1.1 Enforced suppression of voicing emotions sub-theme | 143 |
| 5.6.1.2 Social stigma sub-theme | 144 |
| 5.6.2. Lack of choice: Trapped in Malta theme | 146 |
| 5.6.2.1 Availability of services sub-theme..... | 146 |
| 5.6.2.2 Permanence and constancy of care sub-theme..... | 149 |
| 5.7 Info-emotional cycle..... | 150 |
| 5.7.1 Information balance theme | 150 |
| 5.7.1.1 Quality and quantity of information sub-theme..... | 151 |
| 5.7.1.2 Information seeking initiative cycle sub-theme | 155 |
| 5.7.2 Information channels theme..... | 158 |
| 5.7.2.1 Communication attitude continuum sub-theme | 158 |
| 5.7.2.2 Time allowance sub-theme | 162 |
| 5.7.2.3 Collaborative team approach sub-theme..... | 163 |
| 5.8 Service-needs-resource cycle | 165 |
| 5.8.1 Accessibility theme..... | 166 |
| 5.8.1.1 Awareness based on need sub-theme..... | 166 |
| 5.8.1.2 Reliance on private resources sub-theme..... | 167 |
| 5.8.1.3 Referral to services sub-theme | 170 |
| 5.8.2 Suitability theme | 171 |
| 5.8.2.1 Child's benefit sub-theme | 171 |
| 5.8.2.2 Effects on parents sub-theme | 174 |
| 5.9 Experiential challenges..... | 176 |
| 5.9.1 Acceptance journey theme..... | 176 |
| 5.9.1.1 The 'healing' process sub-theme | 177 |
| 5.9.1.2 Acceptance as a threshold sub-theme | 180 |
| 5.9.1.3 Spiritual beliefs sub-theme..... | 181 |
| 5.9.2 Developmental challenges theme | 183 |
| 5.9.2.1 Hospital-home transition sub-theme | 183 |

| | |
|----------------------------------------------------------------------------|------------|
| 5.9.2.2 Development concerns sub-theme | 187 |
| 5.9.2.3 Schooling challenges sub-theme | 189 |
| 5.9.2.4 The mature expert sub-theme..... | 190 |
| 5.10 Conclusion..... | 192 |
| Chapter 6 Discussion | 193 |
| 6.1 Introduction | 193 |
| 6.2 Study contributions overview..... | 193 |
| 6.3 Parents' experiences | 196 |
| 6.3.1 Cultural influences..... | 196 |
| 6.3.2 Living with risks: Family impact and adjustment | 201 |
| 6.3.3 Age-related experiential differences..... | 209 |
| 6.4 Needs of parents in promoting their 'at risk' child's development..... | 213 |
| 6.4.1 Physical needs..... | 213 |
| 6.4.2 Emotional needs..... | 218 |
| 6.4.3 Psychosocial needs | 222 |
| 6.4.4 Communication needs..... | 228 |
| 6.5 Methodological discussion: Strengths and limitations..... | 235 |
| 6.6 Conclusion..... | 238 |
| Chapter 7 Conclusion | 239 |
| 7.1 Implications for Malta | 239 |
| 7.1.1 Maltese services..... | 239 |
| 7.1.2 Professionals working with Maltese parents | 240 |
| 7.2 Recommendations | 241 |
| 7.2.1 Education in Malta..... | 241 |
| 7.2.2 Specialised services in Malta..... | 242 |
| 7.2.3 Maltese family policy | 244 |
| 7.3 Future research recommendations..... | 249 |
| 7.4 Conclusion..... | 250 |
| References | 252 |
| Appendix I Literature search terms..... | 290 |
| Appendix II Intellectual disability definition | 292 |
| Appendix III Ethical permissions | 295 |
| Appendix IV Examples of analysed text | 320 |
| Appendix V Reflections | 326 |
| Appendix VI Published Abstracts from this study | 334 |

List of tables

| | |
|-------------------------------------------------------------------------------------|-----|
| Table 3.1 Assumptions of Family Systems Theory (Friedman et al., 2003, p.154) | 59 |
| Table 3.2 Common ground principles (Guralnick, 2008b) | 61 |
| Table 3.3 Family-centred principles (Dunst, 2007, p.162-3) | 62 |
| Table 4.1 Accumulation of experiences due to child's developmental age | 92 |
| Table 5.1 Participants' demographic details | 104 |
| Table 5.2 Thematic hierarchical network | 106 |
| Table 5.3 Experiencing is true understanding themes | 107 |
| Table 5.4 Family functioning themes | 124 |
| Table 5.5 Micro-system sociological framework themes | 143 |
| Table 5.6 Info-emotional cycle themes | 150 |
| Table 5.7 Service-needs-resources cycle themes | 165 |
| Table 5.8 Experiential challenges themes | 176 |

List of figures

| | |
|--------------------------------------------------------------------------------|----|
| Figure 3.1 Bronfenbrenner's Bio-ecological Theory | 57 |
| Figure 3.2 Relationship of four theoretical models adopted in this study | 64 |

List of abbreviations

| |
|-----------------------------------------------------|
| ID – Intellectual disability |
| EU – European Union |
| SLT – Speech and Language Therapy |
| NSO – National Statistics Office |
| kg – Kilograms |
| VLBW – Very low birth weight |
| NICU – Neonatal Intensive Care Unit |
| NPICU – Neonatal and Paediatric Intensive Care Unit |
| CDAU – Child Development Assessment Unit |
| ENT – Ear nose and throat (medical specialists) |
| LSA – Learning Support Assistant |
| IPA – Interpretative Phenomenological Analysis |
| OT – Occupational Therapy |
| WHO – World Health Organisation |

Chapter 1 Introduction

Early intervention is described as a set of support services and experiences to either prevent or minimise long-term difficulties in children, as early as possible (Dunst and Trivette, 1997; Rosetti, 2001; Guralnick, 2008a). Exploring parents' experiences and needs is a starting point in the provision of early intervention services in such a way that they benefit the whole family. This study focuses on the experiences and needs of Maltese parents of children born with biological risks for intellectual disability (ID). Prior literature evaluated parents' experiences and explored their needs to improve services for the population under study but none have considered Maltese parents' needs. Also, due to the different methodological choices, wide variety of ages of children and disabilities explored, diverse cultural backgrounds and differences in the inclusion criteria, comparison and transferability of available findings is challenging. In this chapter I introduce the Maltese context, my personal perspective, the importance of a child's early years, rationale for the study, the study's aims and objectives, and an overview of the subsequent chapters.

1.1 The Maltese context

The present study is situated in the archipelago of Malta. It comprises of six islands, the largest being Malta itself, situated in the middle of the Mediterranean Sea. The islands cover an area of 316km² with a population of 410,290 inhabitants (National Statistics Office, NSO, 2008). It is reported to be the most highly densely populated country in the European Union (EU) with 1,261person/km² (Eurostat, 2009). It also had the tenth highest congenital anomalies prevalence rate in Europe between 2000-2005 (European Surveillance of Congenital Anomalies, EUROCAT, 2007) and the second highest infant mortality rate in the EU (10 per 1,000 live births, Eurostat, 2009). Its culture is significantly influenced by its long colonial history (Zammit, 2009). Malta is a bilingual country with Maltese and English as the official languages. The predominant religion is Roman Catholicism with 91% of the population considering themselves as Roman Catholics (Vallejo and Dooly, 2008). Religion is also considered as highly intertwined with the culture of the Maltese islands (Abela, 1994). Abortion and termination of pregnancy is illegal and divorce was legalised in 2011.

In 2009, there were 4,143 live births in Malta, of whom 3,713 had Maltese national parents (NSO, 2010). During the year of 2009, 58 children were born at less than 31 weeks gestation age and 51 were born weighing less than 1.5 kilograms (kg) (National Obstetric Information System, 2011). These statistics may overlap as premature children have a tendency to have lower birth weight (Rosetti, 2001). The Maltese Congenital Anomaly Register (2011) registered 62 live births for the year 2009, including children born with conditions directly related to ID amongst other disabilities. The 2003 Congenital Register (Department of Health Information, 2006, p.7) states that these families and their need for services are prioritised:

‘Congenital anomalies carry a high burden to affected individuals, their families and the community in terms of quality of life, participation in the community and need for services. They are therefore of significant Public Health importance.’

Early intervention service in Malta is delivered to referred children from birth to 5 years of age. The service is in its infancy and is currently child-focused rather than family-centred (see details in section 2.4.3). This further highlights the relevance of exploring the needs of Maltese parents whose child was born at risk of ID in order to support their child’s development and the family as a whole. Moreover, the small geography and the relatively small cohort population in Malta allow the advantage of gathering a sample from all the regions of Malta.

1.2 Personal perspective

As part of my undergraduate training in speech and language therapy (SLT) in Malta I learned the importance of being a source of information to parents who ultimately have to take decisions regarding to their child’s intervention journey. Working within the paediatric field and coordinating SLT services in special schools in Malta, I was sensitised to the ecological nature of developmental progress, the importance of parental involvement as a crucial part of the child’s intervention team, as well as the individuality of each family’s needs and priorities. I also noted how we, as professionals, seemed to regard the mother as the main carer of the child.

Given my professional interest in paediatric services and early intervention, I was aware of my limited understanding of the perceptions of parents when raising a child with the

possibility of developing ID. What are the needs of these parents? How do professionals take parents' needs into consideration when planning intervention programmes? My belief in preventive measures increased throughout my professional experience since many of the children in my caseload had pre-, peri- and post-natal complications or congenital anomalies.

Being brought up in a nuclear family where both parents work outside the home and support each other, I learned to appreciate the family unity, a team approach to coping and the use of the family's strengths to overcome difficulties. This has influenced the way I work and how I view family life. Out of respect for my family and my clients, I learned to compartmentalise my emotions in order to take full account of each individual with whom I interact, through active listening. My personal background and principles have assisted me during my educational journey, in order to maintain a healthy work-life balance and to maintain a genuine open-minded perspective for each participant's story.

1.3 The importance of the child's early years

The early years of a child's life is marked with intensive myelination and brain developmental processes (Couperus and Nelson, 2008). The success of early childhood intervention strategies rests to a great degree on the relative plasticity of the human brain (Nelson, 2000), and environmental stimulation, mainly from parents, amongst other developmental aspects. Parents' emotions were reported to affect their biologically-at-risk child's development (Zelkowitz, Papageorgioi, Bardin and Wang, 2009). The first five years of life have a high potential to affect later cognitive and socio-emotional development (Grantham-McGregor, Chueng, Glewwe, Richter and Strupp, 2007; Glascoe and Leew, 2010). However, specific age limits for benefits of early intervention are not clear cut (Nelson, 2000; Couperus and Nelson, 2008).

Guralnick (1998) points out that analyses of the course of intellectual development for children 'at risk' of and those with established disabilities in the absence of early intervention have revealed a general decline in children's intellectual development that occurs across the first 5 years of life. Disagreement in the literature exists on whether early intervention services should be delivered with children from birth-three years of age (Meisels and Shonkoff, 2000; Rosetti, 2001) or birth-five years of age (Guralnick,

1998, 2008a). Declines in intellectual development may occur in the absence of a systematic early intervention during the first three years of life (Ramey, Bryant, Sparling and Wasik, 1985) and five years of age (Martin, Ramey and Ramey, 1990; Guralnick, 1993; Burchinal, Campbell, Bryant, Wasik and Ramey, 1997). Critical stimulation periods are known to interact with different neural systems, such that some neural systems remain open to modification longer than others (Nelson, 2000), in particular experience-based brain plasticity (Couperus and Nelson, 2008). Malta, where this study is oriented, delivers early intervention services from birth to five years of age. (Vella, 2009); thus this age range was considered for this study.

1.4 Rationale for the study

Parents' experiences and perceptions are known to influence their child's upbringing, with effects on the child's socio-emotional perspectives (Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex and Ansermet, 2003). The role of early intervention is to enhance the development of children who have a developmental delay, a disability or who are 'at risk' due to biological and/or environmental factors (McCollum, 2002; Baker and Feinfield, 2007). It includes services and support designed to minimise the potential for or extent of developmental delay, the need for special education services and to enhance the capacity of families as caregivers (Guralnick, 1998; Ramey and Ramey, 1998; Rosetti, 2001). A significant emphasis is given to the role of the parents of children with disabilities requiring such services (Bailey and Simeonsson, 1988; Brooks-Gunn, Berlin and Fuligni, 2000; Dunst, 2007).

Internationally, early intervention services have shown effective short and long term benefits (Rosetti, 2001), especially when these are focused on the needs of the families (Dunst, 2007), such as long-term family functioning and relationships (Guralnick, 1998, 2000), child performance (Rosetti, 2001) and financial benefits (Barnett, 2000). Experiences of families are reported to change as the child grows (Jackson, Ternstedt and Schollin, 2003); however, there is little evidence about how such changes occur specifically during the first five years of life. Family-centred early intervention services tend to have better long term results than those services that do not employ such a framework in USA (Guralnick, 1998; Brooks-Gunn et al., 2000; Meisels and Shonkoff, 2000). These service characteristics include a high parental involvement as decision makers in the multi-disciplinary team, tailored towards the needs of parents/families and

strong parental engagement throughout in all service delivery. Consequently, understanding parental experiences can assist professionals to support parents in their care-giving responsibilities as the child grows (Dunst, 2007).

The Maltese culture treasures the family institution (Abela, 1994; Abela, Frosh and Dowling, 2005; Abela, 2009a, 2009b). Moreover, Vella (2009, p11) recommended that early childhood intervention services should ‘meet the needs of families and children so that families are well informed, share with professionals an understanding of the meaning and the benefit of the intervention recommended, participate in the decision making and implementation of the early childhood intervention plan’. Yet to date there are no studies in Malta primarily concerning the lived experiences of parents of children who were born with a biological risk for ID and the actual needs of these parents. This highlights the presence of a research gap, leading to a potential service void in the Maltese islands, due to the lack of information from families about what they want from an early intervention service targeting children with such a significant risk from birth.

1.5 Aims and objectives

The study focuses on the following aim using a cross sectional qualitative design.

To explore the experiences and needs of Maltese parents of children aged 0 to 5 years, who were born with a biological risk of intellectual disability.

In order to achieve the above aim the following objectives were devised:

To explore the experiences of Maltese parents in raising a child who was born with a biological risk of intellectual disability, when the child is 0;6, 2;0, 3;6 and 5;0 years of age.

To investigate the perceptions of Maltese parents of children aged 0;6, 2;0, 3;6 and 5;0 years of age whose child was born with a biological risk of intellectual disability, concerning the parents’ physical, emotional, psychosocial and communication needs to nurture their child.

1.6 Overview of chapters

This thesis is divided in seven chapters. This introductory chapter presents the rationale of the study and my personal perspective. The second chapter critically discusses available literature on experiences and needs of parents raising their child born with biological risks for ID, including the available information on Maltese family experiences and paediatric services. Chapter three presents the theoretical underpinnings of the study. The subsequent chapter consists of the methodology, which discusses the research approach and method of inquiry, ethical considerations, data collection process, analysis procedure, reflexivity and quality of the study. Results were analysed and are depicted using a thematic framework in chapter five. The subsequent chapter discusses the findings in relation to the available literature and the theoretical framework of the study, including methodological strengths and limitations of the study. A concluding chapter outlines implications and recommendations for social policymakers and professionals who assist the population under study.

Chapter 2 Literature Review

2.1 Introduction

The family is the primary environment in which an infant develops and creates the first social relationships (Bronfenbrenner, 1994; Roush and McWilliam, 1994; Guralnick, 1998, 2008a). Parents play a vital role in the promotion of optimal development, early identification of delays and disorders, as well as the provision of opportunities for developmental stimulation (Erickson and Kurz-Riemer, 1999; Rosetti, 2001). The role of parents whose children are born with vulnerabilities cannot be underestimated. An outline of who is considered to be ‘at risk’, as well as the experiences of parents of children with risk factors for ID focusing on biological risks, are explored and discussed in this chapter.

A series of searches for literature using Web of Knowledge, PsychoInfo, CINAHL, and GoogleScholar amongst other databases (see Appendix I) was performed to systematically identify all relevant literature from 1985 till 2013. Given the lack of randomised control trials on this topic, the wide variability of methodologies adopted and the presence of varied cohorts in the identified literature, a critical narrative review seemed more appropriate than a systematic review and/or meta-synthesis. Moreover, a paucity of literature was observed directly addressing experiential changes during the first five years of parental experiences of rearing children who were born with biological risks for ID. Although literature identified as directly relevant was given its due importance, literature exploring experiences of parents raising children with ID or diagnosed with developmental disability manifesting ID in their sample was also included. These, however, were included with caution given the potentially different nature of parents’ experiences, due to the unspecified cause or origin of ID, which might not have been from risks at birth (birth complications) but from developmental delays without birth complications.

2.2 Biological risk factors for later intellectual disability

Poverty, premature and low birth weight infants, parenting difficulties, abuse and neglect, prenatal exposure to illicit drugs or alcohol, continuing exposure to toxic substances during early childhood, and hazards found in hostile environments, all

constitute risk factors that can significantly compromise young children's health and development (Rantakallio, Jones, Moring and von Wendt, 1997; Guralnick, 2000; Leonard and Wen, 2002). The presence of increased risk of developing ID is particularly noticeable amongst those who experienced a complication at birth involving the central nervous system (Kirkby, Brewster, Canino and Pavin, 1995; Kirkby, 2002). The ID definition characteristics employed in this study are discussed in Appendix II. Rosetti (2001, p.5) included an exhaustive medical list of causes and described risk as 'anything that interferes with a child's ability to interact with the environment in a normal manner as a potential cause of, or contributing factor to, developmental delay'. While Erickson and Kurz-Riemer (1999, p.39-40) defined risk factors as 'characteristics of the child, the family or the broader environment that decrease the likelihood that the child will be competent and have a sense of well-being'. Arguably, both definitions offer a wide-ranging perspective including both biological and environmental aetiologies of risks; namely biological from the child's physical aspect and environmental from external influences.

Moreover, Guralnick (2008a, p.50) indicated that 'stressors' in daily family life may arise when children are born with biological risks (premature birth or low birth weight) and/or with an established risk, due to the child's developmental risks in cognitive, motor, communicative, affective or sensory systems. Hanson and Lynch (1995) and Guralnick (1998) differentiate 'established risk' from 'biological risk'; they define children with 'established risk' as those with a definite medical disorder or known aetiology with a relatively predictable developmental prognosis including developmental delay. Arguably, children with 'established risk' can still present a biological aetiology for the development and degree of ID during childhood whilst 'biological risk' seems to offer an unpredictable yet probable prognosis for ID.

Children with 'biological risk' have a history of prenatal, perinatal and/or neonatal complications, which suggests the presence of an insult to their central nervous system. Hanson and Lynch (1995) specified that since their aetiology is an unknown and undocumented insult, there is a greater likelihood for these children to develop atypically as compared to those who are 'typically-born'. Accordingly, children with biological risk also include those born with low birth weight, premature birth (before the 37th gestational week) or with an illness. Hanson and Lynch (1995) stated that no reliable set of predictors have been found to identify which at-risk children are at

greatest need for intervention. Conrad, Richman, Londgren and Nopoulos (2010) suggested that birth weight was a strong predictor of hyperactive behaviour but not of cognitive ability. Aetiology research is as yet inconsistent to date mainly due to the individual differences and nature of developmental brain plasticity (Couperus and Nelson, 2008).

Children born very prematurely (<31 weeks) and/or with very low birth weight (VLBW, <1.5 kg) are prone to more post-natal health risk factors and to developing ID (Rosetti 2001), growth-failure syndrome (Dusick, Poindexter, Ehrenhraz and Lemons, 2003; Wardlaw, Blanc, Zupan and Ahman, 2004) and delayed development (Schendel, Stockbauer, Hoffman, Herman, Berg and Schramm 1997). Van Baar, van Wassenaer, Briet, Dekker and Kok (2005) noted that only 39% of their monitored children born before 30 weeks gestation had typical development at 5 years of age. Furthermore, children with very (<31 weeks) and extreme (<25 weeks) preterm birth may also experience added risks such as myelination disorders (Nelson, 2000), which may themselves affect the functioning of the central nervous system and may manifest delays in multiple areas of development (Charkaluk et al., 2010). Children born with VLBW are reported to perform less efficiently than those born with typical weight on visual and auditory visual tasks, when observed from 6 months to 7 years of age (Ortiz-Mantilla, Choudhury, Leever and Benasich, 2008). Howard, Roberts, Lim, Lee, Barre, Treyvaud, Cheong, Hunt, Inder, Doyle and Anderson (2011) further identified a significant association between their Australian very preterm-born children with moderate-severe white-matter abnormalities and lower expressive language scores by 5 years of age. Disagreement exists in the literature regarding 'catching-up' phenomena, particularly involving receptive language (Luu, Vohr, Allan, Schneider and Ment, 2011).

Rautava, Andersson, Gissler, Hallman, Hakkinen, Korvenranta, Korvenranta, Leipala, Tammela and Lehtonen (2010) observed higher developmental and behavioural difficulties among 5 year old VLBW-born Finnish children than those born with typical weight including difficulties in memory, perception, language, executive functioning, motor skills and social skills. These difficulties may be underlying variables among VLBW children, that may account for the higher frequency of cognitive impairment (Rieck, Arad and Netzer, 1996; Lowe, Erickson and MacLean, 2010) and developmental disabilities (Hollomon et al., 1998). Rieck et al. (1996) agree that, worldwide, children born with VLBW may manifest difficulties in their cognitive

abilities (Roussounis, Hubley and Dear, 1993; Sansavini, Rizzardi, Alessandrini and Giovanelli, 1996; Olness, 2003).

Children born with perinatal complications, such as perinatal asphyxia, have been reported to obtain low Apgar scores (<7) at birth (Moster, Lie and Markstad, 2002). Apgar score is an internationally acknowledged method to describe the child's condition at birth; yet, these scores on their own are not used as predictors for future outcomes (Marlow, 1992; van de Riet, Vandenbusche, Le Cessie and Keirse, 1999). Haddad, Mercer, Livingston, Talati and Sibai (2000) and Ehrenstein, Pedersen, Grijoti, Nielsen, Rothman and Sorensen (2009) argued that the use of the Apgar score on its own might not be a powerful predictor for future intellectual abilities during childhood. Nevertheless, retrospective studies, which used recorded Apgar scores in conjunction with other medical complications at birth, found associations of low IQ scores during later life (Moster et al., 2002; Odd, Ramussen, Gunnell, Lewis and Whitelaw, 2007; Odd, Gunnell, Lewis and Ramussen, 2011), neurologic disabilities (Ehrenstein et al., 2009), higher morbidity risks (Haddad et al., 2000) or behavioural difficulties (Hwang, Soong and Liao, 2009).

Congenital anomalies were present in 30.2% of monitored children with ID, when studied retrospectively in Australia (Pettersen, Bourke, Leonard, Jacoby and Bower, 2007). Decoufle, Boyle, Paulozzi and Lary (2001) indicated that children in Atlanta (1991-1994) born with major birth impairments had a severe developmental disability, with a prevalence of 7.2% compared to 0.9% of children with no major birth impairments. While, Himpens, Oostra, Franki, Vansteelandt, Vanhaesenbrouck and Van den Broeck (2010) indicated 4.5% of their cohort developed cognitive complications and/or cerebral palsy later in their lives. The latter study explored a sample of low-birth-weight-born children (<2.5 kg or unstated) in order to understand the range of their complex needs, rather than focusing only on congenital disabilities, as in Decoufle et al. (2001). Westrupp, Mensah, Giallo, Cooklin and Nicholson (2012) also mentioned that their Australian low-birth-weight sample of young children (0-5 years of age) manifested a small increased risk for emotional difficulties. Literature on this sample population seems to be more accurately reported from developed countries than from developing countries, perhaps due to the potential incomplete statistics for analysis or strong influences of a country's poverty where the environmental risks present an added impact to the biological risks themselves.

Theunissen, den-Ouden, Meulman, Koopman, Verloove-Vanborick and Wit's (2000) Danish project concluded that two-thirds of VLBW and very preterm children under study manifested later childhood health difficulties. Nevertheless, Kessenich (2003) claimed that, although this population manifested poorer outcomes when compared to term-born children, the majority of VLBW and 33-50% of extreme-low-birth-weight children performed adequately from infancy to adolescence. This highlights that the presence of a biological risk for ID at birth does not necessarily determine the existence or severity of ID during later childhood. Consequently, Guralnick's (1998, 2000) 'established' risk may thus be considered as inter-related with biological risks for the purpose of the current study, given that both indicate the presence of risk for ID. Rosetti (2001, p.165) further specified that risk is a continuum concept that continues throughout the child's developmental and communication milestones.

All neonates born with any biological risks were reported to have a longer hospitalisation period in neonatal intensive care units than typically born babies (Hanson and Lynch, 1995; Schmucker, Birsch, Kohntop, Betzler, Osterle, Pohlandt, Pokorny, Laucht, Kachele, Buchheim, 2005). The lower their birth weight, and the shorter their gestation period, the higher the morbidity rates (Kramer, Demissie, Yang, Platt, Sauve and Listo, 2000; Farooqi, Hagglof, Sedin and Serenius, 2011; De Jesus, Pappas, Shankara, Kendrick, Das, Higgins, Bell, Stoll, Laptook and Walsh, 2012), risks of disability (Ohgi, Arisawa, Takahashi, Kusumot, Goto, Akiyama and Saito 2003; Boulet, Schieve and Boyle, 2011; Kerstjens, de Winter, Bocca-Tjeertes, ten Vergert, Reijneveld and Box, 2011; Lin, Lin and Lin 2011; Potharst, van Wassenaer, Houtzager, van Hus, Last and Kok, 2011; Ribeiro, Zachrisson, Schjolberg, Aase, Rohrer-Baumgartner and Magnus, 2011), psychiatric difficulties (Nosarti, Reichenberg, Murray, Cnattinguis, Lambe, Yin, MacCabe, Rifkin and Hultman, 2012), lower ultimate educational attainment (Foster-Cohen, Friesen, Champion and Woodward, 2010; Larroque, Ancel, Machand-Martin, Cambonie, Fresson, Pierrat, Roze, Marpeau, Thiriez and Alberge, 2011) with potential socio-economic status impact even 19 years later (Conley and Bennett, 2000) and reduced cognitive performance (Liaw and Brooks-Gunn, 1993; Koller, Lawson, McCarton, Rose and Wallace, 1997).

Petterson et al. (2007) observed that structural or functional disabilities of the central nervous system may co-occur with ID, suggesting that the ID was secondary to the

congenital disabilities. They argued that both birth complications and ID can be the result of antenatal, genetic or environmental influences, as well as the possibility of other causal pathways. These may include heart diseases/deficiencies, for example, which may lead to cerebral damage, due to hypoxia or in the course of cardiac surgery (Olness, 2003; Robertson, Justo, Burke, Pohler, Graham and Colditz, 2004). Such potential added cerebral damage may occur regardless of the child's birth weight or gestation age. It further highlights the unpredictable nature of the biological risks of developing ID in children at birth. Osofsky and Thompson (2000) added the importance of environmental influences post hospital discharge, as these may affect the child's intellectual development, regardless of premature birth, presenting variable effects on the development of the young child based on brain plasticity principles (Nelson, 2000; Shonkoff and Marshall, 2000; Couperus and Nelson, 2008). Hence biological insults to central nervous system may have variable effects on the development of the young child.

Children diagnosed with ID may also be susceptible to multiple disabilities. Many disabilities co-occur, such that children with cognitive delays may contend with motor impairments, language problems, sensory difficulties, epilepsy (Boyle, Decoufle and Yeargin-Allsopp, 1994), behavioural (Scott, Taylor, Fristad, Klein, Espy, Minich and Hack, 2012) and/or psychiatric difficulties (Wallander, Dekker and Koot, 2006). These might be considered as being 'doubly vulnerable' since they increasingly find themselves experiencing disadvantages associated from the above mentioned secondary difficulties. Thus both children born at biological risk and those with established disabilities create potential additional stressors with which families must contend.

Definition of Biological risk

Following Guralnick's (2000, 2008a) and Rosetti's guidelines, in conjunction with the variation of biological risks discussed from the available literature, the current study has adopted a moderately stringent criteria due to the unpredictable nature of ID and brain plasticity.

These include children with one or more of the following:

- born very prematurely or extremely premature (<31 weeks)
- born with very or extreme low birth weight (<1.5 kg)
- born with certain congenital anomalies which are known to have a direct influence on the central nervous system (Kirkby, 2002; Nelson, 2000), for example Down syndrome.
- born with severe asphyxia, as diagnosed by the medical professionals at the time of birth

Recorded low Apgar scores are also indicative of reduced intellectual activity at birth (Moster et al., 2002). This would be accepted for inclusion in this study only when accompanied by other medical conditions.

2.3 Experiences and needs of parents of children born with risk factors

The past decades have witnessed a variety of parent-reported reactions to life-changing events, including the birth of a child with complications for later development (Rosetti, 2001; Guralnick, 1998, 2008a). When birth complications occur, such as prolonged labour, complications with child's health, unexpected child health hazards and congenital anomalies, these are observed to bring about insecurity and feelings of shock in parents (e.g. Heiman, 2002; King, Zwaigenbaum, King, Baxter, Rosenbaum and Bates, 2006). Parents in different countries showed similar reactions, nevertheless, culture was also observed to affect parents' reactions to birth complications (McConkey, Truesdale-Kennedy, Chang, Jarrah and Shuki, 2008). Parents' experiences cannot be overlooked, especially due to their potential effect on the affected child's development (Zelkowitz et al., 2009; Ramchandani, 2012). This review is organised following inter-related dimensions of reported parental experiences, as described in the literature: namely emotions, coping strategies, family functioning, support needs, information and communication needs, financial needs and changes of reported experiences over time.

2.3.1 At risk birth experiences

Parental reactions to the birth of their ‘at risk’ child may be similar to an ‘impending catastrophe’ (Schmucker et al., 2005, p.425) and may persist throughout a number of years as the child grows (Rosetti, 2001). This section focuses on the parents’ emotions around the birth period of the biologically at risk child and presents a brief critique of these papers.

A study which took place in North West of England examined the perceptions of 36 women who had preterm infants hospitalised at the NICU using a content analysis with a phenomenological design (Padden and Glenn, 1997). The authors sought congruence between their analyses in a randomly-chosen 25% of their sample as a credibility criterion for this study. Participants were not confirmed as English nationals but as fluent English speakers. Hence ethnicity may have played a role in the findings of this study, however, this was not acknowledged by the authors. Identified maternal feelings included both positive and negative emotions around the delivery process, first sight of the infant and holding the baby. Themes also included interactions with medical and nursing staff; maternal sensitivity and feelings of competence; adaptation to preterm birth and search for meaning. Padden and Glenn (1997) did not specify their study’s limitations. Nevertheless, this study highlighted a need for professionals to address mothers’ feelings during their preterm child’s hospitalisation at the NICU leading to the development of family-centred practice.

Golish and Powell (2003) explored the stresses of American parents, whose child was born prematurely (<34weeks), that arose from their grieving for the loss of a full-term pregnancy. The authors also looked at the parents’ use of communication strategies to manage such tensions. The research adopted an interpretative approach, using constant comparison as their method of analysis. An open-ended retrospective questionnaire was completed by 48 participants, who consisted mainly of mothers (95%) and a few fathers. Although, there was lack of information about the study’s credibility checks the researchers reported that they sought agreement between themselves regarding identification of stress feelings.

Parents of children born prematurely reported contradicting feelings of joy and grief when having a new baby in life-threatening circumstances (Golish and Powell, 2003). These authors noted that parents described their NICU experience as a ‘roller coaster

journey' (Golish and Powell, 2003, p.320), which also led to complications with extended family members, in addition to anxiety, denial and disbelief, sadness, anger, self-blame, and guilt feelings. The authors claimed that the results pertain to parents, however most participants were mothers. In addition credibility and trustworthiness were insufficiently addressed. Hence, one needs to interpret such results cautiously.

Hollywood and Hollywood (2011) used a different methodology from Golish and Powell (2003) by adopting Van Manen's (1990) interpretative phenomenological approach to explore the lived experiences of 5 Irish fathers whose child was born very prematurely (<30 weeks). Participants were interviewed during the first year of the child's life. The authors aimed to raise awareness of these fathers' experiences amongst health care professionals towards family-centred care. Although the process of data collection and analysis was clearly described, the authors did not outline their process for establishing credibility. Results revolved around the effects of hospitalisation filled with anxiety, feelings of helplessness and fears of the unknown. Hollywood and Hollywood (2011) also highlighted the participants' realisation of becoming fathers, information sharing as carrying two meanings, fathers' observations of reduced attention towards paternal role during hospitalisation and the constraints imposed by their work. The study outlined a number of strengths and limitations however they did not mention the limited transferability of the study's findings. Regardless of this findings have the potential to raise awareness amongst health professionals caring for fathers in similar circumstances.

Another study compared mothers' experience of having a premature infant in the NICU with post-traumatic stress (Holditch-Davis, Bartlett, Blickman and Miles, 2003). Holditch-Davis et al (2003) adopted a mixed method approach using semi-structured interviews on retrospective perceptions when the child had 6 months corrected-age together with specialised NICU stress and depression scales. Results from the interviews shed light on mothers' re-experiencing triggers, avoidance feelings and heightened arousal such as over-protection of affected child and persistent fears for their child's life, while scales correlations implied that married mothers had more post-traumatic-like symptoms at enrolment to the NICU and greater worries about the infant at 6months of age. Both methods in this study demonstrated adequate rigour outcomes and checks. This study highlighted that there may be some mothers whose

psychological distress during their child's NICU hospitalisation is predictive of posttraumatic stress symptoms.

Shah, Clements and Poehlmann's (2011) study explored grief resolution at NICU discharge of preterm babies, amongst 74 mother-child dyads in Wisconsin. They utilised a longitudinal design to collect data at three different time points. A number of scales with good reliability levels were adopted in the structured interviews. Findings from Shah et al (2011) suggested that grief resolution of preterm birth and early parent-infant interaction quality act as significant predictors of preterm infant attachment security. Although both Shah et al (2011) and Golish and Powell (2003) explore grief in preterm birth, the latter explored the parents' grieving process while the former focused on mother-child attachment security through longitudinal statistical analysis.

The above mentioned studies highlight the fragility of the parents' emotions during and soon after their at risk child's birth. These used different methods of exploration and thus provided diverse perspectives on the emotional upheaval taking place during hospitalisation and its effects at NICU discharge. One also needs to be cautious when generalising such results to all at risk children since these studies focused on preterm birth. As argued in section 2.2, children born at risk for intellectual disability may not necessarily be only preterm children, hence the adoption of a more comprehensive inclusion criteria in this study.

2.3.2 Emotional experiences continuum

Theories of life course and family development suggest that family-life changes create conditions of stress (Friedman, Bowden and Jones, 2003). Even under the best of circumstances, the birth of an infant, especially a first born infant, is a time of change for parents (Rosetti, 2001) including higher levels of stress (Borg Xuereb, 2008). The ways in which individuals respond to these experiences may differ markedly (Redshaw and Martin, 2012). Previous literature has greatly focused on the negative perspectives of raising a child with a disability (Helff and Glidden, 1998; Roll-Pettersson, 2001; Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhur and Wood, 2005), while others focused on positive influences (Hastings and Taunt, 2002). Emotional domains seem to be intertwined with other aspects in a person's lifeworld such as family functioning, financial circumstances and adaptation over time. Hence

this section focuses on the reported emotional well-being aspects of parents of children born with biological risks and/or diagnosed with ID from a continuum perspective: negative emotions, co-existence of positive and negative emotions, and positive emotions.

2.3.2.1 Stress perceptions

Parents of young children with disabilities have increased risks of developing depressive symptoms and distress (Barnett, Lockhart, Bernard, Manicavasagar and Dudley, 1993; Dudley, Roy, Kelk and Bernard, 2001; Shaw, Bernard, DeBlois, Ikuta, Ginzburg and Koopman, 2009; Parkes, McCullough, Madden and McCahey, 2009; Shin and Nhan, 2009). Indeed, Calhoun and Tedeschi (1998) pointed out that mothers who have non-ordinary birth-experiences may go through post-traumatic stresses. Mothers of children born with risks for ID may also be at a greater risk of postpartum depression than mothers of children born under typical circumstances (Barnes, MacPherson and Senior, 2006). This added risk seems to be present during the affected child's first year of life (Vigod, Villegas, Dennis and Ross, 2010), more than those in the general community (Barnett et al., 1993).

According to Dudley et al. (2001), maternal depression during the first year of the child's life was associated with infant-related difficulties, parent's personality and perinatal factors amongst others. Added depression risks or high stress related symptoms may be due to a longer hospitalisation period and life-threatening intensive care of the neonate. Zelkowitz, Na, Wang, Bardin and Papageorgiu (2011) suggested that maternal anxiety during their child's Neonatal Intensive Care Unit (NICU) hospitalisation predicted intellectual and behavioural development of VLBW-born children during toddlerhood. Yet, Zelkowitz et al. (2011) acknowledged that their sample was too small for generalisability of their quantitative findings. However, Gueron-Sela, Atzaba-Poria, Mein and Marks (2013, p.90) noted that Bedouin mothers experienced more depressive symptoms compared to Jewish mothers of preterm babies, in their quantitative study, due to cultural conflicts with the Jewish medical staff and self-criticism characteristics which led to interpreting the premature birth as a 'failure-related event'. This also implies that participants' culture cannot be disregarded when exploring parents' emotions.

Parents of children born prematurely reported joy and grief contradictions of having a new baby in life-threatening circumstances (Golish and Powell, 2003). These authors noted that parents described their NICU experience as a ‘roller coaster journey’ (Golish and Powell, 2003, p.320), which also led to complications with extended family members, in addition to anxiety, denial and disbelief, sadness, anger, self-blame, and guilt feelings. Hollywood and Hollywood’s (2011) investigation using interpretative phenomenological analysis reported that their Irish parents of prematurely-born babies realised the seriousness of the situation after seeing their child in intensive care.

Upon discharge from intensive care, parents reported lack of confidence in their abilities to care for their child as they transition from hospital care to home (Lovett and Haring, 2003). Holditch-Davis et al. (2003) also observed post-traumatic stress symptoms accompanied by overprotection and over-vigilant behaviour after hospital discharge. Indeed, Kralik, Visentin and van Loon (2006) added that transitions over time may influence the individual’s self-identity with loss of self while adapting to their new parenting roles and responsibilities. Helitzer, Cunningham-Sabo, Van Leit and Crowe (2002) also identified perceived similar loss of identity however, these were not associated with hospital-home transition.

Kenner and Boykova (2007) outlined the needs of Russian parents during transition from hospital to home care; however, they did not explain their preliminary findings in detail. Boykova and Kenner (2012) added that their Russian sample parenting preterm-born infants felt their transition period from hospital to home was influenced by the health of the infant, parents’ discharge readiness, timeliness of discharge and appropriateness of post-hospital care. Lopez, Anderson and Feutchinger’s (2012) review also identified the need for home-visits by nurses as a key component for parental education and support during parents’ transition to home from the NICU. In addition, Olshtain-Mann and Auslander (2008) noted that, even after two months of caring for their preterm child at home, Israeli mothers maintained an ‘insecure’ attitude regarding their parental ability and functioning.

Parents of children manifesting intellectual and/or developmental disability were also reported to suffer from stress-related health difficulties due to child behaviour and extreme caregiving needs (Miodrag and Hodapp, 2010). In a longitudinal qualitative study with parents of eight infants with ID, most of whom had a congenital anomaly,

Graungaard and Skov (2006) noted that the diagnostic process was a period of uncertainty, hope, and despair. Information was important to these parents, who often ended up very frustrated with and mistrusting health professionals, due to incoherence of information provided. Graungaard and Skov (2006) further indicated that the majority of interviewed parents of children with lengthy hospitalisations, in relation to a difficult diagnostic process, seemed to experience human- and system-related errors such as lack of communication, uninformed health professionals, medication errors and lack of sufficient observation of their child. Although the authors aimed to observe parental needs, these were not discussed in depth. These included equality in co-operation between parents and physicians, individualised information strategies, empathetic approach by physicians, treatment of child as a person not a case and consideration of the child's potential despite disabilities.

Graungaard and Skov (2006) separately interviewed their Danish participants who were cohabitating as a couple with their child. Nevertheless, Graungaard and Skov's (2006) findings seemed to differ from Pelchat, Levert and Bourgeois-Guerin's (2009), who also interviewed each parent separately. The former did not provide a rationale for separate interviews whilst the Canadian cohort of Pelchat et al. (2009) aimed to avoid cross-contamination of data. This procedure gave importance to the separate individual's perceptions. However living as two-parent families they may still pose a significant influence on each other's perceptions (Friedman et al., 2003).

Pelchat et al. (2009) found that both parents of children with a disability expressed the need to adjust their daily routines, such as sharing normative pleasures with their child. On the other hand, the parents' perceptions in Graungaard and Skov's (2006) study were similar to those of Feldman, McDonald, Serbin, Stack, Stecco and Yu (2007), who reported higher distress among Canadian parents when the cause for their child's developmental disability was unknown, compared to parents of children with known syndromes. Arguably, in Graungaard and Skov (2006), parents who received a diagnosis earlier in the child's life had prior warning of possible atypical development, where stress dissipated over time. This seemed to be similar to Glidden and Schoolcraft's (2003) research findings of reduced depressive symptoms over time upon comparing parents own- with adopted-children with ID.

Child behaviour difficulties were identified as predictive of mothers' depression and marital adjustment (Baker, Blacher and Olsson, 2005) with a bidirectional relationship over time (Neece, Green and Baker, 2012). Using a quantitative design, Raina et al. (2005) found that 632 Canadian parents of children with cerebral palsy reported that child behaviour problems are the single most important child characteristic that predicted poor caregiver psychological well-being. Gerstein, Crnic, Blacker and Baker (2009, p.982) also found that the comorbid behaviour problems associated with ID was more related to parenting stress, rather than the rearing 'hassles' of their child with a disability. Research conducted with populations from different cultures and using various methodologies, show that there is a strong relationship between child's behavioural problems and high parental distress (King, King, Rosenbaum and Goffin, 1999; Kashdan, Pelham, Lang, Hoxa, Jacob, Jennings, Blumenthal and Gnagy, 2002; Saloviita, Italinna and Leinonen, 2003; Baker et al., 2005; Hassall, Rose and McDonald, 2005; Lloyd and Hastings, 2009a; Bostrom, Broberg and Hwang, 2010b; Bostrom, Broberg and Bodin, 2011; John, 2012).

Findings on the relationship between parents' gender and stress-effects seem to be complex (Gray, 2003; Hastings, 2003; Pelchat, Lefebvre and Levert, 2007). Mothers seemed more affected than fathers by the child's behavioural difficulties as they seemed to take up the caregiver role of the child with disability (Lloyd and Hastings, 2009b). In fact, mothers reported spending more time with the child (Kashdan et al., 2002) and had greater child care demands (Lloyd and Hastings, 2009a) than fathers. Likewise, in Baronet's (2003) investigation, a similar caregiver's impact was perceived by 70% of their sample who were mothers rearing their child with disability. Reported stresses may also be interpreted as concern about the child's development; however such a 'concern' may have different cultural connotations (Kiing, Low, Chan and Neihart, 2012). This places culture in a vital role to understand parents' reported concerns. Hence, cultural aspects could have an influence on the criteria applied in interventions to assist child development (e.g. Goldbart and Mukrejee, 1999a). Bartlett, Nijhuis-van der Sander, Fallang, Fanning and Doralp (2011), in their quantitative based investigation with Canadian, Dutch and Norwegian parents raising preterm-born child, also argued that parent-reported perceptions of vulnerability were culturally-differentiated.

The mothers' personality throughout infancy might itself act as a predictor of stress, even when raising typically-developing young children (Mulsow, Caldera, Pursley,

Reifman and Huston, 2002). Acceptance was described as the ‘active non-judgmental embracing of experience in the here and now’ (Hayes, 2004, p.656). This concept seem to act as a mediator for paternal anxiety and depression (MacDonald, Hastings and Fitzsimons, 2010), when it was studied on a sample of fathers of children with ID. Nevertheless, these symptoms could also be related to economic pressures (Kersh, Hedvat, Hauser-Cram and Warfield, 2006), and the increased hardship for mothers more than for fathers (Olsson and Hwang, 2008). High degree of reported findings regarding maternal distresses could also infer that the majority of research was performed mainly with mothers rather than with both parents together.

Pelchat et al. (2009) compared Canadian mothers’ and fathers’ adaptation strategies for their child with disability, using grounded theory. They noted that emotional strategies used by fathers involve suppression of emotions whilst mothers expressed them more concretely. Fathers seemed to report a greater need for distancing or denial as a coping mechanism after diagnosis. Conversely, on using a quantitative approach, one month post-diagnosis of a congenital anomaly, Fonseca, Nazare and Canavarro (2011) did not observe gender differences in the intensity of emotions amongst parents of children with congenital anomaly. Both mothers and fathers expressed similar high intensity of negative feelings mainly: sadness, anxiety and shock. Nonetheless a strong element of hope was also expressed by both parents (Fonseca et al., 2011).

One could argue that differences in the nature of experiences of mothers and fathers could exist, rather than intensity of emotions. Hollywood and Hollywood (2011, p.37) observed that mothers were more present near the preterm baby during neonatal hospitalisation unlike fathers who aimed to stay ‘out of the way’. Indeed, Vermaes, Janssens, Mullaart, Vinck and Gerris (2008) reported that the individual parents’ personality influenced stress variations. However, a marked similarity was also noticeable in negative reactions and perceptions of stress in both mothers and fathers of children with ID, whether born with biological risks or diagnosed at a later stage. One needs to take into consideration the variability of the sample population explored in prior research and the potential cultural influences (McConkey et al., 2008), thus interpretation and application of their results could be limited.

2.3.2.2 Co-existence of positive and negative emotional well-being

Families of children with ID were widely reported to experience elevated levels of parental stress compared to families of typically developing children. The premature delivery of an infant is considered as a crisis for parents who have to manage and cope with the many issues that have risen unexpectedly (Goldberg and DiVitto, 2002; Tracey, 2000; Rosetti, 2001; Guralnick, 2008a). However, several authors reported simultaneous positive and negative aspects of wellbeing during the child's early years.

Upon exploring 17 Swedish parents' experiences (8 mothers and 9 fathers) while raising their children diagnosed with ID (0;5-5;0 years), Bostrom, Broberg and Hwang (2010a) found that most parents gave a balanced and affectionate description of their child. This was observed through their child's positive and negative descriptions, well-functioning routines and parent-child interactions, as well as recognition of the child as an individual person. Nonetheless, Bostrom et al. (2010a) did not specify the origin of ID diagnosis; this could have presented in either biological risk from birth or diagnosed as the child developed without a history of birth complications. In addition, the study's inclusion criteria were non-specific as it included parents of children who were diagnosed within the past 6 months or in the process of receiving a diagnosis.

Bostrom et al. (2010a, p.98) suggested that emotional acceptance was observed as an individually established construct over time and may 'contain opposing thoughts and emotions about the disability without being preoccupied with or dominated by the conflict of thoughts.' The authors combined the exploration of content and meaning via interpretative phenomenological analysis as well as format and narrative style of individually telephone-interviewed parents. They aimed to explore parents' descriptions of their child without acknowledging the potential daily influences of the other partner in their framework (see Casey, 1996). Although Bostrom et al. (2010a) implied a balanced picture, McKim (1993) and Nicolaou, Rosewell, Marlow and Glazebrook (2009) reported that the early days and weeks post-discharge from hospital were perceived as the hardest for parents of children born 'at risk'.

On using a grounded theory approach to understand the adaptation process of parents of children with varied disabilities and ages (14-60 months), Pelchat et al. (2009) found that a quarter of the interviewed mothers and fathers expressed positive appraisal of their situation by viewing it as a challenge, or a mission, accompanied by other negative

adjustment perceptions. Authors reported that 61.5% of children were born prematurely (25-37 weeks) and 61.5% of children manifested quadriplegia, although they did not report any intellectual dis/abilities of the children. Regardless Pelchat et al.'s (2009) differences in their Canadian cohort or methodology, the co-existence of positive and negative thoughts agreed with Bostrom et al.'s (2010a) findings of their Swedish cohort.

Co-existence of both polarities is not uncommon and has many facets (Hastings and Taunt, 2002) across cultures (McConkey et al., 2008). Trute, Benzies, Worthington, Reddon and Moore (2010) reported that both positive and negative experiences have independent associations whilst Trute, Heibert-Murphy and Levine (2007) observed a direct relationship between them. Heiman (2002) explored the emergence of resilience, using grounded theory, in 32 parents of children with a disability from central Israel. Parents in Heiman's (2002) study seemed to experience significant negative changes in the family's social life, yet, they attempted to maintain a routine, found initial support from family members and benefitted from available services. Maintaining an optimistic outlook along with a realistic view and acceptance of a situation dominated the strong beliefs in the child's future prognosis. Three main factors were observed to help parents function in a resilient way namely: open discussion and consultation with family, friends and professionals; positive bond between parents that support and strengthen them; and a continuous and intensive educational, therapeutic and psychological support for family members.

Only 28% of Heiman's (2002) sample showed frustration, anger or guilt about rearing a child with disability while the majority expressed feelings of joy, love, acceptance, optimism and satisfaction related to developmental successes of their child with disability. Similarly, Irish mothers of older children (6-8 years) with cerebral palsy, also expressed added satisfaction when their child's communication development progressed, arising from the mothers' high emotional investment (Power, McManus and Fourie, 2009). Although the cultural background of Heiman's (2002) participants differed from that of Power et al.'s (2009), satisfactions drawn from developmental successes seemed to occur across cultures.

In Australia, Davis, Shelly, Waters, Boyd, Cook and Davern (2009) explored the quality of life of parents of children with cerebral palsy aged 3-18years using grounded theory. In their study, parents reported negative aspects such as demands on physical health,

disrupted sleep, difficulty maintaining social relationships, pressure on marital relationships, difficulty taking family holidays, limited freedom and time, child's long-term dependence, difficulty maintaining maternal employment, financial burden, difficulty accessing funding and insufficient support from services. Parents in Heiman's (2002) study also reported a lack of freedom, together with loss of own identity and lower career expectations whilst parenting older children with ID. The co-existing positive impacts, in Davis et al. (2009), included parents' ability to build new social support networks and draw inspiration from their children. Although limited positive perceptions were reported in Davis et al. (2009), they provided support for the co-existence of both positive and negative perceptions in parents of children with disabilities.

In agreement with Davis et al. (2009), Padden and Glenn (1997) also stated that more negative than positive aspects were reported. The latter observed 14 mothers who expressed mixed reactions to the news of having an 'at risk' child, reporting relief and happiness combined with fear and worry; while 10 mothers felt distressed at the first sight of their child due to the small size and appearance of their baby. Seven participants expressed concern about future pregnancies during their early weeks of their 'at risk' neonate's life. However, Padden and Glenn (1997) focused on mothers of preterm-born neonates during their first few weeks of life, unlike Davis et al. (2009) whose participants shed light on their experiences throughout their child's upbringing.

2.3.2.3 Positive perceptions

Receiving news that one's child is 'at risk' or is born with a disability is commonly looked upon as a negative experience by parents (King et al., 1999; Rosetti, 2001; Heiman, 2002; Dykens, 2005). Despite this, positive perceptions are also commonly expressed by these parents (Hastings and Taunt, 2002; Dykens, 2005; Blacher and Baker, 2007). Indeed, Scorgie and Sobsey (2000, p.204) indicated that their sample of Canadian parents rearing their child with a disability felt 'positively transformed' by their relationship with their child.

Maternal positive perceptions were predicted by the belief that external factors influence child behaviour and by feelings of parental control over their child's behaviour (Lloyd and Hastings, 2009a). Other characteristics that were observed to

influence and predict parental psychological well-being included: positive reappraisal (Glidden and Natcher, 2009), family-centred support (King et al., 1999), strong social network (Hassall et al., 2005, Nachshen and Minnes, 2005), strong family functioning (Raina et al., 2005) and spouse support (McConkey et al., 2008).

Parents of children with ID as early as 6 months post-diagnosis showed positive interpretations of their daily experiences (Bostrom et al., 2010a). Green (2007) highlighted that American mothers of children who were at risk of dying showed heightened appreciation of life amongst other benefits as a result of their perceived life-changing experience with: increased perceived awareness, increased competence, strengthened character and deepened relationship with family and friends over time. Moreover, Green's (2007) qualitative study's outcomes suggested that even though parents felt thrown into this experience, exposure to other persons with disabilities increased the level of comfort and adjustment over time. Indeed, positive experiences among American parents of children with disability are interpreted as vital since they reflect parents' growth through their daily adjustment and are not classified as coping strategies (Resch, Mireles, Benz, Grenwelge, Peterson and Zhang, 2010).

Trute et al.'s (2010) longitudinal quantitative exploration with Canadian primary caregivers (85% mothers) of children with ID indicated that time seemed to have played a role in exposing more the positive experiences during their child's upbringing. Poehlmann, Clements, Abbeduto, Farsad and Ferguson's (2005) findings agreed with this notion, regardless of the use of qualitative methodology (grounded theory) and different cohorts (American mothers of children with Fragile X and Down Syndrome). These studies agreed that the older the children with ID were, the more parents perceived positive experiences. Since Trute et al. (2010)'s sample were parents of 1-18 year old children while Poehlmann et al. (2005) interviewed mothers of 11-23 year olds, this finding need to be applied with caution to the current study, which focuses on the early years of parents' child-rearing experiences.

Although Hastings, Beck and Hill (2005) used a qualitative methodology, which differed from Trute et al. (2007) and Trute et al. (2010), they all agreed that mothers reported more positive perceptions than fathers, on the child's contribution to their family. Arguably, mothers might have had more opportunity to observe positive contributions made by the child due to potentially spending time more with the child.

Hastings et al. (2005) also argued that mothers held more positive perceptions than fathers in an effort to balance their increased experience of negative outcomes such as parenting stress. Researchers seem to adopt broad child diagnostic criteria in this research area in conjunction with a wide child's age range in order to capture the variety of potential positive perceptions parents may experience. This limits the application of prior literature to parents of children born with biological risks for ID in particular during the early years of life.

2.3.3 Coping styles

Parents of children who are born 'at risk' or with a disability seem to adopt a number of different coping styles (Guralnick, 1998, 2008a; van der Veek, Kraaj and Garnefski, 2009). Positivity, optimism and humour have been reported as frequently adopted coping styles amongst parents (King, Baxter, Rosenbaum, Zwaigenbaum and Bates, 2009). These coping strategies had predictive power to enhance the positive impact of parents raising a child with risks for developmental delay, as well as of parents raising children with disabilities (Heiman, 2002; Baker et al., 2005). Graungaard and Skov (2006) identified a number of emotional coping strategies adopted by their sample: namely retaining hope, creating future images, ignoring the seriousness of the condition, seeking social support, evaluating one's beliefs and identifying positive aspects. Information seeking, problem solving or seeking social support were also considered active coping strategies for parents related to a more positive attitude toward their child's disability and a decrease in psychological stress (Frey, Greenbarg and Fewell, 1989; Shapiro and Tittle, 1990).

Acceptance has been observed to be associated with personality traits, support systems, education of parents, financial stability of parents, family cohesion, spousal relationship and level of child's difficulties (Kandel and Merrick, 2007). Timing of emotional acceptance also seems to be individual (Bostrom et al., 2010a). Nevertheless, Lloyd and Hastings (2008) noted that by improving parental acceptance they predicted positive effects on the adjustment of parents of children with ID. Although the latter study identified a direct relationship between maternal acceptance and adjustment using longitudinal quantitative methods, their participants' children's ages varied widely when compared to Bostrom et al.'s (2010a) qualitative investigation. This also implies

that methodological influences and differences in child's ages could influence the results and acceptance interpretations.

Some parents of very preterm children reported clinging to 'day-to-day attitude' due to their child's life-threatening circumstances (Golish and Powell, 2003). In Ireland, Greer, Grey and McClean (2006) did not observe significant associations between positive reframing and maternal positive perceptions using social support as a coping strategy. Hastings, Allen, McDermott and Still (2002), however, in the UK, identified that reframing coping strategies were significantly associated with maternal positive perceptions. While Taiwanese fathers valued the incorporation of rehabilitation principles into their daily play with their child (Huang, Chen and Tsai, 2012).

Darling, Senatore and Strachan (2012) reported greater stress, more intensified daily routines and lower family coping among American fathers who had a child with disability when compared to fathers whose child was typical. Trute et al. (2010) added that mothers' psychological coping skills were strongly associated with family adjustment to childhood disability. Associations were observed between mothers' ability to perceive positive family consequences of childhood disability and to maintain higher proportions of positive emotion in their daily activities, placing the mothers' emotional coping in a central position. This outcome, however, could be influenced by the fact that research evidence focused on individual parents' reactions, mainly mothers', rather than on both parents together.

Hope was identified as an effective coping strategy, when this was reported with positive problem solving attitudes; it was also negatively associated with maladaptive and passive behaviours (Kashdan et al., 2002). Huang et al. (2012) also noted that Taiwanese fathers acted as hope seekers during their child's intervention programme. Moreover, hope was stronger than optimistic attributions, since there was a unique relationship between hope and perceived positive parenting behaviours, high family functioning and adaptive coping strategies. A similar strong relationship was also observed by Lloyd and Hastings (2009b). These authors observed that hope functioned in a compensatory fashion; hope increased positive well-being and decreased psychological distress. In particular, higher levels of motivational thinking could be the most relevant aspect of hope for psychological well-being being akin to positive thinking or the absence of learned helplessness or hopelessness. Lloyd and Hastings

(2009b) argued that since hope is a cognitive variable it is amenable to change, where the higher hope conveyed, the better psychological well-being and could thus provide a positive life outlook and a positive adaptation to change by employing hopeful, goal-oriented thinking.

Coping can also be associated with one's beliefs, such as spiritual beliefs, where parents of young children with ID felt enriched (King et al., 2006; King et al., 2009) and strengthened (Stainton and Besser, 1998). Hastings and Taunt (2002) noted that parents reported growth in spirituality and/or faith as a positive life-aspect. Similarly, Lin (2000) and Howarth, Lees, Sidebotham, Higgens and Imtiaz (2008) implied that parents raising a child with disabilities described spiritual support as an effective coping style in relation to parental well-being. Nonetheless, Nehring (2007) and Triandis (1995) warn of potential cultural differences in religious connectedness, value system and coping attitudes. For instance, Heller, Markwardt, Rowitz and Farber (1994) pointed out that Hispanic families interpreted having a child with ID as a test from God, whilst Latino parents, in Shapiro and Simonsen's (1994) study, interpreted having a child with Down syndrome as God's gift.

2.3.4 Family functioning and management

Children born with risks for developing ID may have a significant impact on their family, both on the family as a unit and on the individual family members. It may present disruptions to optimal family patterns of interaction which may further compromise a child's development (Guralnick, 2008a) and may also create further stress on the family as a whole (Rosetti, 2001, Raina et al., 2005). Graungaard and Skov (2006) indicated that the experiences of parents of children born with complications were marked by frequent hospital visits during early development, which added commitments to their child care routine. Similar findings were reported by Wade, Lorch, Makewell-Sachs, Medoff-Cooper, Silber and Escobar (2008), where parents whose child was very preterm, reported a high frequency of hospital visits and pharmacy prescriptions. Caring for a child with disability could also have a greater impact if the family has more than one child since they could perceive added family management difficulties (Padden and Glenn, 1997).

Australian parents of 2 year old children born very preterm have reported poorer family functioning when compared to families of term-born peers, using a family functioning survey (Treyvaud, Doyle, Lee, Roberts, Cheong, Inder and Anderson, 2011). When European American parents of children with disabilities experienced a high level of 'daily hassles', they reported low marital adjustment (Stoneman and Gavidia-Payne, 2006). Marital adjustment is referred to as the adaptation over time of a husband and wife to their context. Gerstein et al. (2009) noted that for parents of children with ID, psychological distress could be a particularly important risk factor but marital quality and perceived well-being had a compensatory effect over-and-above their perceived hectic schedules; an effect which levelled out the reported risk factors. Kersh et al. (2006) also added that social support from relatives and friends, predicted paternal parenting efficacy, even after controlling for socioeconomic status influences and child characteristics.

Stress has been identified as 'an important determinant of family functioning and family relationships' (Gerstein et al., 2009, p.982). Parents of children with ID identified high levels of depressive symptoms (Emerson, Robertson and Wood, 2004; Feldman et al., 2007), often higher than parents of typically developing children (Olsson and Hwang, 2001). Hodapp, Ricci, Ly and Fidler (2003) also identified higher levels of stress amongst mothers of children and adolescents with Down syndrome associated with child behavioural difficulties. However, they also acknowledged that it was still unclear whether reported stresses were solely due to the presence of the child's disability and the resulting increased support needs. Indeed, Parker, Mandlco, Roper, Freeborn and Dyches (2011) did not find significant differences between mothers and fathers' marital satisfaction and marital conflict when comparing parents raising typically-developing children or a child with disability. One needs to take into consideration the varied sample of the population and the wide children's age-limits explored in the above studies which present a challenge for interpretation of results and application to the current study.

The experiences of families raising children at risk for cognitive delay may affect their marital status and family composition during their first five years of life. Fertig (2004) compared a UK with a USA sample parenting children born with low birth weight and chronic conditions. The study indicated that in the USA parents had an increased likelihood of divorce whereas the UK parents did not. Fertig (2004) suggested that the

presence of cultural influences in the UK may be potentially protecting these families from the risk of divorce. On the other hand, Risdal and Singer's (2004) meta-analysis of marital adjustment while parenting children with disabilities stated that raising a child with a disability might not pose a threat to and damage the marital unit. Yet, Clarke and MacKay's (2008) study of family formation and its relationship with disability, observed an increased divorce rate in the UK during the disabled child's early years of life.

Urbano, Hodapp and Floyd's (2007) population study compared British parents of children with Down syndrome with parents whose child did not have a disability. They reported that when divorce did occur, among families of children with disability, it was more likely to occur during the early years of the disabled child's life and if parents have low educational background. This agrees with Clarke and MacKay (2008), that if marital breakdown occurs, it is more likely to take place during the early years of the 'at risk' child's upbringing. Arguably, Mazer, Gishler, Koot, Tibboel, van Dijk and Duivenvoorden's (2008) sample of Dutch couples parenting infants with congenital anomalies suggested that agreement between the couple increased over time. This could place time in a vital position, one which affects marital adjustment and family coping while raising a child with biological risks for ID.

Culture may play a role in perceived family daily coping and stress interpretations. Australian mothers were reported to be responsive to their husband's coping strategies (Stoneman and Gavidia-Payne, 2006). Vietnamese mothers reported higher levels of stress than fathers whilst parenting a child with ID, attributing this finding to the assumed caregiver role (Shin, Nhan, Crittenden, Hong, Flory and Ladinsky, 2006). Yet, Vietnamese paternal stresses was more focused towards social acceptance of the child, unlike in Huhtala, Korja, Lehtonen, Haataja, Lapinleimu, Munck and Rautava (2011) whose Finnish fathers' stress was related to VLBW-born child's cognitive delay. Although the literature seem to view greater marital stress amongst mothers of children with ID (Kashdan et al., 2002; Gerstein et al., 2009), greater focus in the general literature is dedicated to mothering rather than parenting (Gerstein et al., 2009), or fathering (Macfadyen, Swallow, Santacroce and Lambert, 2011).

Parents' interpretation of the family impact while raising a child with a disability includes negative and positive appraisals. Trute et al.'s (2010) longitudinal and

quantitative findings implied that Canadian caregivers' reported positive and negative coping family appraisals while raising children with disabilities. They noticed that family stresses associated with caring for the child with intellectual or developmental disorders might appear high, but these were not evident in family adjustment. Trute et al. (2010) found that positivity in mothers and their level of positive appraisal of impact of a child with disability were jointly associated with overall family adjustment. Trute et al. (2007) also observed that for both parents caring for a child with ID, the negative assessment of their situation predicted parental stress. Similarly, Saloviita et al. (2003) indicated that the negative situational appraisal was strongly associated with parental stress, amongst Finnish parents of children with ID.

Laurvick, Msall, Silburn, Bower, Klerk and Leonard (2006), agreed with Trute et al.'s (2010) findings that mothers' mental health was positively associated with better family functioning, even though the sample population was different in both studies. Moreover, during the early months of parenting a child with developmental disability, a positive appraisal of the demands of child caring may be salient for Canadian mothers (Trute et al., 2007). This places mothers in an empowering position to mitigate the effects of negative emotions experienced on an everyday level within family adjustment as a unit.

Furthermore, Veddovi, Gibson, Kenny, Bowen and Starte (2004), who studied maternal adjustment in healthy preterm births, observed that during the neonatal period, maternal positive reappraisal and planned coping style was accompanied with more knowledge of child development while previous experience with child-care was associated with better infant development, maternal adjustment and mother-infant relationship at 12 months postnatal. Arguably, although a marked difference existed between Veddovi et al.'s (2004) and Trute et al.'s (2007) methodological approaches and sample population, the importance of maternal positive reappraisal was not only important for mothers' psychological wellbeing but also for infant development in both studies.

Communication within the family, especially spouse-to-spouse communication transmitted a sense of teamwork and understanding unique reactions to their child's very preterm birth in an unexpected turn of events (Golish and Powell 2003). During similar experiences, married parents perceived a strain on their relationship due to possibilities of having different coping strategies in managing one's grief between the husband and the wife (Stroebe and Schut, 2001). Upon comparison of siblings of

children with Down syndrome with matched controls, Cuskelly and Gunn (2006) did not notice differences in parent-reported adjustment behaviours. However, Stoneman and Gavidia-Payne (2006) observed a relationship between families using effective communication and problem-solving skills, with siblings' adaptation outcomes, amongst Australian families raising children with varied disabilities. Siblings may have adopted these coping strategies as their own following their parents as role models. This supports the ripple effect of the family systems theory (Friedman et al., 2003), where one individual's behaviour could influence the other within a family unit.

2.3.5 Support needs

There is agreement in existing literature about the constant need for support expressed by affected families (Bosch, 1996; Rosetti, 2001; Guralnick, 2008a; G. A. King et al., 2009). Literature tends to use 'informal' and 'formal' support networks to differentiate support from family and professionals, respectively. Parents reported benefitting from both support services (Bosch, 1996; Rosetti, 2001; Heiman, 2002). A strong support network was a positive contributing factor towards raising a child with risks and/or difficulties (Davis et al., 2009) which might also predict future psychological well-being (Greer et al., 2006) and better family functioning (Raina et al., 2005). Such support is increasingly being viewed as an essential aspect that cannot be overlooked.

Parents' ability to meet their needs may depend on the strength of their social support network (Bosch, 1996). McConkey et al. (2008) studied mothers from Taiwan, Jordan and Ireland, using qualitative methodology. They reported inter-cultural differences in support network systems. This indicated that inter-cultural differences may influence the perception of the helpfulness of the support received (McConkey et al., 2008). Outcome may vary given that this study is oriented in the Maltese culture.

2.3.5.1 Informal support

Informal support consists of help and assistance from extended family, friends and the general community where parents reside (Bosch, 1996). This involves inter-family support from extended family members, other families who had similar circumstances, friends, community and intra-family support. Mothers of children with ID reported helpfulness from informal support contributing towards positive daily perceptions

(Hastings, Allen, et al., 2002) and assisted them to develop a sense of personal growth and maturity (Hastings, Thomas and Delwiche, 2002).

Parents of children with disability seem to build a network of support which includes other parents who themselves have children with disability called parent-to-parent support (Farmer, Marien, Clark, Sherman and Selva, 2004). Kerr and McIntosh (2000) found parent-to-parent support to be highly effective in helping parents accept their situation and learn other information about child care as well as access to services. In fact, reduced awareness of support was associated with disempowered feelings among Japanese parents raising a child with developmental disability (Wakimizu, Fujioka, Yoneyama, Iejima and Miyamoto, 2011). Although Kerr and McIntosh's (2000) study focused on parents rearing children with upper limb deficiencies, their findings agreed with other research that focused on the positive attributes of parent-to-parent support among parents raising children with ID. These parents felt uniquely qualified to help each other (Kerr and McIntosh, 2000; Farmer et al., 2004). Taunt and Hastings (2002) found that half of their interviewed British sample reported support from other families as a positive experience. Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis and Santelli's (1998) qualitative exploration of parental experiences in America, with parent-to-parent support, observed an agreement on its benefits such as feelings of empowerment, reduced isolation, emotional well-being, mutuality of support, learning of practical skills from each other's experiences, as well as perceived sameness. Kerr and McIntosh (2000) also found various positive outcomes from this support including feelings of 'normality' reduced isolation and future visualisation of their child's abilities.

However, there were situations where parent-to-parent support did not prove helpful for a number of parents with lack of perceived sameness, lack of opportunities for downward comparisons and individual preferences and values (Ainbinder et al., 1998). Downward comparison refers to comparing oneself with other parents whose child had more severe difficulties; these were reported as beneficial to positively visualise their quality of life (Davis et al., 2009). A number of logistical barriers acted against building effective parent-to-parent support such as long distances between British parents, lost phone numbers, parents' busy lives and negligent support follow-up (Kerr and McIntosh, 2000). Moreover, Brett's (2004) hermeneutic phenomenological exploration indicated that some of her sample of British parents of children with profound

disabilities interpreted support-seeking as an admission of failure and loss of autonomy. Transferability of these results is limited to the participants' context explored as the individuality of parents' interpretation of parent-to-parent support may vary.

Raising a child with a disability is often accompanied by reports of friendship losses, which added to parents' feelings of social isolation (Tracey, 2000; Gray, 2002), or perceptions of pity (Barton, 1996). However, those who maintained contact with friends, reported stronger and deeper relationships (Green, 2007). The daily commitments whilst rearing a child with ID may further exacerbate, reduce or limit friendship networks, increasing social isolation (Rosetti, 2001; Baker, McIntyre, Blacher, Crnic, Edelbrok and Low, 2003; Chang and McConkey, 2008; Guralinick, 2008). Davis et al. (2009) added that mothers found it difficult to maintain relationships that were established prior the birth of their child, as some friends found it difficult to interact with their child.

Mothers felt reluctant to socialise or maintain relationships with friends as they felt their lives were very different and that they were only able to contribute to disheartening conversations (Davis et al., 2009). Erickson and Kurz-Riemer (1999), Minde (2000) and Singer, Fulton, Davillier, Koshy, Salvator and Bailey (2003) agreed with Davis et al. (2009) where parents, including some in Malta (Borg, 2006), also felt a strong sense of social isolation and feelings of stigma. In McConkey et al.'s (2008) cross-cultural study, Irish mothers reported having significantly fewer informal contacts than mothers from Jordan. One needs to interpret these results with caution, as McConkey et al. also acknowledged that the number of contacts one has in a diary does not necessarily imply an active informal social network.

Extended family members, such as grandparents, have been reported to provide informal support to parents raising a child with ID across cultures (Blacher, Feinfield and Kraemer, 2007; Chang and McConkey, 2008), more than other sources of support (Green, 2001). Grandparents were reported to be instrumental in providing support to families in terms of offering some practical assistance (Green, 2001) and family management (Woodbridge, Buys and Miller, 2009). In Sweden, the child's disability was reported to strengthen the relationship between the parents and grandparents (Lindblad, Holritz-Raumusse and Sandman, 2007).

Conflict or disagreement with the affected child's grandparents is not uncommon; such conflict seemed to influence maternal stress regardless of the presence of grandparent support (Hastings, Thomas, et al., 2002). Hornby and Ashworth (1994) indicated that reactions to or lack of understanding about their grandchild's disability among UK grandparents might lead to conflict or a lack of willingness to give support for these families. Such reported conflict might also be borne from feelings of 'double concern' (Hall, 2004), or 'double grief' (Woodbridge et al., 2009), as they 'mourn' for both their child (the parent) and grandchild and yet still felt pride towards both family members. Although such evidence may not be generalisable to a larger cohort, Ravindran and Rempel (2010) added that grandparents were observed to report 'triple concern' as their participants recognised the siblings' position.

Spousal/partner support sheds light on support within the couple on an emotional and psychosocial perspective, and perceived views of family as a team (Green, 2007; Maul and Singer, 2009). It was also reported as being part of family support across cultures (McConkey et al., 2008). Partner relationship, was reported as more important than intimacy when predicting parenting stress during the typical child's second year of life; whilst when the child was 6 months of age intimacy was regarded as more important than other forms of social support (Mulsow et al., 2002). Wieland and Baker (2010) indicated that spousal support amongst parents of children with ID did not differ from those who had typically developing children. However, a mother's good relationship with an intimate partner, be it the father of the child or not, was associated with a decrease in parenting stress while raising a typical child (Mulsow et al., 2002). It also seemed to strengthen family cohesion amongst parents of children with disability (Chang and McConkey, 2008), while single parenthood predicted greater levels of parenting stress (Williford, Calkins and Keane, 2007). Indeed, Trivette and Dunst's (1992) cross-sectional quantitative investigation implied that intra-family role sharing and extra-family support available to mothers of preschoolers with ID could buffer potential adverse effects of bio-cultural stressors such as those from employment and marital status.

A paucity of literature exists on division of labour and family-members' roles whilst raising young children with ID. Nevertheless, Dillaway and Broman (2001) noted that division of household labour and chores among dual-earning parents of typical children was associated with increased marital satisfaction. Older parents caring for adult

children with ID inferred traditional role responsibilities with more spousal sharing of grocery shopping and washing dishes (Essex and Hong, 2005), yet these are considered as less gender-stereotyped chores (see Twiggs, McQuillan and Ferree, 1999). In India mothers have more child care and domestic responsibilities than fathers in families with a child with cerebral palsy, whilst fathers had family shopping responsibilities (Goldbart and Mukherjee, 1999a). This indicates that division of family roles could reflect culture-specific features.

2.3.5.2 Formal support

Formal support refers to both professionals' and services' support from hospitals, educational institutions, health and human services in public and private agencies (Bosch, 1996). The positive impact of formal social support depends on the ability of providers of formal resources to match parents' needs; as well as the quantity and quality of services offered (Liptak, Orlando, Yingling, Theurer-Kaufman, Malay, Tompkins and Flynn, 2006; Dunst, 2007). MacDonald and Callery (2008) also recommended continuity of child care services in order for professionals to have full knowledge of the intervention programme rather than from a given point in time. Feinberg, Donahue, Bliss and Silverstein (2012) indicated that maternal stress levels did not affect their level of participation in services. Indeed, Asscher, Hermanns and Dekovic (2006) showed that the need for support was mainly predicted by risk factors of the child, individual and family levels, namely maternal depression (parent level), difficult temperament (child level) and negative life events (family level).

Moreover, Nachshen and Minnes (2005) identified that a strong network of social support amongst parents of school-age children, combined with family-centred services, greatly contributed towards a sense of empowerment. Families of children with disabilities expressed the urgent need for increased availability of services and access to service information (Hollingsworth, 1992). Gaining access to services has been reported as strongly related to parental stress (Davis et al., 2009) and failure in accessing the needed services reflected negatively on their involvement (Paige-Smith and Rix, 2006). Service access may also be achieved via referral from professionals. Smith, Akai, Klerman and Keltner (2010) identified a significant amount of developmental delays among children 0-5 years of age that were unnoticed by both the children's mothers and

the medical professionals, implying the need for other means of developmental delay identification or service access.

Bailey, Skinner and Sparkman's (2003) quantitative study implied that parents of a young child with Fragile X who obtained a diagnosis were enabled to access support networks: diagnosis also meant that they could reframe their perspective on life and family leading to personal growth, improved access to funding for services, or providing hope for a cure. Ygge and Arnetz (2001) also noted that the highest parental satisfaction was expressed about staff attitudes, care processes and medical treatment; whilst the lowest was access and environment of services. Arguably, according to Davis et al. (2009) parents of children with cerebral palsy expressed concern on the perceived difficulty of accessing support from services, as well as financial support, which affected their perceived quality of life negatively. Hence, these parents expressed a dire need for improved access to services, and an environment conducive to their child's needs. While, Redmond and Richardson's (2003) mothers of young children with severe ID suggested the wish for home-based respite services for employment reasons and reliable co-ordination of services allowing flexible care and emotional support for them as parents.

Early intervention (EI) services are delivered internationally with children and their families who are 'at risk' or manifest developmental difficulties (Meisels and Shonkoff, 2000; Guralnick, 2005). Infants who have a biological risk for developmental disorders are reported to benefit from early intervention; their cognitive development has been reported to be improved with consequent long-term benefits (Hadders-Algra, 2011). Early intervention services in paediatrics are also recommended to take into consideration those family circumstances which may place children at risk of negative educational and life outcomes (Carpenter and Egerton, 2005; Carpenter, 2007). The Head Start programme in the USA and Sure Start programme in the UK have provided early intervention services to children who are considered to be at risk for lower educational attainment.

Some barriers for EI services were identified by Jimenez, Barg, Guevara, Gerdes and Fiks (2012) among American parents and EI employees. These barriers included misinterpretation of professional's 'reassuring' communication attitude that they did not need EI services or some families may wish to wait for the developmental problem to

resolve itself, while some parents who were unaware that their child might have developmental difficulty agreed to be referred (Jimenez et al., 2012, p.553). However, not all those referred for EI services may opt to attend such services, as parents may disagree or delay their service attendance out of personal choice (Jimenez et al., 2012).

Ramey and Ramey (1999) indicated that investment in preventive interventions appears to be sound both in terms of cost savings on future child's educational specialised needs and also in the theoretical benefits related to improved educated citizenry. These services were delivered in various ways and approaches, such as early parent education (Sofronoff, Jahnel and Sanders, 2011) and collaborative approaches, such as family-centred care (Dunst, 2007; Dempsey and Keen, 2008), all focusing on multi-disciplinary service delivery methods (Carpenter, 2007). Family-centred service principles have manifested a close partnership with parents (G. A. King et al., 1999; Madsen, 2009) and tailored their programmes to the individual parents' needs that go beyond therapy-related issues (Dunst, 2007; Dyke, Buttigieg, Blackmore and Ghose, 2006). This approach to service delivery is viewed as highly effective to meet parents' perceived-needs over time (Trute, Hiebert-Murphy and Wright, 2008). Family-centred principles for early interventions services are discussed in section 3.5.

Parents reported experiences of advocating for their child's needs. This may be due to increased circumstances of having unmet care needs (Inkelas, Raghavan, Larson Kuo and Ortega, 2007; Jackson, Krishnaswami and McPheeters, 2011). Goldbart and Marshall (2004) indicated that their British sample, who parented children with cerebral palsy and who needed an augmentative and alternative communication, felt responsible for seeking help elsewhere for their child's communication needs when they perceived lack of assistance from professionals. Parents reported that advocating for their child was one of their top priorities, together with paying their bills, ensuring physical safety and security, encouraging child's self-esteem and doing things together as a family (King et al., 2006). Nevertheless, advocacy in Goldbart and Marshall (2004) was reported to be an activity which some parents reverted to as a last resort to achieve their child's needs. Mitchell (1997) added that this experience may be interpreted by parents as a tiring, exhausting contributing to the negative impact of raising a child with disability. On the other hand, Green (2007) showed that American parents of children with disability interpreted advocating for their child's needs as a positive experience, adding that they became experts in navigating through services. Parents also indicated

that advocating activities in the long term assisted them to gain skills and self-confidence as well as enhanced self-esteem (Green, 2007).

Furthermore, Thyen, Sperner, Morfeld, Meyer and Ravens-Sieberer (2003) found that psychosocial needs, health education, care co-ordination and medical needs were interpreted as unmet by parents of children with disability. This may also push some parents to involve themselves in their child's services in order for their child's needs to be taken seriously, which may in turn lead to 'over-involvement' with child's services (Falik, 1995, p.338). Indeed, some parents expressed a need for more parental involvement in their child's education and care (Case, 2000). When a child was allocated a key worker within the education services, in the UK, higher levels of parents' satisfaction and parental involvement was noted, unlike those not utilising such services (Liabo, Newman, Stephens and Lowe, 2001); which, given the key worker's increased communication contact with parents might itself lead to lower levels of unmet needs (Sloper, Greco, Beecham and Webb, 2006). McBride and Lin's (1996) investigation with American parents of young typical children in early childhood programmes recommended the need for staff to establish mechanisms for informing and educating parents as well as parental involvement. Such educational need was highlighted since it is an unrealistic expectation for parents to automatically have partnership-building skills. McBride and Lin's (1996) outcomes do need to be understood with caution, since their 'at risk' population consisted of economically disadvantaged families.

A number of English parents of young children with Down syndrome have expressed anger, perseverance, tension and conflict regarding parental involvement as educators and therapists in their child's development, in particular regarding accessing their child's services (Paige-Smith and Rix, 2006). Paige-Smith and Rix (2006) identified frustration amongst a few parents regarding staff replacement and the approach of their child's support teachers. Similarly, parents of children with developmental disabilities expressed feelings of exclusion and lack of expertise in addition to insufficient specialist services and ineffective strategies (Wodehouse and McGill, 2009).

2.3.6 Information and communication needs

Parents whose children are at risk for ID reported a need for information from professionals and available literature, in order to understand their child's developmental expectations, to take informed decisions as well as for preventive measures (Perrin, Lewkowicz and Young, 2000; Nicolaou et al., 2009). Families suggested that there is the strong need for information as soon as they receive the news that their child is born 'at risk' (Farrell and Frost, 1992; Guralnick, 2008a) and when the child is in a life-threatening health state (Rosetti, 2001).

Golish and Powell (2003) indicated that information gathering on the immediate environment and their child's conditions, when preterm birth occurred, seemed to have reduced perceptions of shock. Nevertheless, Padden and Glen (1997) noted that despite communication with staff being positively regarded, the majority of interviewed mothers reported high levels of anxiety and distress during their child's neonatal hospitalisation. Both Golish and Powell (2003) and Padden and Glen (1997) used qualitative methods, with the former using an interpretative approach whilst the latter adopted content analysis. These qualitative explorations were more in depth than Farrell and Frost's (1992) investigation, which identified information needs as one of the most critical among 30 parents of children admitted to neonatal intensive care using a survey method.

Parents found themselves, during neonatal hospitalisation, unexpectedly dealing with decisions on medical treatments and complex machinery. Apart from strong feelings of shock, they needed to be well informed to make decisions for their child (Jackson, Baird, Davis-Reynolds, Smith, Blackburn and Allsebrook, 2007) and needed to be aware of potential future consequences of their decisions (Guralnick, 2008). Moreover, children who were born with biological risks for ID might experience frequent hospital visits (Rosetti, 2001; Graungaard and Skov, 2006), further increasing stress on the family interaction patterns (Guralnick, 1998, 2008a) and insecurity (Graungaard and Skov, 2006). Apart from emotional distress on the family, parents needed information from professionals to visualise their future with their child (Graungaard and Skov, 2006). Information was also needed about child development or available support services (Popich, 2003; Ertem, Atay, Dogan, Bayhan, Bingoler, Gok, Ozbas, Haznedaroglu and Isikli, 2007).

Parents' reported the need for information as being most notable (Guralnick, 2008a) and the one they complained most about (Liptak et al., 2006). This was also noted when a family-centred service approach was adopted (King, Rosenbaum, and King, 1997; Wilkins, Leonard, Jacoby, MacKinnon, Clohessy, Foroughi and Slack-Smith, 2010); regardless of the reported high level of information giving in this service approach (Dempsey and Keen, 2008). Similarly, Verma and Kishore (2009) noted similar prioritised need amongst her Indian parents of children with disability. The children's specific developmental characteristics and related circumstances create this need for families to focus primarily on their child's current level of health and development as well as anticipated needs (Gurlanick, 2008). This may especially be the case for parents of very young children with risk factors for disabilities.

The importance of information-giving to parents of 'at risk' children is fundamental, in particular during the early months post-hospital discharge, due to reported increased distress and to stimulate the child's development (Nicolaou et al., 2009). The internet was identified as a source of information providing perceptions of being well-equipped among Norwegian parents of children with rare genetic disorders (Gundersen, 2011). Although Erickson and Kruz-Reimer (1999) and Rosetti (2001) indicated that a crucial part of a professional's role was to provide information to affected parents, yet this might not take place as required (Rosetti 2001). Hummelinck and Pollock (2006) highlighted that individual information needs were influenced by factors underlying personal issues reported by parents of chronically-ill child. Although some parents in their sample expressed the need to know 'everything' and receiving honest information about their child's condition, few parents reported active information seeking whilst others felt distressed with the information provided.

Parents perceived professionals, such as GPs, as consistent collaborative partners (Fredheim, Lien, Danbolt, Kjonseberg and Haavet, 2011) with whom longer appointment times were required (Liptak et al., 2006). Information from medical professionals such as nurses and doctors was interpreted as vital for decision-making processes, depending on the situation. If the infant required medical assistance or there were other concerns on the child's health, the doctor's input was prioritised over other sources of information (Padden and Glenn, 1997). Nursing staff were also identified as a source of information and in showing sensitivity to the parents' needs during the child's hospitalisation (Padden and Glenn, 1997).

The UK Education and Skills Committee (2006) argued that the professionals' partnerships with parents of typical or disabled children were not taking place as required. Similarly, Runswick-Cole (2007) showed perceptions of disempowerment in parents' relationships with health and education professionals as well as conflict about resource allocation to meet their child's needs. Runswick-Cole (2007) inferred that some parents perceived frustration about the lack of two-way communication about their child with special needs with professionals, although others felt they had a positive and effective communication relationship. Yet, Hodge and Runswick-Cole (2008, p. 645) concluded that little was done to equalise 'power relations' as professionals maintain their 'expert' identity seeing parents as 'passive partners'.

The American Academy of Pediatrics (2002) highlighted the essence of effective communication among services, between private and public sectors, as well as within the individual teams, to address perceived family's needs as a sign of commitment towards family-centred care with respect to cultural considerations. Unfortunately, Maguire and Pitceathly (2002) noted closed interviewing techniques used by clinicians with parents; who perceived them as indicative of a lack of interpersonal interest, which might result in poor health outcomes and treatment failure. Moreover, parents almost always welcomed physicians' encounters to share concerns which was observed not to increase the duration but increased the perceived helpfulness of the meeting (Street, 1992). On the other hand, the triadic nature of paediatric-patient-carer interactions were observed to require more time than with adult patients (Towle and Godolphin, 1999); this was considered essential due to giving value to child's preferences in addition to those of the parents.

Parents reported the need for more accessible information that was typically delivered in all care settings (Jurkovich, Pierce, Pananen and Pivara, 2000; Levetown, 2008) and with simple use of language (Padden and Glenn, 1997). Parent-staff communication, for informal reasons or gathering information, was reported by parents as providing therapeutic benefits; yet it was considered as an optional aspect of care within the medical professional field (Reid, Bramwell, Booth and Weindling, 2007). The process of gathering and receiving information was reported to have a double-edged nature for parents themselves, which highlighted the importance of professionals' understanding of parents' lifeworlds and concerns about their child's illness (Hummelinck and

Pollock, 2006), as misinterpretations might adversely affect the communication process (Sudia-Robinson and Freeman, 2000). Indeed, Huang et al.'s (2012) qualitative exploration, among Taiwanese fathers of children with disability, reported that fathers felt frustrated at insensitive communication and disregard of health professionals to their concerns.

Moreover, Cone (2007, p.35) indicated that a nurturing environment with single beds in NICU wards, as opposed to the 'traditional open bay' 'baby barns', was understood to be conducive to facilitating effective communication between parents and hospital professionals. Sudia-Robinson and Freeman (2000) observed the need for adequate time to establish a trust relationship with professionals and the need for information as a means to validate their concerns in order to play an active role in the decision making process.

Baile, Lenzi, Kudelka, Maguire, Novack, Goldstein, Myers and Bast (1997), however, revealed that medical professionals felt uncomfortable communicating unwelcome information that was likely to upset parents. Moreover, a quantitative research observed discomfort and dissatisfaction amongst parents who had primary information-intermediary role between the various professionals assisting their child as they felt to be acting as sole-coordinators of the child's care whilst simultaneously paediatricians reported more comfort in this perspective (Stille, Primack, McLaughlin and Wasserman, 2007). The lack of professional team communication may also explain to some extent, the increased reported parental involvement with the 'at risk' population during preschool education (see McBride and Lin, 1996), especially since these 'at risk' children may experience early school maladaptive behaviours (McIntyre, Blacher and Baker, 2006).

2.3.7 Financial needs

Child development needs often disrupt typical family routines, placing numerous unexpected time and financial demands on family members (e.g. Greer et al., 2006). Indeed, Emerson, McCulloch, Graham, Blacher, Llwellyn, Gwynnyth and Hatton (2010) pointed out that the family's socioeconomic circumstances might contribute to the parents' risks for psychiatric disorders whilst parenting their child with ID. It was argued that in the United States, for example despite federal and state programmes

together with private insurance, the financial difficulties of families should not be underestimated (Shannon, Grinde and Cox, 2003). Indeed, Resch et al. (2010, p.143) noted that American parents, although they had 'deductible' financial assistance, they still had significant service expenses. Hollingsworth (1992) stated that although financial needs of families parenting children with disabilities were not addressed in their exploration it was brought up frequently. According to Guralnick (2008a) resource needs, involving financial aspects, have the potential to unsettle family functioning (Guralnick, 2008a) and reduce quality of life (Davis et al., 2009). In fact, administrative professionals working with these parents view their roles as providing empowerment through resource management for the benefit of the family of the child in need of services and government-provided funds (Epley, Gotto, Summers, Brotherson, Turnbull and Friend, 2010).

Leijon, Finnstrom, Sydsjo and Wadsby (2003) reported that Swedish mothers of preterm born children used parental leave from their employment more often than those with typically born children. However, the relationship between maternal employment and their child's cognitive performance has been reported in an inconsistent manner. Olsson and Hwang (2006) observed that when both parents were less involved in paid work they seemed to report lower levels of wellbeing. Whilst Youngblut, Brooten, Singers, Standing, Lee and Rodgers (2001) did not report such relationship amongst mother-headed single parent families using psychometric test batteries and stress indexes. Cuskelly, Pulman and Hayes (1998) revealed a strong association in two-parent families. They indicated that mothers of a young child with a disability were less likely to be employed full-time outside the home than mothers of young children without disability despite non-significant differences between mothers' characteristics. Arguably the increase of demands in the home including caring for their child with disability may restrict the opportunities available for mothers to work outside the home.

Mothers may not perceive the necessity to return to the employment world due to the perceived caregiver burden (Oh and Lee, 2009). Mirfin-Veitch, Bray and Watson (1997) and Shpancer and Bennet-Murphy (2006) found some inter-generational influences on decisions about non-parental child-care services. However, the majority of their sample still preferred extended family care as the optimal non-parental care, despite their history of formal non-parental care. Although mothers of typically developing children and those parenting a child with severe activity limitation shared similar desire to work

outside the home (Gordon, Rosenman and Cuskelly, 2007), limited opportunities for parental leave to maintain prior-birth jobs might prove to be unhelpful for the latter (see Galtry and Callister, 2005; Earle, Mokomane and Haymann, 2011).

Added distress was reported in association with caregiver burden and maternal employment in relation to increased disability related costs, less social support as well as maternal characteristics, such as being young and having higher educational attainment. Allen (2007) added that families with greater needs for resources might not receive more intensive interventions than those with lower levels of needs agreeing with findings from Mahoney and Bella (1998). Stabile and Allin's (2012) study highlighted that there were contemporaneous (family expenditure, earnings, stability and programme spending) and lifelong costs for American parents raising a child with disability; further justifying the cost-benefit ratio of interventions to prevent and reduce childhood disability. Cuskelly et al. (1998) added that medical needs of raising a child with a disability influenced 42% of their sample's unemployed mothers in their decision not to seek employment outside the home. In order to meet the range of needs experienced by families of children with a disability, financial resources are essential to assist in not only family subsistence but also to support optimal development of the affected child.

2.3.8 Changes over time

The needs of children with developmental disabilities are complex and change as the child develops (Paschos and Bouras, 2007). This may also be reflected in the family's experiences and needs (Rosetti, 2001; Jackson, Tentedst and Schollin, 2003). Limited research has been carried out on changes of parents' experiences during the first five years of raising a child with or at risk for ID. Possibly, the first five years of the affected child's life could be marked as the diagnostic period for ID (Lin, 2000).

Longitudinal qualitative research, by Jackson et al. (2003), observed changes in the perceptions of 7 sets of Swedish parents whose child was born with preterm birth complications (34 weeks or less gestation). Jackson et al. (2003) reported that these parents perceived alienation after the birth of their child, moving to responsibility, confidence and familiarity by the time the child was 18 months old. Their exploration outlined alienation as dominated by maternal ambivalent feelings and a sense of

unreality by fathers. Maternal concern for the baby and fathers' feelings of responsibility for the baby's care predominated in the 'responsibility' theme. By the time the child was 18 months of age mothers had expressed a relationship with the child as being part of their family and fathers reported that they were living in the present with no thoughts of the neonatal period.

MacDonald and Callery (2008) also observed that the child's developmental experiences strongly influenced the caregivers' accounts. However, they interviewed caregivers of children with 'major cognitive impairments' and tracked experiential changes based on their retrospective experiences from the child's infancy to adulthood (MacDonald and Callery, 2008). For example the caregivers' experiences were based on the care needs of the child: as the child grew, their care-giving needs changed. Family's experiences of support, psychosocial responses of families, environmental and home adaptations as well as policy statements' influences on care were amongst the areas of changing parental experiences as the child grew. Although, MacDonald and Callery included mothers, fathers and a few grandfathers as main caregivers of children with complex disability, they recommended that professionals should be aware of parents' changing needs for the benefit of the child and the whole family involved.

Using a cross-sectional design, Davis et al. (2009) also examined potential changes in quality of life of families raising children with cerebral palsy from young childhood to adolescence. Their findings suggested that the primary issues related to caring for a child with cerebral palsy remained similar throughout childhood and adolescence, such as gaining access to services and the degree of dependency of the child's condition. Parents also pointed out that the perceived level of impact was more prominent during the early years while raising their child. These two major age groups, childhood and adolescence, have different experiential events however perceptions related to the caring of their child remained the same (Davis et al., 2009). Conversely, Jackson et al.'s (2003) results reflected distinguishable changes in parents' perceptions, regardless of the small intervals between groups and the variation of hospitalisation experiences. Likewise, Hsieh, Huang, Lin, Wu and Lee (2009), who used a quantitative analysis, noted that Taiwanese parents of young children with general developmental delay adapted to their child's delayed development as they grew. Such differences may be attributed to the nature of child's impairment and/or the different qualitative analysis

adopted; where Davis et al. (2009) used grounded theory whilst Jackson et al. (2003) used Giorgi's descriptive phenomenological method of inquiry.

A change over time was also observed by Lin's (2000) cross-sectional quantitative exploration of adaptation of parents of children with cerebral palsy from childhood to adulthood. Results suggested that family adaptation differed in terms of the family life cycle stages based on the child's age, agreeing with Davis et al.'s (2009) findings. The more the child grew the more the parents adapted to their situation. Lin (2000) showed that families of young children with cerebral palsy were marked by experiences related to the diagnostic period, intensive medical services as well as initial crises. Perception shifts were reported by parents of children with disabilities based on the child's age whilst certain aspects, such as downward comparisons, seemed to maintain their influence throughout the child's life. Although changes were revealed in the experiences and perceptions of parents raising children with a wide span of ages (childhood to adulthood) or with during the first 18 months of life, none focused solely on the child's first five years of life.

2.4 The Maltese culture

An international exploration involving 76 cultures, including Malta, was extensively discussed by Hofstede, Hofstede and Minkov (2010). According to these authors, Malta seems to have moderate power-distance (emotional distance based on social inequality) and masculinity values (assertiveness versus nurturance), moderately high individualism (ties between individuals are loose) and high uncertainty avoidance values (intolerance of ambiguity) (Hofstede et al., 2010). These values may not represent each individual's views in the Maltese culture due to the statistical method employed from a socio-cultural and anthropologic perspective. Hofstede et al. (2010) interpreted these values based on the linguistic nature of a given culture. Yet, power-distance values seem to contradict some Maltese anthropological studies (Abela, 2009; Savona-Ventura, 2009).

According to Sultana (1994) the Maltese have high regard to professional hierarchy, similar to Hofstede et al.'s (2010) high power-distance values. However, the Maltese culture also reports close family relationships (Abela, 2009), especially when young infants are involved (Borg Xuereb, 2008), which represents low power-distance values according to Hofstede et al. (2010). Thus, Malta's culture has both high and low power-

distance values. However, these could have been averaged out during the statistical explorations employed by Hofstede et al. (2010) marking the country with moderate power-distance values. Nevertheless, the high uncertainty avoidance values agree with O'Reilly Mizzi's (1994) finding of high gossip in the Maltese culture (see section 2.4.2).

2.4.1 The Maltese family

Maltese families, according to Tabone (1995), were in a transition towards more secular nuclear families. This also influenced smaller family sizes when compared to earlier decades (Savona-Ventura, 2009). Although Abela (2000) reported a strong religious influence in the Maltese culture, the religion-cultural supremacy seems to be decreasing (Montebello, 2009). The family is valued by the Maltese society especially in the national economy and cultural beliefs (Abela et al., 2005) and is considered as 'the most important building block of society' (Abela, 2009b, p.44). Children are cherished and prioritised within the family (Abela et al., 2005). Maltese mothers tend to have greater responsibility of childhood upbringing than fathers (Borg Xuereb, 2008). The Maltese Islands, together with the Philippines, were the only countries where it was not possible to obtain a divorce until late in 2011. Abortion or termination of pregnancy for foetal anomaly is illegal in Malta. This may have contributed to the reported Maltese high neonatal mortality and morbidity rate in EU statistics (Khoshnood, Greenlees, Loane and Dolk, 2011).

In Malta, it is obligatory for couples to participate in preparation for marriage courses which focus on enhancing relationship stability, should they wish to marry in church (Abela et al., 2005; Mallia, 2010). Moreover, Abela (1994) indicates that there has been a strong emphasis on traditional families and on family values: positions stemming from the strong Maltese Catholic tradition. Abela (2009a, p.149) states that 'the unity of the family and the need to uphold marriage as a permanent relationship continue to be important values' that are entrenched in the Maltese culture. Moreover, Abela et al. (2005) inferred that a strong influence of child-oriented family values and high level of marital satisfaction were more prominent in Malta than in other countries, while, McGregor (2008) added that Malta is one of the most family oriented countries in Europe.

Traditional gender roles are reflected in Maltese family characteristics (Sammut, 2003; Mintoff, 2003; Borg Xuereb, 2008), even when compared to other European countries (Aquilina, 2007). Statistically significant results are noted regarding gender roles in housework, child care but not shopping, playing with children and listening to children's problems, or financial decision making (Sammut, 2003; Borg Xuereb, 2008). Moreover, Sammut (2003) noted that a difference in the educational background existed, where housework seemed to be reported as shared when the parents have post-secondary or tertiary education. Similarly, Mintoff (2003) reported that Maltese husbands' and wives' traditional ideologies, presence of children, time availability and greater relative resources emerged as possible factors impeding the attainment of gender equality in married couples. Sollars, Attard, Borg and Craus (2006, p.8) indicated that culturally child-care is highly associated with the mother, and they are socially expected to terminate or halt their prior employment to 'raise their family'. However, Abela, Casha, Borg Xuereb, Clark, Inguanez and Sammut Scerri (2012) emphasised the lack of child-care services for young children with disability (0-3 years of age); an aspect that could influence the family's financial status.

A longitudinal mixed methods study on first time Maltese parents with a child born under typical circumstances noted strong gender influences in Maltese parents' child rearing decisions and work related plans (Borg Xuereb, 2008). Moreover, she implied that sharing family responsibilities between the couple seems to have a direct impact on marital relationships and possibly emotional well-being. Abela (1998) and Azzopardi (2007) pointed out that young married working women and women with higher educational levels, together with their husbands, are finding it difficult to reconcile a traditional belief system based on traditional gender roles in the emotional wellbeing of the family, with the new challenges of their own family life. Nevertheless, feelings of happiness, fulfilment as well as strong attachment and pride of being a parent were reported by first time Maltese parents of typical children (Borg Xuereb, 2008). She also noted that the adoption of a more traditional division of family tasks in the postnatal period may be responsible for the lowering of marital satisfaction compared to those experienced during the antenatal period.

Malta has 'face-to-face' community characteristics (Abela et al., 2005, p.5), where given the country's small size, the Maltese have generated a *savoir-faire* which enables them to handle conflict in a constructive way (Sultana and Baldacchino, 1994). This is

also a distinct feature of the Maltese in international literature (Abela et al., 2005). Indeed only 5.65% married couples were officially separated in Malta (NSO, 2008). From an anthropological perspective, O'Reilly Mizzi (1994) implied that the family system, the size of the island and the Catholic Church have a great influence on the Maltese family value system in general. It is believed that one of the main explanations for the successful transmission of this legacy of family life from one generation to another lies in the strong social fabric which is characterised by social control and a cautious attitude to change (O'Reilly Mizzi, 1994; Abela, 2009b). This cautious attitude may present an ideal situation to prepare for future changes through evidence-based practice, further highlighting the importance of the present study for Malta.

2.4.2 Experiences of Maltese parents

Children are the future of every society. Pre-birth full-time working mothers in Malta are typically granted an 18 week paid maternity leave. Optional parental leave depends on whether one works with public or private enterprises; this varies from 6 months to a 5 year-period of unpaid leave. Paternal leave is also offered however this is not widely publicised and men still show reluctance to make use of such an unpaid service due to traditional gender roles (Sollars et al., 2006). Malta, therefore, seems to present similar conditions to other European countries (Wall, Pappamikaaail, Leitao and Marinho, 2009). Research carried out exploring parents' experiences have mainly been undergraduate studies and have included small and varied samples focusing mainly on nursing (Portelli, 2006) and social work perspectives (Galea, 1989; Testa, 1991; Frendo Cumbo, 1998; Portelli, 2006; Borg, 2006). One undergraduate dissertation focused on the parents' emotional adjustment to having a child with Down syndrome (Ferriggi, 1993). Such studies have used quantitative and qualitative perspectives to study family adjustment to a child with disability. However, none have recorded experiences of parents whose child were born at risk for ID and focused on the early years of the child's life.

In Malta 8.9% of postnatal mothers manifested true postpartum depression since delivery, which is lower than Anglo-American populations (Felice, Saliba, Grech and Cox, 2004). Felice et al. (2004) attributed this finding to the social support available to women living in a cohesive community (Tabone, 1994, 1995). However a more recent study about Maltese parents rearing typically born infants also found that 26.8% and

15.4% of mothers and 10.5% and 5.4% of fathers were distressed in the postnatal period at six weeks and six months, respectively (Borg Xuereb, 2008). Strong family support from the couple's families was observed to include emotional and practical support; such as household chores and caring for the baby of first-time parents under typical circumstances (Borg Xuereb, 2008).

Maltese parents of children with a disability perceive that they are marginalised, devalued by society and expressed feelings of discrimination and social stigma (Borg, 2006). Persons with disability perceived themselves as excluded from the rest of society (Callus and Bezzina, 2004). This may tentatively be explained by the relationship of the small size of the island and the reported 'gossiping' about other people's lives in the Maltese culture (see O'Reilly Mizzi, 1994, p.369). Borg (2006) also indicated that Maltese parents of a child with Down syndrome reported distress during the diagnosis-giving period. Arguably, Borg (2006) and Ferriggi (1993) focused on the negative experiences of parents of children with disability, regardless the neutrality of their research aims.

Abela et al. (2012) explored the needs of Maltese families with dependent children. A number of needs were identified such as lack of access to services due to high waiting lists and lack of child-care services for young children with disabilities. Abela et al. highlighted that policymakers should prioritise families most in need including families with disability. Although this study incorporated needs of parents rearing children with disabilities, such needs were identified from the professionals' perspectives as parents were not included in this study. The exploration of families' needs from the parents' perspective was recommended by Abela et al. (2012) to assist their survival in modern society.

Portelli (2006), who explored parents' perceptions of children who were hospitalised, noted a number of positive perspectives such as perceived well-being in a technologically equipped environment, support from nurses' behaviour and that both nurses and doctors worked together as a team. One need to take into consideration that Portelli (2006) did not specify whether the children had a disability but only mentioned that these children needed 'elective surgery'. Nevertheless, similar to other countries some mothers of children who were hospitalised but who did not have a permanent disability expressed a strong need for information, learning needs, a need for change in

service delivery, as well as a need for emotional support. These studies, mainly undergraduate, that focused on parents of children with disabilities were carried out with small samples whose ages and type of disability varied widely. It is not specified whether all the children were born with congenital disability, 'at risk' or were diagnosed at a later stage.

The experiences and needs of Maltese parents of children born with biological risks for ID are as yet unexplored in significant depth. It would be of great benefit if their needs were explored and identified in order to be able to offer more personalised and tailored services required by these families.

2.4.3 Paediatric services in Malta

Currently, in Malta there are both public and private paediatric health services throughout the archipelago. Medical and pharmaceutical public services are focused at the national hospital, in Malta, and at another hospital in Gozo. These consist of both in-hospital services and outpatient hospital services. General and specialised medical services are also spread throughout the islands in 8 health centres and their local respective district centres. Allied health professionals such as physiotherapists, speech and language therapists and occupational therapists have outpatient hospital services. However, only physiotherapy and speech and language therapists offer paediatric public services in health centres while the latter extend their services in district centres and in public schools as well.

Public services typically take place during the morning and early afternoon whilst private services extend their services throughout the day and evenings. Parents of children with a diagnosed disability are entitled to a disability pension of 16.31 Euro /week provided by the government to assist with potential added fees until the child's age of 14 or 16, depending on the type of diagnosis (National Commission for Persons with Disability, 2009). This however, is not given to parents whose child is born with biological risk for ID without an official diagnosis. A number of individual paediatric private services exist, although, only two multi-disciplinary organisations exist, offering private non-governmental services to children with disabilities based on self-referral by parents. A number of parent-run voluntary and non-profit organisations exist in Malta, such as the Down Syndrome Association amongst others, who provide support to

parents of children with disabilities (National Commission for Persons with Disability, 2009).

The Neonatal and Paediatric Intensive Care Unit (NPICU) at the national hospital offers intensive care to children who are born with complications such as congenital anomalies, prematurity, having low birth weight and low Apgar scores amongst other conditions that are considered at risk or life threatening for the baby's life (from birth to 3 years of age). At present the NPICU functions primarily with the medical professional team, namely midwives, nurses, specialist paediatricians and specialised paediatric surgeons. It does not have other allied health professionals as part of their team. Occasionally, when parents are visibly very distressed, they are referred to a bereavement midwife. A community midwife visits the parents at home for approximately 3 times to support them in the caring for their baby.

After hospital discharge the child's paediatrician follow the affected children on a regular basis through outpatients appointments. At the paediatrician's discretion, they may be referred to the Child Development Assessment Unit (CDAU) which is a multi-disciplinary government service for children from birth to 6 years of age (Soriano and Kyriazopoulou, 2010). This is run by a specialised paediatrician and was founded in 1995. Referrals are received from family doctors, baby clinics or speech and language therapists since these are reported to be the first 'to work with children as young as 2 years' (Soriano and Kyriazopoulou, 2010, p.15). The multi-disciplinary team working at CDAU include all paediatric outpatient hospital services such as ear nose and throat (ENT) services, ophthalmic services and dentistry services as well as physiotherapists, occupational therapists, speech and language therapists, clinical psychologist amongst other allied health professionals.

CDAU has also recently linked to education through early childhood educators from the Directorate for Educational Services. These offer Early Intervention Services to CDAU-referred service users. This is carried out via home-services to ensure that children maximise progress prior to formal education entry and they cater for children from birth to 5 years of age manifesting 'developmental, medical, psychological, physical, learning and/or other difficulties' (European Agency, 2009a, p. 1).

'Early intervention aims at helping the child to develop his/her full potential in spite of the child's needs. It also provides support to parents/ legal

guardians, tutors, teachers and learning support assistants (LSAs) in the holistic educational development of the child paving the way for his/her future scholastic experience.’ (European Agency, 2009a, p.1)

Early intervention services in Malta are provided from the public education sector via a multi-disciplinary approach. Critically, its aims although they include a ‘holistic’ nature are still confined within the ‘education development’ and ‘scholastic experience’ by comparison to international early intervention service concepts (see section 2.3.4.2) and seem to remain within the child-focused perspective (see section 3.5). This service is however ‘not widespread in Malta although the government has introduced schemes to increase the participation rates at this level of education’ (European Agency, 2009b, p.1). Vella (2009) indicates that the early intervention services in Malta is open to all ‘referred’ children ‘whose development is not progressing according to the norm’ (p.7), also offering a Home Start programme to families identified as ‘being in need of support’ (p 5). However, literature on such Maltese family needs is, as yet, unavailable.

A number of child-care centres have been available around the country since 1996/7, financed through parental fees (Sollars et al., 2006). The government has introduced tax rebates on tuition fees for such day centres to the parents and for employers who provide such services at their workplace (European Agency, 2009b). Sollars (2002, cited in Sollars et al., 2006) indicated that 17.6% of grandparents are available for a limited time while 9.3% were unavailable concerning child-care assistance to young parents. It is understood that child-care centres educationally cater for children from birth to three years; however these are paid services for those who do not live on a minimum wage. European Agency (2009b, p1) also specified that premises are suitable and accessible to children with disabilities following Equal Opportunities Act.

Maltese children typically begin schooling at 3 years of age at preschool kindergartens. Although this is not compulsory, more than 90% of Maltese parents utilise this service (Sollars et al., 2006) as it is considered to be preparation for their children for acquiring literacy skills and compulsory formal education that officially starts at 5 years of age. There are a number of government and private schools; the latter include independent and church-run schools. Once the child with a disability enters schooling at 3 years of age, they may be allocated a LSA for in-class support, following a series of assessments and permissions from Statementing Moderating Panel. This is provided during the scholastic period (European Agency, 2009a). Children with disabilities who are

allocated a LSA are included in mainstream schooling, however a number of special schools exist around Malta, catering for those children with more severe needs and at the discretion of parents (European Agency, 2009a).

2.5 Conclusion

This chapter has outlined the current available literature on the influences of biological risks for ID during childhood. Parents' experiences while rearing children with diagnosed or at risk for ID seem to result in intense emotional experiences during the early years of the child's life. Unmet support, information and financial needs seem to contribute to added distress amongst these parents. Changes in parents' perceptions whilst raising an 'at risk' child may occur, however there are some inconsistencies in the literature due to explored child's wide age range and different methodologies. There is a paucity of research focusing on changes in parents' experiences during the first five years of the child's life. There is also a lack of data about lived experiences of Maltese parents that would inform social policymakers, in order to mobilise service delivery towards their actual needs and experiences. Theories informing this study will be discussed in the following chapter.

Chapter 3 Theoretical framework

3.1 Introduction

This chapter discusses the theories upon which this study was based. It includes the bio-ecological model (Bronfenbrenner, 1994), developmental niche model (Super and Harkness, 1999), family systems theory (Broderick, 1993; Friedman et al., 2003), early intervention model (Guralnick, 1998; 2005) and family-centred principles (Dunst, 2007). Each theory or model is linked to the next in a hierarchical manner, due to their inherent principles, which act as stepping-stones to the next. All of these theories give importance to children and their families while some focus more on children with disabilities and their families. These are individually outlined followed by a discussion on their relationship to this study.

3.2 Bio-ecological model and developmental niche

Bio-ecological model

Bronfenbrenner's (1979, 1992, 1994) work focused on the importance of viewing the child in the context of his/her family as well as the family in the context of their social conditions (Krauss, 2000). He gives importance to the child's developing environment depending on the individual proximity influences. His model (see figure 3.1) adopted a series of concentric circles placing the child in the central position. S/he is surrounded by his/her immediate family and significant others in the innermost concentric circle, labelling this layer as the micro-system. Each surrounding layer consists of a set of individualised interactive processes and relationships with the child's social environment; the farthest, such as society in general, being less close but still significant (mesosystems and exosystems, see figure 3.1). A continuous dynamic process of developmental influences (transactional process) takes place across all systems in the bio-ecological model resulting in adaptation of the relationships between individual and context (Sameroff and MacKenzie, 2003). This theory has helped clinicians and researchers to appreciate that child development results from the interplay of biology and environment (Garbarino and Ganzell, 2000). Bronfenbrenner suggested that successful intervention programmes view children as individuals within a family rather than as isolated experimental beings (Meisels and Shonkoff, 2000).

The bio-ecological model has had several reformulations, the latter involving time effects on individual development (Chronosystem, see figure 3.1) and developmental consequences in chaotic environments (Bronfenbrenner and Evans, 2000). It asserts that the child's developmental growth and learning is influenced by each concentric layer in individual hierarchical manner (Bronfenbrenner, 1979, 1994), where each layer can be enhanced to assist or stimulate child development (Wolery, 2000).

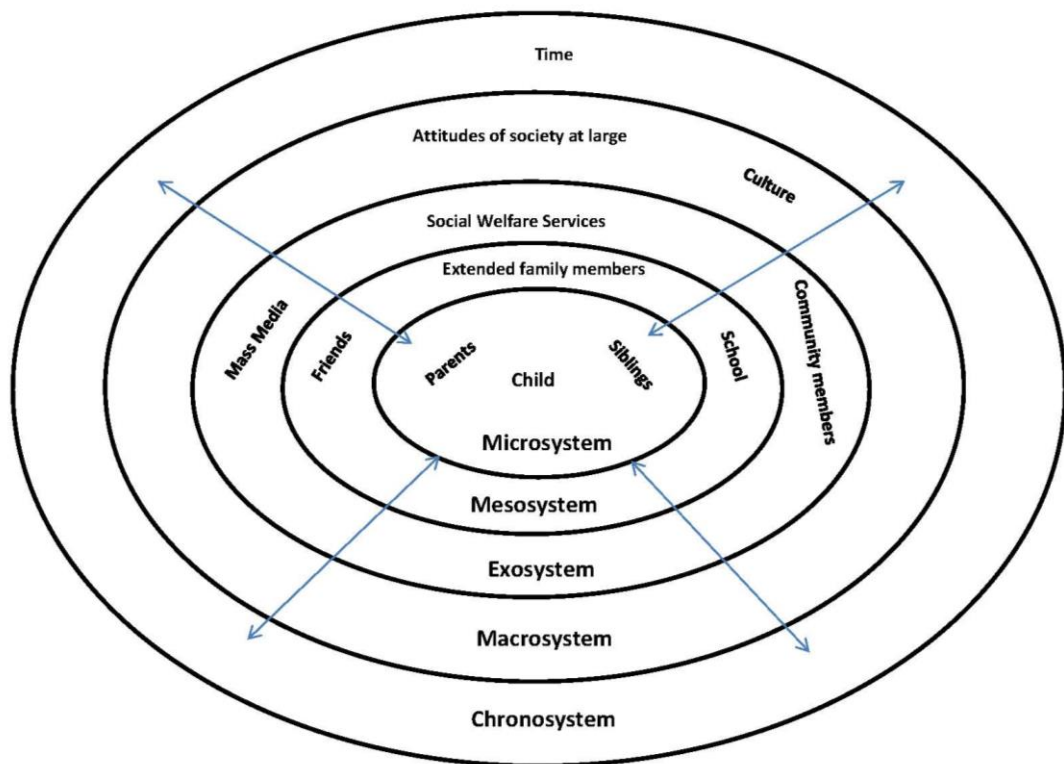


Figure 3.1: Bronfenbrenner's Bio-ecological Theory

Bronfenbrenner's perspective had theoretical origins (Bronfenbrenner and Evans, 2000) and was criticised that it has outlived its usefulness (Ramey, Krauss and Simeonsson, 1989). Nevertheless, it had significant impact on intervention planning over the years (Wolery, 2000) and has been widely and successfully adopted in developmental research, early intervention and empowerment models, to date (Turnbull, Turbiville and Turnbull, 2000; Wilder, 2008). Bronfenbrenner (1992) gave considerable importance to children with disabilities and their environment as it supported the understanding that development was a joint function of environmental influences. Environmentalists see the child as shaped by the immediate environment (Sameroff and Feil, 1983), while Bronfenbrenner (1992) considered the child as an active individual influencing and contributing to his/her environment.

Houston (2002) identified a lack of direct exploration towards addressing social inequalities society-at-large in order to compensate for the disadvantaged in the bio-ecological model. Bronfenbrenner did acknowledge the effects of social class and unequal distribution of resources in society, however, this model focused on the developmental paradigm (Bronfenbrenner and Evans, 2000) rather than the sociological perspectives as such. Bronfenbrenner's theory is of particular importance for this study since it addresses the developmental needs of the child through the parents and the home environment to plan successful early intervention services.

Developmental Niche

From an anthropological perspective, the concept of a niche, as described by Super and Harkness (1999) regards culture as a direct influence on the development of individuals. It expands Bronfenbrenner's micro-system concept with three sub-systems: settings, customs and caregiver psychology. Settings involve the physical and social settings where the child engages in daily experiences. Customs encompass culturally regulated routines and attitudes in childrearing embedded in the child's life, while caretaker psychology includes the cultural belief systems shared by parents in a given community. Each subsystem is also surrounded by other aspects of human environment in unique and different ways, initially labelled as homeostatic mechanisms (Super and Harkness, 1986). The three subsystems influence each other and have a common adaptation process that is individual for each child, based on inherited dispositions and family composition (Harkness, Super, Sutherland, Blom, Moscardino, Mavridis and Axia, 2007).

Wachs (2000) pointed out that there is a bidirectional relationship between individuals and their niches. Children are considered to be active participants in their niches, thus children with disabilities also influence their niches through their individual needs (Wilder, 2008). Bronfenbrenner considers that although motivational forces in developmental change "can be external to the individual in learning theory, it is the individual's perception of the environmental properties that exerts the most influence on development in ecological theory" (Sontag, 1996, p.328). This argument likewise agrees with Super and Harkness (1999) and Harkness et al. (2007).

3.3 Family systems theory

An approach to family systems theory was developed by Bowen (Friedman et al., 2003) and this has evolved along the years. The family systems theory is grounded in bio-ecological principles and has been widely adapted to various research areas, such as psychology, social work, family health and developmental fields (Broderick, 1993; Casey, 1996). The current study acknowledges the family's role as a unique and adaptive social system, consisting of a small group of closely interrelated and interdependent individuals who are organised into a single unit, in order to attain family functions or goals (Friedman et al., 2003). This model claims that the family unit has an adaptive nature and has the potential for the understanding of individual family lifeworld experiences. Using a holistic approach, a system must be understood as a whole and cannot be comprehended by examining its individual parts and interactions in isolation from each other (Whitchurch and Constantine, 1993, p.328).

Table 3.1: Assumptions of Family Systems Theory (Friedman et al., 2003, p.154)

Assumptions of family systems are as follows:

- Family systems do not exist in a vacuum (the context in which system functions is critical)
 - All parts of the family system are interconnected or inter-related
 - The whole is greater than the sum of its parts (non-summative)
 - Understanding is only possible by viewing the whole family
 - Whatever affects the system as a whole family affects each of its parts (the ripple effect)
 - Causes and effects are interchangeable (circular causality notion)
 - Family systems are self-reflexive and goal seeking.
-

It is understood that family members interact with each other and affect each individual's characteristics and life circumstances. Consequently, a child's ID would have ramifications on the parents, family system and siblings (Pfeiffer, Gerber and Reiff, 1985; Dyson, 1996). This theory does not specify its focus solely on families raising children with disabilities, although it offers an opportunity to understand how the child's disability can affect the other family members through the interconnectedness of its members via the ripple effect (see table 3.1). The family system itself may consist of various sub-systems (e.g. spouse sub-system, parent-child sub-system etc.). It is acknowledged that three related limitations exist. These include the individual characteristics of each family member (gender, age etc.), the family's structural characteristics (size, composition etc.) and the family's placement in the

larger society (socio-economic status, locality etc.) (Broderick, 1993). Each of these aspects may develop an individualised ripple effect within the family system, limiting the method of exploration and generalisability of outcomes.

In family systems theory it may be assumed that the ‘traditional’ nuclear family may be the blueprint against which other family types should be compared (Hay and Nash, 2002), although this theory has an open reference to family, including all compositions of families. Contemporary developmental science criticises such a theory as describing child development and rearing that equate to middle-class and developed western societies (e.g. Bornstein, 2002). Adopting a family systems approach to research, however, provides the opportunity to understand how to approach families in a given situation that is effective and comprehensive, yet sensitive to their unique experience (Head and Abbeduto, 2007). Additionally, family systems theory underpins many models of service delivery that recognise the inter-relatedness of family members and the importance of acknowledging the needs of all family members, not just the individual person (Dunst, Trivette and Johanson, 1994; Carpenter, 1997; Knox, Parmenter, Atkinson and Yazbeck, 2000; Brown, Nolan and Davies, 2001). Consequently, family systems theory influenced the decision in the present study to interview both parents together, as they were influencing and were being influenced by each other.

3.4 Early intervention model

Guralnick’s (1998) early intervention model highlights the pivotal role of the family on the child’s development, giving importance to the interaction patterns influenced by the individual family characteristics: including personal characteristics, financial resources, social supports and child temperament. This model also incorporates family systems theory principles. Developmental science focuses on three patterns of parent-child transactions: namely sensitive responsiveness processes, family pattern of interaction and patterns ensuring child’s health and safety (Guralnick, 2008a). This model proposes a number of potential stressors that may hinder optimal family interactional patterns during the child’s development process namely: information needs, resource needs, interpersonal and family distress and confidence threats. Although, Guralnick (1998, 2005, 2008a) labelled such needs as stressors, he viewed them as secondary to the child’s biological vulnerabilities to create a preventive awareness in professionals’

intervention programmes. It is understood that the combined effect of these stressors added to the consequent environmental risks on these three parent-child interaction patterns, may produce a more significant effect on the child's intellectual development (Belsky and Fearon, 2002).

According to Guralnick (1998, 2005) in the absence of early intervention services, children born with biological risks and established risk may manifest a substantial decline in intellectual development during the first 5 years of the child's life. Feldman (2004) shows that there is considerable empirical support for Guralnick's model. However, although this theory is comprehensive in its details, Erickson and Kruz-Riemer (1999) criticise this approach in that it is only focused on the cognitive perspective rather than on all aspects of child development. Yet, this model is widely used in early assessment and intervention programmes because of its inclusion of family stresses and influential features on the child's development (Guralnick, 2007).

Table 3.2 Common ground principles (Guralnick, 2008b)

Common ground principles:

1. A developmental framework informs all components of the early intervention system and centres on families
 2. Integration and coordination at all levels of the early intervention system are essential
 3. The inclusion and participation of children and families in typical community programmes and activities are maximised
 4. Early detection and identification procedures are in place
 5. Surveillance and monitoring are an integral part of the system
 6. All parts of the system are individualised
 7. A strong evaluation and feedback process is evident
 8. True partnerships with families cannot occur without sensitivity to cultural differences and an understanding of their developmental implications
 9. Recommendations to families and practices must be evidence based
 10. A systems perspective is maintained recognising interrelationships among all components
-

Guralnick (2008b) also identified 10 principles that could strengthen early intervention services fostering common grounds in the international community (table 3.2). Contrarily to his prior criticism, Guralnick (2008b) offered a wide spectrum of values that can be applied on an international basis.

3.5 Family-centred principles

Falling within the family systems milieu, the family-centred philosophy has developed from both the help-giving and empowerment literatures (Dempsey and Keen, 2008), incorporating an additional help-giving concept to the aforementioned early intervention model (Guralnick, 2005); it actively prioritises affected families' needs and wellbeing rather than just creates awareness. Family-centeredness is both a philosophical standpoint and a service delivery method for children and parents (Truesdale-Kennedy, McConey, Ferguson and Roberts, 2006). At the core of the family-centred approaches is the recognition of the centrality of the family (Bailey and McWilliam, 1993). The goal of family-centred intervention is one of improving the well-being of the family as a whole (Bailey and McWilliam, 1993) through family strengths. Since the mid-to-late 1980's, family-centred approaches have become more prevalent in the USA.

Table 3.3 Family-centred principles (Dunst, 2007, p.162-3)

Family-centred principles:

- The experiences and opportunities afforded infants and toddlers with disabilities should strengthen children's self-initiated and self-directed learning and development to promote acquisition of functional behavioural competencies and for children's recognition of their abilities to produce desired and expected effects and consequences.
 - Parent-mediated child learning is effective to the extent that it strengthens parents' confidence and competence in providing their children with development-instigating and development-enhancing learning experiences and opportunities.
 - The role of early-intervention practitioners in parent-mediated child learning is to support and strengthen parents' capacity to provide their children with experiences and opportunities of known qualities and characteristics that are most likely to support and strengthen both parent and child competences.
-

Consequently, the principles in Table 3.3 give parents the responsibility of creating response-contingent learning opportunities in the child's environment (Dunst, 2002) while viewing the professional as a help-giving instrument to support these families achieve a greater sense of control, rather than being the recipients of professional expertise (Seligman and Darling, 1997; Dunst, 2007). It is considered as an empowering perspective for parents' competencies, tailoring services for individual families in a consistent manner with their culture and family traditions (Turnbull, Turbiville and Turnbull, 2000), encouraging positive power-sharing communication and partnership

perceptions (King et al., 1997; Fischer, 2003). Brinker (1992) also promoted the notion for early intervention to be embedded within family-centred values rather than child-focused principles. Family-centred services seem to be well-received by parents, contributing to the family's positive perception of the child, as well as manifesting added benefits to other family members (Truesdale-Kennedy et al., 2006) and perceived family well-being and empowerment (Dempsey and Keen, 2008).

However, parents themselves may not necessarily want to participate in their child's intervention as educators (Paige-Smith and Rix, 2006). Moreover, professionals who do not value collaborative partnership and mutual responsibility may experience difficulties in their relationships due to adhering to an 'expert-client' relationship (Bruder, 2000; Turnbull, Turbiville and Turnbull, 2000). It could also be difficult to implement such an approach when services are, by tradition, child-focused within the rehabilitative model of intervention (Bruder, 2000). Nonetheless, family-centred caregiving is associated with parents' emotional wellbeing, greater satisfaction with services assisting the development of problem-solving and coping skills, including the support of emotional expressiveness among family members (Mullins, Cheung and Lietz, 2012).

In Malta, the child has a central position in early intervention and parental involvement is encouraged for the benefit of the child's development (Vella, 2009). However this service remains a child-focused service; professionals focus on the child's benefit rather than that of the family as a whole. For this reason, the current study adopted family-centred principles as exploring Maltese parents' experiences and needs may be considered as paving the way for change from the Maltese child-focused service delivery to family-centred help-giving whilst still maintaining a focus on the child's prognosis in context.

3.6 Relationship of models with the current study

There is a hierarchical interaction between the theories, models and principles adopted in this study. Contemporary research on child development evolved towards taking into account the child in the context of his or her family. Figure 3.2 shows the inter-relationship between the theories used in the present study. Each theory seems to act as building block for consequent models. Bio-ecological, developmental niches and family

systems theories act as baseline for the early intervention model and family-centred principles in an ascending fashion.

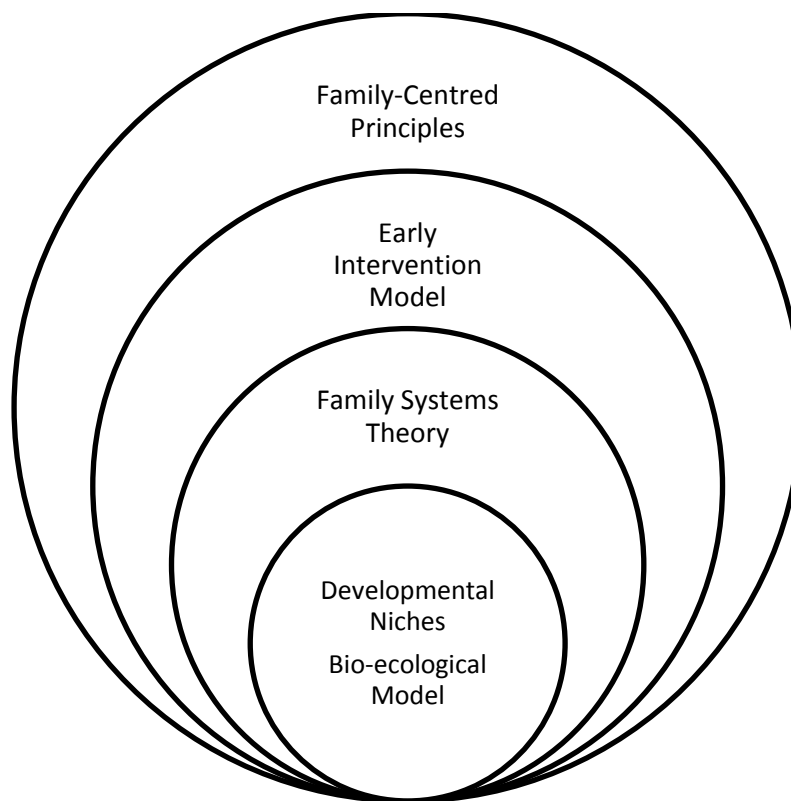


Figure 3.2: Relationship of four theoretical models adopted in this study

The bio-ecological theory gives importance to the child within his/her context assuming that the family is the most intimate and immediate environment (Bronfenbrenner, 1994), similar to developmental niches (Super and Karkness, 1999). These both present the importance of the child's environment for his/her development as the first level of the model for this study (figure 3.2). The family systems theory is grounded on the bio-ecological model (Broderick 1993; Friedman et al., 2003). This theory focuses on the family as a whole, whose interconnectedness and constant interaction influences each member's daily lives (Casey, 1996). It influenced the data collection procedure of the current study via interviewing both parents together (see section 4.11.2). Although the family systems theory encompasses a multitude of inter- and intra-family relationships, the current study focuses on the nuclear family's perspective from the eyes of the parents who are raising a dependent young child acting as 'leaders' of their nuclear family system. Both levels of figure 3.2 emphasise 'the interactive and synergistic, rather than additive and competitive nature of the links between the family and other

influences' (Collins, Maccoby, Steinberg, Hetherington and Bornstein, 2000, p.227). Their applicability to the current study place the individual and families in the context of the wider society and culture (Bronfenbrenner and Morris, 1998). The family systems theory's positioning above the bio-ecological model and niches, in figure 3.2, revolves around the parents' perceptions as a sub-system of the family in the current study. The harmonious and stepwise relationship between these theories provides the baseline for both early intervention model and family-centred principles.

Guralnick's (1998) model of early intervention complements Bronfenbrenner's model, as he gives the family its pivotal importance for child development and acknowledges external influences on the family. Additionally, Guralnick's model and common ground principles (Guralnick, 2008a, 2008b) build on both Bronfenbrenner's and family systems theory as these focuses on the family itself, specifically for the benefit of the child with difficulties. The adoption of Guralnick's early intervention model is critical for this thesis as it is focused on the early intervention concept as a way to assist the family as a whole through maximising their child's abilities. The early intervention model provides an opportunity to alleviate the family's potential stressors.

For the success of family-centred care, it is necessary for the definition of the family to be shared at a conceptual level by all parties involved (Brinker, 1992). In this study, an open definition of family is assumed to be embedded within family systems theory concepts (see section 3.3). Given that the Maltese culture gives great importance to the family (Abela et al., 2005; Abela, 2009a, 2009b), cultural family concepts are acknowledged. Following cultural family perspectives, family-centred principles could integrate well within the Maltese society.

Family-centred values also fit with Bronfenbrenner's core model in the aim to strengthen and support experiences and opportunities that have development-enhancing qualities (Dunst, 2002). Family-centred principles seem to follow a similar family focus as in Guralnick's model. The former focuses on service delivery perspectives in order to enhance family wellbeing whilst simultaneously assisting their child's development through help-giving style that builds relationship, which offers practical support (Dempsey and Dunst, 2004; Dunst, 2007). Guralnick's model focuses on the prevention of potential negative stressors that may impede optimal family interactions whilst Dunst's (2007) principles add service delivery ideals to achieve similar results.

Following these principles, family-centred principles are considered as an ideal context, yet realistically given that in Malta change processes are slow (O'Reilly Mizzi, 1994; Abela, 2009b), it may be an unachievable ideal. Indeed, 'expert-client' relationships might be difficult to change; given the cultural high regard towards the hierarchy of perceived professional standards (Sultana, 1994; Hofstede et al., 2010). One may view such principles as an idealistic goal towards which professionals should move rather than expect them to achieve a full radical change over a short period of time.

3.7 Conclusion

The ecological theory and family systems theory seem to present a foundation of the early intervention model and family-centred principles. The interrelationship of these theories was deliberated in view of the current research. The research approach, method of inquiry and analysis process will be discussed in the next chapter.

Chapter 4 Methodology

4.1 Introduction

Following the aims and objectives outlined in the introduction chapter, this chapter focuses on the research journey with the research questions, operational definitions, design, approach, methods and ethical considerations. Appraisal of the data collection, sample, analytical procedures and quality of the study are also presented. This chapter ends with researcher's reflections on the analysis of the interviews.

4.2 Research questions

Primary research question

- What are the experiences and perceptions of Maltese parents in raising their children born with a biological risk of intellectual disability during the children's first five years of life?

Secondary questions

- What are the perceived physical, emotional, psychosocial and communication needs of these parents in promoting their child's development?
- What are the differences and similarities in the experiences of parents of children with biological risk of intellectual disability when the child is 0;6, 2;0, 3;6 and 5;0 years of age?

4.3 Operational definitions

Biological risk of intellectual disability – Biological risk in this research follows Guralnick's (2008a), Nelson's (2000), Meisels and Shonkoff's (2000) and Rosetti's (2001) guidelines. These include:

- Children born very or extremely premature (<31 weeks)
- Children born with very or extremely low birth weight (<1.5 kg)
- Children born with a congenital anomaly that is known to have an effect on brain development or related to intellectual disabilities.

- Children born at term with birth complications compromising brain functioning and the transmission of oxygen towards the brain, such as asphyxiation (Kirkby, 2002) are also considered at risk for ID (Nelson, 2000).

Children born with a low five minute Apgar scores of 0-3, and 4-6, accompanied by other medical conditions (above-mentioned), may present an increased risk of developing a variety of intellectual difficulties during later school age (Morse, Barrett, Mayan, Olson and Spiers, 2002). For more details see section 2.2.

'Maltese parents' include those parents who are citizens of Malta (Maltese archipelago) or residing in Malta during the early years of the child's development. The mother must have given birth in Malta.

Experiences is a conscious reflection on one's own actions and thoughts through a particular lived time-period, whether present or past, within the interviewee's lifeworld, while raising a child born with biological risks. It constitutes "a lived aspect of everyday flow which is of significance for people brought by an event" (Smith, Flowers and Larkin, 2009, p.1).

Physical needs is defined as requirements perceived by parents from the physical and corporeal environment within one's society throughout their experience such as those related to services (e.g. health and/or educational services) and immediate environment (e.g. needed materials).

Emotional needs are identified as needs related to feelings within-the-person, including emotional support perspectives, support systems as well as factors that affect parents' emotions when raising a child born with risks for ID.

Psychosocial needs refer to factors related to parents' experiences in raising a child born with biological risks, such as resources (financial and work related needs) and management (family coping) needs.

Communication needs focus on information requirements perceived by parents. Although communication needs are typically identified as psychosocial needs, this study viewed them separately.

4.4 Research approach

The approach adopted in a study depends on the questions asked (Robson, 2002). The literature review has demonstrated that a substantial number of quantitative studies across different cultures have examined possible effects on individuals' experiences of raising a child with disability. Conversely, some studies used a qualitative perspective to capture the depth and individual perspectives of participants as these go through their lived experience of the phenomenon.

A qualitative approach was adopted as the individuality of the person's experience, meaning-making and lifeworld interpretation seem to provide a better stance to answer the research questions of this study. Quantitative research may not capture the individually-coloured worlds of the participants in its full depth since it looks at the individual from an objectivist perspective: investigator and investigated are assumed to be independent entities in the 'true' reality (Guba and Lincoln, 1994). Quantitative research also believes that findings are replicable, reflecting the 'truth' and that biases should be controlled in order to observe the explored concept free from external influences (Denzin and Lincoln, 2000). However, when exploring individuals' feelings and thoughts one cannot underestimate the uniqueness of the person's viewpoint and reasoning, which may not be similar to another person within the same society.

Qualitative research involves the adoption of a naturalistic approach where the researcher studies entities in their natural settings, whilst 'attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them' (Denzin and Lincoln, 2005, p.3) and understanding linguistic meanings within textual material (Madill, Jordan and Shirley, 2000). Qualitative methodologies are widely used to explore relatively new and insightful areas of research (Robson, 2002), as in the current study. Knowledge is created in dialogue between two individuals, in this case the researcher and the participants. It also provides an opportunity to 'witness the individual's world through a full range of awareness and to understand our chance of being helpful to the individual' (Munhall and Oiler, 1986, p.61). Therefore, a qualitative design was considered the approach most suited for this study.

4.4.1 Philosophical background of research approach

Phenomenology paradigm

Phenomenology focuses on the study of the individual's lived experiences. It emphasizes the world as lived by the person experiencing it, not as a reality separate from the person (Valle, King and Halling, 1989). According to Husserl, phenomenological inquiry denotes that experience should be examined in the way that it occurs and on its own terms (Smith et al., 2009; Dowling, 2007).

Transcendental phenomenology, focuses on the consciousness of the world 'as that which makes possible the world as such, not in the sense that it makes possible the existence of the world, but in the sense that it makes possible a significant world' (Drummond, 2007, p.61). Phenomenologists bear 'witness to individual consciousness and the consciousness of the same event perceived quite differently' (Munhall 2011, p.170) by attempting to unfold meanings as the experiences are lived in everyday existence (Lavery, 2003; Dowling, 2007). Indeed, Husserl viewed it as a way of understanding true meaning through probing deeper into reality. Koch (1996) noted that Husserl envisaged intentionality and essences as key to one's understanding; as a process where the mind is directed toward objects of study. Smith et al. (2009, p.13) indicated that for Husserl, phenomenological inquiry focused on 'that which is experienced in the consciousness of the individual', where conscious awareness is marked as a starting point in building one's knowledge of reality; through intentionally directing one's focus to be able to develop a description of particular realities. This leads to Husserl's suggested need to 'bracket out' the outer world and individual biases about the phenomena in order to achieve a clear uninfluenced vision and successfully achieve contact with the essences of human experiences (Lavery, 2003).

Heidegger's approach, unlike earlier philosophers, makes no attempt to isolate human beings from the world in which they live. Indeed, his ontological stance criticised 'bracketing out' one's judgement (Watts, 2001); as one cannot truly detach him/herself from one's being in the world. Despite this, Moran (2000) depicted Heidegger as developing Husserl's ontological notion of intentionality rather than arguing against it. Following Heidegger's reasoning one's being in the world involves engagement within the world, sociality and self-reflection including a temporal existential position (Watts, 2001; Smith et al., 2009). This stems from his viewpoint that the person is permanently a 'person-in-context' (Larkin, Watts and Clifton, 2006). The ability to communicate and

understand others as people-in-context are the key features of inter-subjectivity (Smith et al., 2009). It is thus important to acknowledge prior pre-conceptions and others' existence as proof of existence in one's world in the present.

Merleau-Ponty inherited Heidegger's notions of inter-subjectivity, however he focused on embodiment of experiences and language use (Haysom, 2009). Embodiment refers to one's body as a means 'to hold inner communication with the world' rather than an object in the world (Merleau-Ponty, 1958, p.111). He views inter-subjectivity as only possible within the fields of the lifeworld. Although Merleau-Ponty agrees with Heidegger that inter-subjectivity creates experiential knowledge via dialogue with others, the former encompasses it within the embodiment concept. For Merleau-Ponty, one's lived experiences as a physical body-in-the-world cannot be entirely understood by another person, due to the person's own embodied position in the world (Smith et al., 2009): a unique sense of self-embodied within each person. Yet, an inter-relation exists between each person in the physical world (Haysom, 2009), as one's perception of the other develops from one's embodied perspective, creating a 'one and only' position in the world (Merleau-Ponty, 1958, p.415). This highlights the uniqueness of each parent's experiences in raising a child born with risks of ID, regardless the similarity of events.

Sartre (1948, p.26) suggests a developmental process perspective of the human being via his notion of 'existence comes before essence' over time; whereby the self is not a pre-existing discoverable entity, but an unfolding process. Time is seen as an added constituent that may assist participants unfolding their transforming inner selves through their daily experiences, possibly with differing hindsight re-interpretations. Heidegger agreed with Sartre's emphasis on time; he called time the 'horizon of being' where one's past lives within one's present as it projects strong influences in one's present circumstances (Watts, 2001, p.17).

Communication via speech and language are, for Merleau-Ponty and Heidegger, vital as mediators between individuals that facilitate their dialogical development through each other. Merleau-Ponty added the importance of the cultural 'constitution'; it provides available meanings that are the basis for language and creative expression which may in turn act as constrained possibilities of interpreted meanings of expression (Merleau-Ponty, 1958, p.406). Accordingly, cultural background influences one's affective

engagement in his/her lifeworld that are already normatively structured (Baerveldt and Voestermans, 2005).

Hermeneutic paradigm

Hermeneutics stemmed from phenomenological philosophy and involves the act of interpretation of one's experiences. Schleiermacher's translated writings offered a holistic view of hermeneutics from a psychological and grammatical perspective with the use of intuition; comprehensive engagement with the text for an holistic analysis to transmit 'an understanding of the utterer better than he understands himself' (Schleiermacher, 1998, p.266). However, Gadamer (1989) argues that one should first understand the content of the text, after which isolate and understand another's textual meaning. Schleiermacher's major contribution in hermeneutics depicts an interpretation of a text as portraying an individualistic perspective due to the inter-subjective lens of the analyst.

Gadamer (1989) agrees with Schleiermacher's reasoning (1998) that the interpreted does not necessarily have interpretative supremacy on the textual meaning; and Gadamer insisted that this does not indicate an understanding of the person, since understanding textual meaning is prioritised. Nonetheless, interpretation of a given text requires open-mindedness regardless one's preconceptions, so as not to limit any potential interpretations of available meanings. Gadamer (1989) linked the interpretation process with the moment when the interpretation was performed. This is vital for the researcher's timing while performing the interpretation and for the participants who present their interpretation of their lived experiences.

For Heidegger, the act of interpretation presents a dual quality, things that carry a visible meaning and also concealed meanings, both of which are connected (Watts, 2001; Smith et al., 2009). From Heidegger's stance, Moran (2000) indicated that the analyst, as a human being who already knows him/herself and the world from his/her approach, already has a lens from which the interpretation of a text takes place. Gadamer (1989) argued that by bringing forward the analyst's preconceptions prior the interpretation may hinder the full meaning of the text at hand. However, he agrees with Heidegger's hermeneutic stance emphasising the complex relationship between the interpreter and the interpreted. Moreover, the phenomenon itself may influence the

interpretation which can affect the preconceptions in a back-and-forth fashion (Smith et al., 2009).

Consequently, Heidegger followed Schleiermacher's footsteps and suggested the concept of the hermeneutic circle as a 'dynamic relationship between the part and the whole, at a series of levels' (Smith et al., 2009, p.28). This notion was criticised due to its circular relationship (Moran, 2000) as it indicates the process of interpretation from a non-linear way of thinking when compared to Husserl's phenomenology. Smith et al. (2009) added that the researcher's interpretation acts as a double hermeneutic perspective: interpreting (me as researcher) the interpreter (the participant's interpretation).

Idiographic paradigm

Idiography gives importance to the individual. Allport (1962) argued that the science of psychology should attend to the uniqueness of the individual person. (Ashworth and Greasley, 2009) highlighted the importance of such a standpoint within the educational research. Moreover, Merleau-Ponty's embodiment of experiences and Heidegger's individual being-in-the-world, idiography specifies that each person interprets his/her experience in a unique manner due to the individual lens. Consequently, each person is understood to be a unique system of interactive dynamic processes; the unfolding of which gives rise to an individual route in a multi-dimensional psychological space (Molenaar, 2004). The idiographical perspective in this study is influenced by the focus on the child as the focal point of the parents' experiences: in two parent families, both parents are sharing the same experiences. However idiographic focus on each parent's interpretations were considered seriously.

4.4.2 Rationale for research approach

The above-mentioned phenomenological standpoints are chosen as the foundation that shapes the research methodology. The hermeneutic and idiographic perspectives provide depth to understand the individuals' experiences from their own points of view. These philosophical viewpoints were selected as they seem to offer a perspective that highlights the participants' voices within their spatio-temporal context, giving each participant his/her individual importance. The double hermeneutic stance, acknowledges the influence of my own past experiences on the interpretation of the findings, while

still being led by the participant's interpretations (Smith et al., 2009). Hence adopting phenomenology, hermeneutic and idiographic concepts in this study threaded a deep involvement with the participants' meaning-making of their experiences through my eyes as the researcher.

Interpretative phenomenological analysis (IPA), as described by Smith et al. (2009), embraces the philosophical underpinnings of this research as described in the theoretical framework. IPA gives importance to listening to the voices of participants across the sociocultural spectrum. It unifies its methodological approach from transcendental phenomenology, hermeneutics and idiographical standpoints as it is a philosophy led approach (Smith, 1999). Heidegger's viewpoint indicates that we cannot be thrown in a world of objects and relationships since we have a temporal and 'in-relation-to' association with our world. It centralises the interpretation of people's meaning-making process of their experiences from their world-view which acknowledges the uniqueness of each individual's lens. Merleau-Ponty's philosophical contributions are critical to this study as they highlight the physical and perceptual position in the world (Anderson, 2003; Thomas, 2005). For him the lived experience of being a body in the world can never be fully captured, however it cannot be overlooked and thus should be given its due importance.

IPA is concerned with the examining of subjective experience as it gives importance to my reflexivity, as the explorer's filtering lens in the research analysis, unlike other methods. Human and health science researchers do not typically examine their own experiences but focus on the experiences of others (Smith et al., 2009). IPA also gives importance to the idiographic perspective due to the uniqueness of each individual's worldview lens in one's meaning-making of lived-experience.

4.4.3 Interpretative Phenomenological Analysis methodology

Interpretative Phenomenological Analysis provides a flexible iterative research method that looks at the participants' meaning-making of their lived experiences coupled with a subjective and reflective process of interpretation. The meaning which is interpreted by the participant from his/her experience represents the experience itself (Smith et al., 2009). IPA advocates a chained connection between embodied experiences, talk about that experience and participants' making sense of and emotional reaction to that

experience (Smith, 2011). Consequently, a ‘double hermeneutic’ philosophical perspective is utilised in this study, where the final output of the research study is filtered through my world-view lens as the researcher, the explorer of the participants’ voices (Smith and Osborn, 2003). IPA makes inferences cautiously, and with an awareness of the contextual and cultural background against which data are generated (Reid, Flowers and Larkin, 2005).

Both IPA and discursive analysis are linguistically based approaches. However, their philosophical underpinnings are different. Discursive approaches focus on the linguistic resources drawn by the participants to provide accounts of experience and/or controversial features occurring while giving that account. Unlike IPA, discursive approaches examine what participants say, so as to learn how they are constructing accounts of experience (Potter and Wetherell, 1987).

Neither does IPA share philosophical foundations with grounded theory approaches (Charmaz, 2008; Mills, Bonner and Francis, 2008). There is some overlap between constructivist grounded theory and IPA in the use of an inductive qualitative method (Charmaz, 2008). IPA emphasises the similarities and differences in participants’ meaning-making using detailed analysis of lived experiences and does not construct ‘theoretical accounts of psychosocial phenomena’ (Smith et al., 2009, p.202). IPA does not utilise data saturation principles like grounded theory approaches, as it acknowledges the uniqueness of each participant’s lived experiences and their meaning-making allocated to such phenomena (Smith et al., 2009).

The application and development of phenomenological research reflects a number of diverse methods (Moran, 2000). This may provoke uncertainty and controversy in the application of philosophical thoughts to the empirical project (Finlay, 2009). Moreover, phenomenologists seek out idiographic meanings in an attempt to understand the individual who may or may not offer general insights (Finlay, 2009). This further strengthens IPA as an appropriate approach for this study. The dynamic and iterative process of IPA, whilst adhering to scientific rigour, seems to be the appropriate method to expand, enrich and strengthen the voices of the participants’ lived experiences in rearing a child at risk for ID.

4.4.4 Rationale for Interpretative Phenomenological Analysis methodology

One may find other phenomenological methods, such as Giorgi's (2008) approach which is Husserl-based and focuses on the description of experiences. From a Husserlian perspective, Giorgi (2010) also criticised IPA for having more than one philosophical tradition; he interpreted multiple philosophies as competing with each other. Nevertheless, in IPA research the use of more than one philosophical underpinning seem to be complementary and create an approach to research that is unique (see Smith et al., 2009; Smith 2010, 2011). IPA, as described by Smith et al. (2009), compared to that of Giorgi's (2008), seems to be the appropriate method for analysing the lived experiences of parents whose child was born with biological risks for ID during later childhood, due to its philosophical underpinnings.

Two important interpretative phenomenological methodologies are described in the available literature. That as described by Smith et al. (2009) and that described by van Manen (1990). They both share similar philosophical underpinnings, which may ultimately depict similar research outcomes (Eatough and Smith, 2006). Van Manen was particularly interested in the phenomenological investigation of everyday practice and gives detailed instances of how he applied his approach to pedagogy and parenting. Both methods have been widely used in psychological and social research. Van Manen's method has been adopted by health researchers and in parenting issues whilst Smith et al.'s (2009) method has been extensively used in psychological and health research (Smith, 2011).

Van Manen (1990) explained his method in 6 pedagogic steps. These were clearly explained and can be viewed as a 'set of guides and recommendations for a principled form of inquiry which neither rejects nor ignores tradition but does not slavishly follows or kneels in front of it' (van Manen, 1990, p.30). He focused on writing and rewriting of analysis, whilst Smith et al. (2009) looked at the reading and re-reading of texts to integrate with the participants' lifeworlds and interpretations of their narrated lived experiences.

Van Manen's (1990) guides, however, seemed to remain on a philosophical level whose steps are not explained in as much detail as Smith et al.'s (2009) method. Given that I have quantitative research background, was a novice qualitative researcher and new to IPA, I favoured Smith et al.'s (2009) method, due to the provision of more detailed

explanations of analytical procedure and a clearer guidance methodological evaluation guidance. Smith et al. (2009) placed a greater emphasis on the interpretative analysis method than van Manen's (1990) method. Smith et al.'s (2009) method indicates that the analytical process should be a multi-directional, iterative and inductive process of fluid description and engagement with the transcribed data, combined with a reflexive perspective of the researcher's own perceptions and pre-conceptions (Smith et al., 2009). Therefore, I adopted Interpretative Phenomenological Analysis (IPA) as a method to guide data collection and analyse the findings, as defined by Smith et al. (2009).

4.5 Research design

Qualitative research may employ imaginative research designs provided they adhere to the theoretical underpinnings of the research (Robson, 2002; Creswell, 2007). This study aimed to explore parents' lived experiences during their first five years of their children's life. This time-frame was chosen from an inclusive early intervention perspective, in order to provide the potential culturally appropriate foundations for future family-centred services, comprising of the child's crucial early-learning years (Nelson, 2000). Furthermore, a lack of 'defensible' reasons for limiting such vital service to 3 years of age was evident (Farran, 2000). In addition, in Malta, where this study is oriented, early intervention services include children from birth to five years of age.

Longitudinal research has an extended period of data collection from participants, utilising repeated interviews with the sample. It has numerous advantages, such as exploration of lived experiences and perceptions over time of the same participants (Flick, 2007; Creswell, 2008). It however carries the risk of participants opting out as the study progresses (Flick, 2007). A longitudinal design would have been the best choice as I would have explored the experiences of the parents as they actually lived the first five years of their child's life. However, the follow-up period required for a longitudinal methodology was not feasible for this study's time-scale. Consequently the cross-sectional design was the preferred choice.

A cross-sectional design studies the breadth of the age-span of the research question and necessitates one or more interviews with each participant for the data collection process.

This design has the advantage of observing ‘snapshots’ of participants' perceptions of their lived experiences and seems appropriate to address the research question (Flick, 2007, p.45). Moreover, it satisfies the rationale of the study in order to enhance and provide social-policymakers with data and the depth of Maltese parents' experiences and needs while raising their child born with risks. IPA methodology acknowledges the use of a cross-sectional design with multiple groups as they observe the phenomena that is of interest to answer the research question across the stipulated time period (Smith et al., 2009). Cross-sectional designs are widely used in developmental research in order to observe the cumulative effects of development in a limited research time frame (Pring, 2005). Hence a cross sectional study had the added benefit of exploring the lived experience of the participants within the available time-frame.

A cross-sectional design excludes the possibility of observing the same participants' experiences over time as their child grows (Flick, 2007). This may produce too varied a perspective, given the nature of research question (parents of 0-5 year old children). The first five years of a child's life are typically marked with significant developmental changes. Consequently, I decided to explore parents' perceptions at major developmental milestone stages (see rationale for age groups section 4.6.2). This also presented an opportunity for more homogenous samples at each age group, as recommended by Smith et al. (2009).

In IPA, data may be gathered on more than one occasion, although Flowers (2008) argues that multiple interviews may maximise the potential for contradictory narratives from each participant in an attempt to please the researcher in what they perceive to be the sought after information. On the other hand it is acknowledged that one may build more trust using more than one interview. Nevertheless, a one-time interview seemed appropriate and sufficient to gather the needed information to answer the research questions (King and Horrocks, 2010).

4.6 Sample

Research using interpretative phenomenological methodology typically uses a small sample of participants (Langdrige, 2007, Smith et al., 2009). Flowers, Duncan and Knussen's (2003) and Flowers, Davis, Hart, Rosengarten, Frankis and Imrie's (2006) research endeavours used qualitative and mixed methods, respectively. They, however,

applied IPA methodology with larger samples than those recommended by Smith et al. (2009), who acknowledged that should a study contain more than one group a larger sample is needed.

In Malta, in 2009 there were 4143 live births, with 58 babies born very and extremely premature and 51 with very or extreme low birth weight (National Obstetric Information System, 2011). Moreover, the Maltese National Congenital Anomaly Register indicates numerous birth conditions including those manifesting ID, such as Down Syndrome (N=7) (Malta Congenital Anomalies Register, 2011). A purposive sampling technique was therefore used to recruit the participants according to the inclusion criteria. This technique is also commonly used in IPA methodologies (see Smith et al., 2009), to recruit experience close participants.

Each group contained 9-10 participants (parent sets): each set /couple representing one child's circumstance within one family as a unit (N=37). The decision to perform joint interviews was influenced by family systems theory (see section 3.3). The estimated sample size of 40 participants was the planned maximum rather than a goal to be reached, given the targeted small population who could answer the research question whilst still maintaining idiographic attention to each participant (see Smith et al., 2009).

4.6.1 Inclusion criteria

Following the review of the literature (see section 2.2), the parents of any child who at birth manifested one or more of the following criteria were included, namely one or more of the enlisted:

- Very or extreme premature (<31 weeks)
- Very or extreme low birth weight (<1.5 kg)
- Significant reduced oxygen in the brain (Nelson, 2000)
 - o Significant asphyxia, needs constant ventilation
 - o Significant congenital heart disease
- Congenital conditions that are directly or indirectly involved with ID such as Down syndrome, Spina Bifida (significant spinal involvement) etc. (Shonkoff and Marshall, 2000; Rosetti, 2001)

Low Apgar score is to be accompanied with other medical complications enlisted above

Homogeneity of the groups, as defined by the above-mentioned inclusive criteria for 'biological risk', is crucial for an IPA study (Smith et al., 2009) and was thus respected at all times. Parents who were Maltese citizens were included in this study. Moreover, my cross sectional research adopted 4 groups based on the children's chronological age, aimed to further maintaining homogeneity of parents' experiences. The sample choice was dependent on the ages of their child who was born with biological risk. The children's ages were planned to be about 0;6, 2;0, 3;6 and 5;0 years of age at the time of data collection.

Clear language use by participants is important in IPA methodology (Smith et al., 2009). Consequently, it was important that the parents themselves manifested good verbal communication. It is essential that participants are able to explain their feelings and perceptions clearly, as the research outcome and philosophical underpinnings give significant importance to the clarity of language as it is the participant's representation of their experience (Watts, 2001). This was also important for informed consent (Morse, 2007). The presence of both parents, in two-parent families, was preferred during the interview, in order to obtain both parents' perceptions. However single parents were interviewed on their own.

4.6.2 Rationale for age groups

The first five years of a child's life is marked by developmental stages which shape his/her adult life (Meisels and Shonkoff, 2000; Rosetti, 2001; Grantham-McGregor, et al., 2007). Early childhood intervention in Malta takes place during the first five years of life. Consequently, I chose the group ages according to the typically developing child's milestone perspectives as outlined by Bee (2000), in addition to other social expectations influenced by a typically developing child's life events (see McCartney and Phillips, 2006).

Moreover, having a well distributed cross-sectional sample, with approximately 18 months gap between each group, could provide a portrait, which focus on the parents' needs as their child develops. The interpretation from my perspective, an outsider exploring insider experiences (see Appendix V) could also add strength in the social-policymakers' eyes to the untapped world of family experiences that exists within the Maltese society.

Group one

The interviewing process with parents was initiated when the child was six months of age, following Borg Xuereb's (2008) local findings that first-time parents of typical children would have more or less settled down as a family. In contrast to Borg Xuereb (2008), the parents in this study could still be in the process of settling at home, given the potentially longer neonatal hospitalisation period than typically-born babies. It could also be highly distressing for the parents to interview them during the immediate birth-hospitalisation period from an ethical perspective, given the added risks with which their child was born. Thus 6 months was the earliest age considered to be sensitive to parental emotional state. Six-month old children who are born in typical circumstances may be in the process of weaning and have advanced babbling, amongst other intensive learning skills (Bee, 2000). At this age intensive brain development and plasticity involved in experience-based learning are known to have a life-long effect in later childhood and adulthood (Couperus and Nelson, 2008, Guralnick, 2008a).

Group two

Two year old typical children would be expected to have achieved independent walking, a number of verbal words or phrases and other major cognitive, socio-emotional and physical skills that help him/her function independently in his/her tomorrow's world (Bee, 2000). Children born with risks for ID may start to show evidence of developmental delay around this age period since physical and communication milestones might not have been achieved (Rosetti, 2001). Markers such as language delay are noted to represent a sensitive marker for varied developmental difficulties, including ID (Buschmann, Joos, Rupp, Dockter, Heggen and Pietz, 2008).

Group three

The third group consisted of parents whose child was 3;6 years old. During this period children in Malta typically start pre-school education (Sollars et al., 2006), that prepares them for the formal educational setting and to acquire a number of early literacy skills needed later on in their education. Preschool education is not compulsory in Malta (Sollars et al., 2006). Three year old children who are developing in a typical manner should use complex sentences, show a preference for peer play and manifest literacy awareness skills (Bee, 2000). This age may also represent a transition in parents' daily experiences, as children start entering the school routine (Bee, 2000; Sollars et al.,

2006). Lugo-Gil and Tamis-LeMonda (2008) indicate that parents' verbal behaviours contribute to children's cognitive performances by 3 years of age, regardless of individual differences.

Group four

Five year old children are formally enrolled into the compulsory education system (Bee, 2000; Sollars et al., 2006). This marks the beginning of formal school learning and also marks the end stage of early intervention services. By five years of age, typically developing children show signs of individual friendships, and are expected to be fully physically independent beings (Couperus and Nelson, 2008, Bee, 2000). Families of children with cognitive or developmental delay seem to experience re-balancing of the impact endured by their family by the child's age of 5 years (Hatton, Emerson, Graham, Blacher and Llewellyn, 2010).

4.7 Ethical considerations and permissions

Ethical issues deserve attention in all research, as participants must be protected throughout the research journey (Munhall, 2011; Morse, 2007). It is the researcher's responsibility to manifest respect for participants' safety at all times (Tilley and Woodthorpe, 2011). Ethical approval for this study was sought and obtained from the Ethics Committees of Manchester Metropolitan University, University of Malta and the Data Protection Office of the main state hospital of Malta. Permissions were also sought and granted from the Director of the Paediatric Department, all the consultants of the Neonatal and Paediatric Intensive Care Unit and the ward manager of the national hospital (see Appendix III).

Informed consent was given key importance in this study (see Appendix III) since the interview was audio-recorded. The data collection procedure approved by the ethics committees was adhered to throughout the study. The allocated ward clinician sought permissions from the potential participants, following which I sent them the participant information and consent forms. Upon receiving the signed consent form and their preferred date of interview, a confirmation letter was sent to the participants. The absence of the researcher from the initial consent process until the potential participant was willing to share their postal address and to take part in the study, helped to ensure

that individuals would not feel coerced (Hegney and Wai Chan, 2010; Houghton, Casey, Shaw and Murphy, 2010).

The audio-recordings and the participants' demographic data were kept separately and in safe-keeping in password encrypted files in my personal computer. Anonymity refers to a key ethical concept of removing or obscuring the names of the participants, of research sites, and not including information that might lead to participants or research sites being identified (Walford, 2005). All the participants in this study were guaranteed anonymity throughout the whole research process. Pseudonyms were used at all times. Given the nature of the children's birth circumstances and the presence of a number of rare conditions associated with age-group and time-frame of data collection, no full transcripts are presented in Appendix III for the protection of the participants' anonymity. Moreover, not all demographic details were associated with each participant, to protect their identity. These are widely reported as typical solutions to solve anonymity dilemmas (Morse, 2007; Tilley and Woodthorpe, 2011). These data are available for scrutiny by the ethical regulatory authorities if required. Permissions were granted by participants to use partial transcripts in the form of quotes, in order to support the themes and interpretative meanings.

Qualitative studies conducted in settings involving human participants require an awareness of the ethical issues that may be derived from such interactions (Orb, Eisenhauer and Wyndaden, 2001). Since the researched topic was of a sensitive nature in participants' experiences, a debriefing session was offered so as to protect the participants from any emotional risks or harm (see Orb et al., 2001; Sim, 2010). I offered to stop the interview when parents appeared emotional (Houghton et al., 2010). The two participants who felt emotional, appreciated the gesture and insisted on completing the interview. Being an experienced health professional, I felt skilled enough to empathise with distressed parents. I planned to refer participants to local psychological contacts if more assistance was deemed necessary: none was needed.

The participant-researcher relationship is based on respect and benevolence (Morse, 2007; Sim, 2010) and this was demonstrated through the participants' trust in sharing their sensitive experiences. I remained conscious of the need to maintain the researcher's role, given my professional background (Houghton et al., 2010). Information required by parents was given after the interview was completed. This

included advice on where to obtain further information to answer their questions that were not within my area of competence.

Participants were offered the choice to opt out of the research at any point during the research journey, in order to ensure their voluntary participation (Houghton et al., 2010; Sim, 2010; Morse, 2007). Participants' and researchers' safety was respected at all times (see Sim, 2010). The interviews were held in the parents' home environment when both parents were present (in two parent families). They were informed about the nature of the interview that was to be held and this enhanced feeling of safety. I always informed my clinical department (Speech and Language Department, Malta) on the nature of my whereabouts and estimated time, without divulging the participants' identity, for my safety. At the end of each interview I called the person I had informed of my whereabouts. Since the interview day and time was at the participants' discretion, it did not always match the working hours of the department's staff hence another trusted person was notified during evenings or weekends.

4.8 Data collection procedure

Data collection took place between October 2010 and April 2011. During this time transcription of completed interviews took place contemporaneously. Due to the importance of family time, given the tight schedule of the interviewees' work-life balance, interviews were suspended during Christmas and Easter periods.

Face-to-face interviews presented a number of advantages over other interviewing methods, due to the observation of non-verbal communication that accompanies the verbal message of the participants (Flick, 2007; Langdrige, 2007; Hartas, 2010). Other methods of non-face-to-face interviews, such as telephone or internet-based interviews could have reduced participation except for those individuals who had such means in their homes. Telephone or internet-based interviews might offer greater feelings of anonymity to the participants, helping them feel more at ease and disinhibited to express their emotions and frustrations. However, this could come at the cost of losing the non-verbal communication, which is considered critical in conveying information. Thus face-to-face interviews were selected for this study.

4.8.1 Participants' recruitment

The data collection process initiated once all the ethical approvals were obtained (see Appendix III). The procedure followed the approved ethical format. The head of the NPICU ward in Malta appointed a clinician to assist in the recruitment process. I gave the clinician the inclusion criteria and estimated sample size. This clinician contacted the potential participants who fell within the inclusion criteria, invited them to participate in the study and upon acceptance s/he requested permission to divulge postal addresses for information and consent sheets about the research to be sent to them by post, following the approved participant recruitment procedure. Voluntary organisations including the Maltese Down Syndrome Association and the Maltese Federation of Parents of Children with Disability, amongst others, were contacted to invite potential participants who could have been missed by the allocated clinician at the main state hospital. The organisations contacted their members who fell within the inclusion criteria, following the same ethically-approved procedure.

Potential participants were informed about the study aims, process, interview and voluntary participation (see Appendix III). Upon receipt of the participants' signed consent sheet an interview date was scheduled at the participants' convenience. The interview was scheduled with both available parents. All participants opted to be interviewed in their home. Occasional distractions such as phone calls, children playing, and excessive background noise occurred but these did not appear to distract the participants during the interview process.

4.8.2 Data collection process

The interviews were audio-recorded, with parents' permission and transcribed verbatim. Prior to each interview, I tested the digital recorder's (Olympus VN 5500 PC DNS) functionality, so as to avoid data collection pitfalls and mishaps (Easton, McComish and Greenberg, 2000) and used new batteries every two interviews to ensure that my audio-recording equipment did not fail during an interview. Reflections before and after each interview were written in a journal so as to maintain an open and genuinely curious mind-set for each story presented. The interview was typically performed in the living area or around the family kitchen table. I took field notes during the interview, noting nonverbal information that may enhance interpretation of the verbal messages, as well as notes for further probing. After the interview had ended a debriefing interview was

held. Any information requested by parents was given after the interview, following the ethical protocol, in order to maintain the researcher's role during data collection at all times. Information requested included contact information for health centres and/or professional advice.

4.8.3 The interview schedule

The interview schedule is a guide that enables the researcher to perform the interview effectively given the constraints of time (Langdrige, 2007). Smith et al. (2009, p.60) suggested that 'for adult articulate participants, a schedule with between six and ten questions, along with possible prompts, could take between 45 to 90 minutes of conversation, depending on the topic.' Both parents in the two-parent families were interviewed together, influenced by family systems theory (see section 3.3, 3.6). These were considered as 1 participant 'unit', since they represent one jointly-lived experience; however both parents' opinions were given their due attention. The interviews typically started by reiterating the topic of the study and asking about the health of their child which lead to their experiences. At the end of the interview I gathered the demographic information and gave them a small thank you token as a sign of appreciation.

The semi-structured interview is the 'exemplary method for IPA' (Smith and Osborn, 2003, p.55), and in phenomenological research in general (Langdrige, 2007). The researcher can follow the participant's interests or concerns, novel areas and thus produce richer data (Hobson and Townsend, 2010). This does reduce the control the interviewer has over the situation and it might take more time (Langdrige, 2007), when compared to a structured interview. The semi-structured interview guide, however, provides some structure to the interview, offering an opportunity to establish a rapport with the participant (Smith and Osborn, 2003) which is useful for trust building whilst attempting to answer the research questions, as it allows for spontaneity and flexibility. Hence this approach was chosen for data collection in this study. In addition, Leonard (2003) showed the advantage of having greater opportunities to clarify the participants' comments for better understanding and avoidance of potential misinterpretations.

The interview questions were designed to elicit the experiences and perceptions of parents whose child was born with biological risks for ID for example, "how is your

everyday experience in caring for your child at present?” Malta being a bilingual country, the language choice depended on the interviewee’s preferences to enhance their communication comfort. As the interviewer, I am competent in both languages and could accommodate to the participants’ linguistic choices. Consequently, two sets of interview schedules were planned one in each national language, Maltese and English, as the potential languages of the respondents. These were back translated to remain true to the intended message. A copy of the interview schedule is attached in Appendix III. The order of the questions was not fixed and not all were compulsory. I followed the participants’ lead as much as possible. Questions were planned to be open and expansive, encouraging the participant to talk at length. Probes were used so as to encourage participants express their deep perceptions of lived experiences.

King and Horrocks (2010) recommend that the interviewer takes substantial breaks between the interviews, should there be more than one a day, in order to minimise the danger of lapses in attention. All the interviews were adequately spaced from each other and were planned at the participants’ convenience. A debriefing session was planned, offered and held after the interview for any parent who wished it. On one occasion when the parents asked for information, this was given, upon request after the interview was completed for the participants’ and their child’s benefit, thus adhering to the ethical procedures (see section 4.7).

4.8.4 Transcription

Transcription is considered to be an active and creative process (Forbat and Henderson, 2005), serving to frame the analysis and interpretation of the research (Lapadat, 2000). The full transcription process was intensive and required an average of 7-8 hours to transcribe 1 hour of interview time, using Olympus Digital Foot Pedal RS28 and Olympus AS-2400 Transcription Kit. This process avoided several pitfalls associated with employing an external transcriber, including the potential higher ‘cost’ to data integration and transcription error risks associated with emotional value of the text. The latter stems from the philosophical underpinnings of the study, where an external transcriber could influence the transcription through his/her own perspective (MacLean, Meyer and Estable, 2004). Moreover, since Malta has a small population, using a Maltese transcriber could have also compromised the participants’ confidentiality and

anonymity. Consequently, I opted to do the transcriptions verbatim and in a detailed manner, to remain true to the recording.

Transcription errors were minimised by re-listening to the audio-recording several times after it was transcribed, so as to understand its thorough meaning and to avoid semantic changes that may occur in erred transcribed material (Easton et al., 2000). Being both the interviewer and the transcriber of the study offered the advantage to re-visualise the participants' non-verbal movements and gestures during transcription. A copy of the transcript was sent to the participants with a cover letter, should they wish to make any changes. None contacted me for information changes or requested omissions from the transcript.

Following completion of all interviews, the analysis took place using IPA, as described by Smith et al. (2009), in the original language of the interview, Maltese or English. Translation of transcripts prior analysis could have presented a risk of losing essential cultural expressions and meanings for the crucial interpretation process (Croot, Lees and Grant, 2011). Postponing the translation as late as possible assisted me to retain as much original language richness as possible. Following the completion of the analysis, the extracts chosen that were to be included in the thesis were translated for the reader's ease of reference. Supervisors were provided with a number of translated transcripts in order to observe, understand and discuss the analytical process for credibility purposes. Quotes used in the results chapter were chosen according to the potential impact on readers, be it professionals or social policymakers, to directly listen to and feel the voices of parents' experiences and needs understudy.

4.9 Data management and analysis

Some qualitative methodologies are reported to adopt contemporaneous time frame for data collection and analysis (Robson, 2002). Smith et al. (2009) suggested otherwise, as IPA views each participant as unique and does not expect the researcher to bring prior acquired knowledge from other interviews to the interview process at hand. I chose to initiate the analysis once all data collection and transcriptions were complete. This assisted me in analysing the transcriptions of one group at a time, as recommended by Smith et al. (2009) following Gadamer's (1989) philosophy (see section 4.4.1). It was more time-consuming than other contemporaneous analysis methods, as I had to wait

until all interviews of each group were completed and transcribed. Nevertheless it provided me, as the analyser, with an important source to maintain a constant and coherent thought process of the same age group to aid coherent interpretative skills for one group at a time. Once each interview was transcribed, these were uploaded in the NVIVO8 software, according to its respective group.

4.9.1 NVIVO8 software

NVIVO8 is a software programme that assists in the management of transcripts during the analysis procedure (Welsh, 2002; Bergin, 2011). The software does not perform the analysis (Welsh, 2002): I guided the analysis following Smith et al.'s (2009) steps (see section 4.9.2). NVIVO8 had the advantages of providing easy access to data and the ability to handle large amounts of data with consistent coding schemes (Weitzman, 2000), as well as assisting in maximising rigour and trustworthiness (Welsh, 2002). Yet, it also presented risks for one to become too engulfed in the functioning of the software, should the researcher not be familiar with it and becoming detached from the data (Bergin, 2011). Following a few introductory courses to familiarise myself with NVIVO8's primary functions I used it to assist my data management process. My NVIVO8 software utilisation was limited to the organisational advantage presented when one deals with a large sample size and consequently a large amount of data, similar to Smith and Hesse-Biber's (1996) context.

NVIVO8 has been observed to promote more rigorous thematic analysis than manual IPA process (Flowers, Davis, Larkin, Church and Marriott, 2011). Hence, its utilisation in this study was to organise the multitude of emerging themes, both at the individual participant level and at group level. The software proved to be useful in giving a clear understanding of the rate of theme expression by participants at group level. Themes were further reduced based on convergent and divergent perspectives (see section 4.9.2). NVIVO8 also provided the advantage of having a flow of transcribed text on a screen, facilitating the deconstruction techniques used to enhance interpretation of text (Smith et al., 2009).

4.9.2 Analytical procedure

The analysis procedure followed the IPA guidelines as described by Smith et al. (2009) in 8 steps. Some examples of these steps may be found in Appendix IV.

Step 1: Integration with the transcript

I initiated the intensive reading and re-reading process of one transcript from the first group (parents of 0;6 year old children). I quickly felt integrated with my data and focused on the participants' 'life stories' since I performed the transcriptions myself. My reflective diary assisted the recollection of the interview itself, including some field notes taken at the time. I also felt the need to re-listen to the interview recording to assist memory of non-verbal reactions based on the participant's intonation.

Step 2: Initial note-taking

Initial note taking was performed using NVIVO8 as the first level 'coding'. The note-taking consisted of descriptive (describes the content of text), linguistic (specific use of language) and interpretative comments (interpreting the participants' overarching understanding: including personal reflections, critically making sense of the participant with provisional meanings). These were performed on three separate readings to enhance the critical process of engaging with the data. This step was based on the semantic content and language use on an exploratory level (Smith et al., 2009) and in a comprehensive manner. It helped me to understand the way the participants understood and thought about specific aspects. Smith indicated that this is close to being a free line-by-line textual analysis, keeping the philosophical underpinnings in mind (section 4.4.1). Strategies of de-contextualisation were employed to bring into detailed focus the participants' words and meanings: such as reading a paragraph backwards, replacing key words for enhanced understanding and reading a phrase at a time, exploring potential different meanings. Notes were written in English and this language was maintained during all steps of analysis, while keeping the original transcript's language intact (see Appendix IV).

Step 3: Developing emergent themes

The analytic process shifted to the primary use of the initial notes. Although the original transcript retained its importance, more attention was given to the comprehensive note-writing in step 2. At this stage the analysis process typically took me away from the participant and included more of my *perspective* (Smith et al., 2009). A collaborative effort of both my position and that of the participant became evident in the resultant analysis. This took place by creating a concise statement creating higher level 'coding' on NVIVO8 which was the theme. This reflected a synergistic process of description and interpretation that conveyed a clearer understanding of the *experience* under study.

Step 4: Searching for connections across themes

Recurrent themes produced in step 3 were moved around to create connections and hierarchical maps based on a mixture of relatedness, polarisation, functionality and/or temporality techniques. Others that were not initially incorporated in a connection were not discarded but left there to be referred back after analysis of further participants was completed. At this point NVIVO8 was very helpful in organising emergent themes which were stored in one file with the transcript and notes. Each coded theme was directly linked to the exploratory notes (lowest 'coding' level of NVIVO8), which are automatically linked with textual quotes; enhancing the flow of the analysis from the original transcript to the super-ordinate theme. Hermeneutic fore-structures were brought forward from the old and new information during thematic emergence for each participant. A number of textual quotes carried multiple layers of interpretation following the hermeneutic cycle (connecting the part to the whole, particular to the more holistic) in order to explore new interpretations and meanings to give the analysed data a richer texture as it increases depth of the analysis.

Step 5: Moving to the next participant's transcript

An inevitable influence of prior findings is in keeping with the hermeneutic background of IPA during the thematic emergence (step 3). However, upon initiating another participant's transcript analysis, I tried to rule out prior findings so that I could give idiographic importance to each participant's transcript. The repetition of every step (1-4) for each of the participants in a systematic manner allowed new themes to emerge with each case. These steps were repeated for each participant within the same group and subsequently for all the groups. Forward and backward movements across participants took place in order to explore different potential interpretations within the hermeneutic cycle.

Step 6: Looking for patterns across cases of one group

Recurrent themes across interviews were taken as indicative of their status as recurrent themes that reflected shared understandings. A theme was accepted when at least 5 of the participants in one group stated it, following Smith et al.'s (2009) guidance. The data set presented in step six was much larger than in steps 1-5 as all participants' hierarchical networks were synthesised together. The synthesis took place using a mixture of functionality, relatedness, polarity and/or temporality techniques in order not

to exclude potential associations. A network of associations was then performed from which hierarchical thematic network was organised on NVIVO8.

Step 7: Repeating steps 1-6 for the other three groups

The same steps 1-6 were repeated for each of the remaining three groups. Each participant was given his/her idiographic importance throughout the whole process (steps1-4). Steps 5 and 6 took place subsequently. On a group level, each group’s network was kept distinct from the other as much as possible, so that my thought process remained true to the group’s lived experiences, according to the presented data. Once all the groups’ networks and hierarchies were depicted, a forward and backward movement took place in order to understand potential meanings from a hermeneutic cycle perspective.

Step 8: Searching for commonalities and divergences across groups

Step 6 was then repeated across groups. The hierarchical thematic networks were compared against each other using NVIVO8 print outs. Commonalities were observed across all groups. Moreover, those themes that were common in two or more of the four groups qualified as common themes, following Smith et al.’s (2009) recommendations. A common recurrent theme qualified for the final step if half of the sample or more from each group mentioned it. A divergent super-ordinate theme was observed belonging to individual groups, one that was perceived differently across groups (namely ‘Experiential Challenges’ see section 5.9). Divergent themes seemed to become evident when participants talked about their past lived experiences. For example, in group 4, parents of 5 years old children had a greater amount of past experiences themes than other groups whose children were younger, based on cumulative parental experiences (Table 4.1). Thus divergent themes were noted across groups based on the child’s ages rather than individual separate groups.

Table 4.1 Accumulation of experiences due to child’s developmental age

| Parents’ reported Lived Experiences | | | | |
|-------------------------------------|---------|---------|---------|---------|
| Child’s age | Group 1 | Group 2 | Group 3 | Group 4 |
| 5 years | | | | |
| 3;6 years | | | | |
| 2 years | | | | |
| 0;6 years | | | | |

4.10 Pilot study

Following approval of all ethical permissions, a pilot study was carried out with two sets of parents from each group (N=8) prior to the actual study. This was performed to test the utility of the research design, research questions, to observe for any changes or updates necessary prior to the implementation of the whole research data collection procedure with all the participants (Sampson, 2004) and to practise my IPA analytical skills including the use of NVIVO8. One of the advantages of conducting a pilot study is that it might give advance warning of pitfalls of the study data collection, by identifying potential practical problems in following the research procedures (van Teijlingen, Rennie, Hundley and Graham, 2001; Holloway, 1997). Pilot interviewees gave positive feedback on the interviewing process and techniques, at the end of the interview.

The data collection process and interview schedule were tested, interviews transcribed and the analytical steps performed, as outlined in section 4.9.2. All the pilot interviews were translated to the English language for supervisory discussions of analytical interpretation purposes. As a result of the pilot study, minor changes were made, including changing the audio-recorder to a digital one for higher quality recording and to enhance the flow of the questions. The pilot interviews were then incorporated into the study sample since no changes were made to the interview schedule. Although Smith et al. (2009) does not recommend analysis of interviews prior other interviews due to potential influence on the structure of the interview, I maintained a reflective journal and always performed an interview with an open mind and genuine attitude to appreciate the uniqueness of each participant's experience (see section 4.11.2). Results from the pilot study assisted me to gain insights on interviewing skills, feasibility of the study and familiarisation with the analytical procedure in full. Upon completion of the pilot study the full data collection on the whole sample was performed, followed by the analysis of each interview led by its respective group.

4.11 Reflexivity

Reflexivity is often defined as an activity of 'self-reflection' (Carolan, 2003), self-scrutiny and criticism self-inspection (Pyett, 2003; Colbourne and Sque, 2004), particularly in making explicit research decisions, including an analysis of the research context and political environment (Hand, 2003). Lamb and Huttlinger (1989, p.766)

state that reflexivity is ‘a self-awareness and an awareness of the relationship between the investigator and the research environment’. The aim of phenomenological reflection is ‘to effect a more direct contact with experience as lived’ (van Manen, 1990, p.78). In critical research, reflexivity involves honesty, relates to research credibility and addresses ethical questions encountered in the research process in order to identify, acknowledge and act upon the limitations of the research (Gough, 2003; Fontana, 2004). It also addresses the interpersonal and institutional contexts of research and the way data analysis methods are used (Mauthner and Doucet, 2003).

4.11.1 Creating a reflective routine prior data collection

As a health professional I was already familiar with reflexive practice, nonetheless maintaining a reflective journal on a daily basis was a challenge. The first part of this study’s time-frame, familiarisation with literature background, acted as ‘an initiation’ for me to create a writing routine of my thoughts and reflections about the study process, on a daily basis. Reflexivity on literature also assisted in maintaining a thorough thought process that supported me to adhere to all ethical procedures throughout the study (Jootun, McGhee and Marland, 2009; Shaw, 2010). The activity of keeping this journal and of regularly discussing its process with my supervisors, took a primary role in my academic journey. It became a vital memory journal and analytical asset in my research decisions throughout the research process.

4.11.2 Reflexivity during data collection

Reflexivity acts as an awareness-raising mechanism that one engages with prior to and during data collection (Shaw, 2010). As Heidegger’s hermeneutic philosophy maintains, each human being carries their emotional world and brings forth their experiences. Indeed, insider-outside balance was noted since awareness of my stance with the participants’ spatio-temporal worlds was vital (see Appendix V). During the data collection period, I felt sensitive to parents’ stories, however, I did not react during the interview in an emotional manner to their strong narratives. Despite this, they had a lasting impression on me. This was felt during the transcription of each interview as I listened to their stories repetitively. Since I had entered a routine of writing in my reflective journal, it acted as a debriefing exercise, where I externalised my thoughts in order to concentrate on the task at hand. Moreover, this study has changed my way of

looking at life as a woman, as a spouse and hopefully as a future mother (see Appendix V).

Parents had a tight schedule available for the interview confirming the choice of a one-time interview due to minimal commitment required from the participants (Flowers, 2008). Both parents were invited to the same interview together, following family systems principles, since both may constantly influence each other's lives, emotions and perceptions during their daily family lives (Sameroff and Fiese, 2000, see section 3.3). I felt I could not separate such influence in two parent families during the research interview, as both parents contributed to their child's development and upbringing.

Arguably, experiences and perceptions held by either parent about the other parent may present a barrier to open communication. In the majority of the interviews in the current study, feelings were expressed in the other partners'/spouse's presence without apparent disinhibitions. For example: *"I didn't tell you (to wife) then, but I used to go and visit him (child) after work before I returned home every day"* (Garry, G2). In some interviews I had the opportunity to observe parents finish the sentence of the other, reflecting the inter-connectedness of their thought processes, similar to Borg Xuereb (2008).

Performing interviews with both parents was not without challenges. Occasionally, a parent who was eager to speak interrupted their spouse/partner or one parent compensated for another when they appeared shy. The presence of the spouse/partner during the interview frequently appeared to act as a source of encouragement for the individual parents to share thoughts and feelings in a 'safe' environment. One parent's perceptions and experiences also appeared to act as a trigger to the other. I, likewise, felt the need to consciously ask for both parents' opinions so as not to favour one parent more than the other and to obtain both parents' sentiments.

As the investigator, I understood that having both parents together during the same interview could have been more difficult for them to care for the child during the interview. Some parents opted to have their children in the interview room and hence distractions occurred, whilst others opted to be interviewed during school hours or during the child's typical sleeping time. Others made child-minding arrangements with their extended family.

4.11.3 Reflections during analysis process

During the first and second steps of the analysis (section 4.9.2) I added reflections from my journal, such as thoughts, questions, doubts and trends. Reflexive note-taking continued throughout the rest of the analytical steps. This journal helped me to refresh my memory regarding thoughts during data collection process, keep track of my thoughts and maintain coherent interpretations during the stages of analysis. The journal was a key aid to cope with a multitude of results when themes needed synthesising across all four groups. Reflexive activity in conjunction with supervisory discussions provided opportunities for interpretation coherence, in terms of not being too interpretative too early in thematic analysis.

I also felt the need to control my interpretation activity due to my professional background. I was observing frequent trends, like lack of awareness of child development milestones. Parents of children from group 1 and 2 aged 0;6 and 2;0 years respectively seemed more concerned about evident physical independence rather than intellectual and communication stimulation. As a professional this created certain concerns at the lack of information or interest manifested by these parents about the importance of stimulation, even more when these children were born with risks for ID. I also felt the need to suppress these thoughts during the interviews in order not to raise doubts or distressing thoughts in parents' lives following the ethical protocol. Smith et al. (2009) may describe this as an added interpretative layer, however these authors also suggested not to perform 'too much' interpretation especially during the initial steps of the analysis. Thus, in order not to influence the interpretation of the results too much I took a step back on this professional issue.

4.12 Assessing the quality of the study

The credibility of qualitative research is an important consideration in establishing the quality of the research study and a wide range of strategies and guidelines for assessing this exist across different traditions. Qualitative methodologies embrace different philosophical and epistemological underpinnings which may in turn further challenge the diversity of available credibility criteria. Indeed, Cohen and Crabtree (2008) observed a general disagreement in qualitative studies on establishment of credibility, reflexivity, and verification importance. The search for a single set of criteria for good qualitative research is grounded in the assumption that qualitative research is a unified

field (Johnson, Long and White, 2001; Rolfe, 2006; Dixon-Woods, Shaw, Agarwal and Smith, 2007; Yardley, 2008) .

The credibility criteria described by Yardley (2000; 2008) offer a variety of ways and broad criteria for establishing quality. Moreover, they can be applied and adopted irrespective of the theoretical orientation presenting an accessible and flexible style of quality assessment (Smith et al., 2009). A rationale for adopting qualitative methodologies in the literature is a recognition that one's knowledge and experiences of the world cannot consist of an objective appraisal of some external reality, but is profoundly shaped by one's subjective and cultural perspective, conversations and activities (Yardley, 1997). In keeping with the philosophical underpinnings of this study, Yardley's (2000, 2008) criteria for credibility of good qualitative research were adopted for this study, namely: sensitivity to context; commitment and rigour; transparency and coherence; as well as impact and importance.

4.12.1 Sensitivity to context

The context of a qualitative study comprises many facets. Theoretical background and understanding of prior research evidence created by other investigators employing similar methods were explored in the literature review during the first phase of the study, including topic related literature and method related philosophical/theoretical understanding. This assisted in creating a thorough awareness of relevant literature and related empirical work so that the analytical outcome is sensitive to the data itself. Upon reflection, given the importance of interpretation in this study the theoretical background did not hinder, limit or built expectations for my analysis. On the contrary, it further assisted me to create an open-minded perspective towards the understanding of the uniqueness of each experience; hence expecting the unexpected whilst acknowledging previously reported aspects. Theoretical integration was also essential to build a sensitive and adequate data collection tool.

Language, social interaction and cultural context are central aspects in qualitative research (Yardley, 2000, 2008; Smith et al., 2009). Language also reflects socio-cultural perspectives, historical and ideological influences on the beliefs, objects and expectations of all participants (Watts, 2001). As a bilingual cultural insider (see Appendix IV), I was aware of linguistic expressions, socio-cultural beliefs and historical

factors that may influence the linguistic choice and language-use of the participants. Additionally, providing the opportunity to choose either language (Maltese or English) provided an inclusive social perspective that would not have been achieved if the study was conducted in one language (Croot, Grant, Cooper and Mathers, 2008). This decision was also considered to assist the participants' feelings of control and ease of expression during the interview process, in adherence with IPA analysis process (Smith et al., 2009).

The analysis in this study took place in the original language as chosen by the participant. This decision was facilitated by the uniqueness of linguistic and socio-cultural aspects related to language use (Briffa and Caruana, 2009; Croot et al., 2011). The process of translation of written or spoken word from one language to another is one of reconstructing meaning rather than uncovering it (Temple and Young, 2004). Thus I attempted to avoid anticipated losses in lexical and linguistic expressions by adhering to the linguistic and socio-cultural context in which the study took place.

The listener contributes to what is said during data collection (Yardley, 2000) as well as actively or passively invoking the relative and shared understandings which provide the framework for speech (Pomerantz and Fehr, 1997). For this reason I kept a reflective diary and wrote reflections before and after each interview, in order to maintain a genuinely open mind towards each participant's unique perceptions and experiences. During the interviews I maintained behavioural sensitivity by remaining constantly conscious of my open posture and empathetic probing to assist parents to elaborate on unclear or ambiguous comments. I tried to follow their lead as much as possible whilst adhering to the semi-structured interview plan. I also took care not to display religious symbols in jewellery or dress so as to portray as neutral stance as possible.

4.12.2 Commitment and rigour

Commitment refers to prolonged engagement with the topic, not necessarily as a researcher (Yardley, 2000). Prior to entering the data collection phase I familiarised myself well with the literature published about the topic under study. My reflexive professional practice with Maltese parents (section 1.4) motivated me to complete the study. Moreover, since I am a novice qualitative researcher, I attended two accredited courses to learn the applied perspective of IPA, as described by Smith et al. (2009):

namely Introduction (prior data collection) and Advanced (upon completion of data collection) IPA programmes.

Rigour is the means by which one demonstrates integrity and competence of the research (Tobin and Begley, 2004). According to Yardley (2000, p.221), rigour refers to the 'resulting completeness of the data collection and analysis'. The need to incorporate rigour and creativity into the scientific process of qualitative research has fuelled debate over the issues of bias and the process of demonstrating validity (Johnson, 1999). Denzin and Lincoln (2000) and Arminio and Hultgren (2002), amongst others, challenged the concept of rigour as an empirical analytical term and argued that it does not fit into an interpretative approach. However, Tobin and Begley (2004) refuted such arguments as rigour was considered as a means by which one manifests integrity and competence regardless of paradigm. I attempted to follow methodological rigour, by utilising comprehensive purposive sampling and completing in-depth analysis, whilst adhering to the study's philosophical and theoretical underpinnings.

Translation

The presented quotes, in the analysis chapter, were chosen to support the findings of the study as well as to transmit parents' voices directly to readers, be it other parents, potential social policymakers and/or professionals. Following the completion of the analysis all the quotes presented in the results chapter, were translated into English for the readers' benefit and then back-translated. A Maltese-English interpreter assisted in order to maintain and adhere as much as possible to the original message expressed by the participant (Squires, 2009; Croot et al., 2011) with more than 90% of lexicon and expression agreement. Consensus on occasional linguistic variations was achieved through discussion. Thus, the translator did not play a role in the analytical process and her contribution was for rigour purposes only, whilst respecting at all times the anonymity of the participants. This highlighted rigour of the provided translated quotes and my linguistic coherence used in analysis process.

Language of analysis

It is acknowledged that analysing interview transcripts in their original language may pose a limitation in peer discussions for interpretation 'control': where text was read in Maltese and analysis output was in English. For this reason all the pilot-interviews' transcripts and large parts of the majority of interviews were translated to English for

discussion purposes with my supervisors. The benefits of this process included methodological rigour and personal perspective rigour from a cultural insider aspect vis-à-vis outsider cultural knowledge of supervisors (see Appendix IV). Feedback from these translated sections was applied in a coherent and rigorous manner to the analysis process.

Independent audit

An independent audit is a powerful way of validating one's research report (Smith et al., 2009) and is recommended as evidence of a systematic and transparent account manifesting commitment to the study's quality. Smith (2011, p.17) outlined characteristics of a good IPA research and these were utilised to guide methodological rigour in the external audit. These mainly include: adherence to theoretical principles of IPA; sufficiently transparent; coherent, plausible and interesting analysis; sufficient sampling from corpus to show density of evidence for each theme.

A bilingual auditor was recruited. This auditor had an academic background and did not share a similar professional background to me. Given the involvement of two languages in the analysis process, she also followed two randomly selected transcripts through the entire analytical trail; this was crucial as analysis began in Maltese and the outcome was in English. The auditor indicated that she found the research outcome to be transparent, coherent, rigorous, logical and consistent. She also stated that analysis was understandable to the reader, she could follow the decision trail and that the trustworthiness of the interpretations ensured that similarities and differences between cases were highlighted. A holistic picture with no assumptions and having chronological attributes of analysed experiences (birth to 5 years of age) seemed evident. The auditor pointed out the presence of an account that systematically and transparently manifested commitment to the study's quality and validity. She also pointed out that the Maltese-English analysis output was true to the participants' original transcripts (Spiteri, 2012, 8th June, personal conversation).

4.12.3 Transparency and coherence

The descriptions of the methodological steps in this chapter and the analysed results in the following chapter are intended to be clear, transparent and understandable for the

reader to follow the decision trail. The external auditor feedback confirmed both transparency and coherence of this research (section 4.12.2).

Qualitative researchers are encouraged to adopt strategies of honesty, openness and reflexivity in establishing validity of their study (Hagey, 1997) and self-scrutiny (Wadsworth, 1997; Pyett, 2003; Shaw, 2010). Reflexivity (see section 4.11) was maintained throughout all stages of the research process in order to promote clarity of the decision trail, thought-processes, as well as rigour and respect at all times for all ethical considerations involved.

Member-checking is frequently utilised in qualitative research as a part of trustworthiness, to redress the researcher-participant power balance (Karnieli-Miller, Stier and Pessach, 2009; Goldblatt, Karnieli-Miller and Neumann, 2011). Morse et al. (2002) indicated that it is not always considered to be appropriate, as it may also cause distress for parents. The process of member checking does not adhere to the double hermeneutic stance in section 4.4.1, where the final interpretation of the results is the researcher's interpretation of the analysed results as defined by its methodology. During all the interviews I repeated one question at the end of the interaction in order to check the participants' coherence. They all presented a repeated response and at times some parents commented "*I already told you its ...*" within the same time frame and context.

4.12.4 Impact and importance

A decisive criterion by which a qualitative study should be judged is the impact and utility of its results upon completion (Yardley, 2000). The rationale for this study (as stated in section 1.4) was to provide a foundation stone for family-centred early intervention services in Malta for parents whose children are born at risk for developing ID. In adherence to Yardley's (2000) notions, a qualitative study arising from particular social context and serving a social purpose with social effects has practical socio-cultural impact.

Swanson, Durham and Albright (1997) argued that qualitative methodologies enjoy the advantage of the emphasis on research-in-context, resulting in a close fit between the research and practice. Transferability of findings remains within the discretion of the reader to match the participants' unique circumstances for theoretical transference to

take place (Smith et al., 2009; Smith, 2010). The findings of this study have potential implications for professionals and social policymakers, to help develop service delivery in association with explored parents' needs (sections 7.1, 7.2). Hence this study could serve as an empowerment opportunity for parents' voices to be heard. It may act an information resource for professionals who wish to enhance their service delivery in order to better understand the carers of their patients'/clients' lifeworlds. This could assist the future transformation of service delivery towards a lifeworld-led client-centred approach (Todres, Galvin and Dahlberg, 2007; Dahlberg, Todres and Galvin, 2009).

In summary, it seems clear that this study has met all four of Yardley's (2000, 2008) criteria for credibility: namely, sensitivity to context; commitment and rigour; transparency and coherence; as well as impact and importance. These were also supported by the external audit outcome.

4.13 Conclusion

This chapter presented the research questions, approach, and rationale for methodological decisions, ethical considerations, recruitment and data collection. Ethical principles were identified, discussed, followed and respected at all times. Qualitative data management using NVIVO8 was described and the steps of the interpretative phenomenological analysis were portrayed. Trustworthiness and credibility aspects of this study were discussed following Yardley's (2000) criteria. Reflexivity in IPA was given an important role during the analytical process as outlined in the analytical steps and reflexivity sections. The findings of the study are reported in chapter 5.

Chapter 5 Results and Analysis

5.1 Introduction

Parents of 37 children born with biological risks for ID during later childhood were interviewed, transcripts were transcribed verbatim and analysed following the analysis procedure outlined in the methodology chapter. This chapter presents the participants' demographic backgrounds and the results interpreted from the analysis of the interviews. Quotes in this chapter were reduced with "...” to maintain the most relevant utterances or parts, some of which include M (mother) and F (father).

5.2. Demographic background of participants

The participants are the parents of children born with biological risks for ID during later childhood, as defined in chapter 2. One- or two-parent families who fitted the inclusion criteria were invited to participate in the study following the approved data collection procedure (see section 4.8). On re-inviting the parents of 40 children, who approved to be contacted, 3 replied that they did not wish to participate due to 'unwillingness to re-open closed wounds'. However they were willing to participate should the study require completing a questionnaire. Since this was a face-to-face interview the final participants included parents of 37 children, who signed the consent forms sent by post. Demographic details are outlined in Table 5.1 using fictitious names.

The majority of the sample were two-parent (1 mother and 1 father) families (N=35, 94.6%) including 3 cohabiting and 32 married couples. The sample also included two single mothers. Initial readings of the data suggested that each set of parents had unique life-circumstances, as well as different opinions and worldviews. However, analysing the interview transcripts in conjunction with my reflections on answering the research questions, they present similarities and differences both within groups and between groups.

Table 5.1 Participants' demographic details

| Parents | Age | Educ. *1 | Status*2 | Employment status*3 | Children | Age (yrs)*4 | Birth-order*5 | Parents | Age | Educ. | Status | Employment status | Children | Age (yrs) | Birth-order |
|-----------------|----------|------------------|----------|----------------------|------------|-------------|---------------|----------------------|----------|-----------------|--------|---------------------|----------|-------------|--------------------|
| Abigail Angelo | 35 39 | P.Sec Sec | M | Par Lv. F.T. | Angela | 0;6 (G1) | 2nd/2 | Francesca Freddie | 35 39 | Sec. Sec. | M | UnEmp. F.T. | France | 2;3 (G2) | 2 nd /2 |
| Ariel Alan | 45 40 | Tert. Tert. | M | Par Lv. F.T. | Amanda | 0;7 | 2nd /2 | Farah Fabio | 30 31 | Tert. Tert. | M | Par Lv. F.T. | Florence | 2;6 | 1 st /2 |
| Brooke Bernard | 30 34 | Sec. Sec. | M | UnEmp. Self Emp. | Bernice | 0;9 | 4rt /4 | Gaia Garry | 32 35 | Sec. Sec. | M | UnEmp. F.T. | George | 2;6 | 1 st |
| Barbara Ben | 36 34 | Sec. Sec. | M | UnEmp. F.T. | Bernadette | 0;7 | 1st | Gladys Glen | 35 38 | P.Sec. Tert. | M | UnEmp. Self Emp. | Gabriel | 2;9 | 4 th /4 |
| Camille Chris | 25 44 | Sec. Sec. | M | F.T. F.T. | Cathy | 0;6 | 2nd /2 | Hannah Hamlet | 31 31 | Sec. P.Sec. | M | UnEmp. F.T. | Henry | 2;6 | 2 nd /2 |
| Carla Carlos | 31 29 | Sec. P.Sec. | M | UnEmp. F.T. | Carol | 0;7 | 2nd /2 | Helen | 34 | Tert. | S | F.T. | Harrison | 2;3 | 1 st |
| Daniela Daniel | 29 33 | Sec. Sec. | M | F.T. F.T. | David | 0;7 | 1st | Irene Igor | 33 35 | Sec. P.Sec. | M | UnEmp. F.T. | Ismelia | 2;4 | 2 nd /2 |
| Doris Drover | 31 31 | Tert. Sec. | M | Par Lv. Self Emp. | Dean | 0;9 | 1st | Isabelle Ivan | 33 35 | P.Sec. Sec. | M | UnEmp. F.T. | Ian | 2;5 | 2 nd /2 |
| Elisa Edmond | 24 25 | P.Sec. P.Sec. | Coh | Par Lv. F.T. | Eliana | 0;5 | 1st | Joanne Joseph | 32 34 | Tert. Tert. | M | P.T. F.T. | John | 1;7 | 1 st |
| Emily Edward | 39 36 | Sec. Sec. | M | UnEmp. P.T. | Ernst | 0;4 | 5th /5 | - | - | - | - | - | - | - | - |
| Kyra Kevin | 34 35 | Tert. Tert. | M | UnEmp. F.T. | Kelly | 3;6 (G3) | 2nd /2 | Paola Paul | 37 37 | Tert. Tert. | M | UnEmp. F.T. | Pablo | 5 (G4) | 1 st |
| Krista Keith | 35 36 | Sec. Sec. | M | UnEmp. F.T. | Kyle | 3;6 | 2nd /2 | Pearl | 30 | Tert. | S | F.T. | Preston | 4;6 | 1 st |
| Lily Lawrence | 20 26 | Sec. Sec. | Coh | UnEmp. F.T. | Logan | 3;1 | 1st /2 | Rose Ronnie | 31 32 | Tert. P.Sec. | M | F.T. F.T. | Ronald | 5 | 1 st |
| Lavender Lewis | 36 36 | P.Sec P.Sec | M | F.T. F.T. | Louis | 3;7 | 1st | Riana Rafael | 37 40 | P.Sec. Sec. | M | UnEmp. F.T. | Radcliff | 5;5 | 2 nd /3 |
| Maria Mario | 20 29 | Sec. Sec. | Coh | UnEmp. Red Hrs. | Mary | 3;1 | 1st | Sarah Samuel | 43 44 | Tert. Tert. | M | F.T. SelfEmp. | Sandra | 5;6 | 1 st |
| Marthese Manuel | 32 33 | P.Sec. P.Sec. | M | UnEmp. F.T. | Martha | 3;2 | 1st | Selene Sergio | 36 39 | Tert. Tert. | M | UnEmp. F.T. | Steve | 4;9 | 1 st |
| Naomi Niles | 26 31 | P.Sec Sec. | M | P.T. SelfEmp F.T. | Noel | 3;6 | 1st | Shanaia Simon | 32 32 | Sec. Tert. | M | UnEmp. F.T. | Samantha | 4;10 | 1 st /2 |
| Nancy Newton | 38 40 | P.Sec. Sec. | M | UnEmp. F.T. | Neville | 3;1 | 2nd /2 | Thelma Thornton | 25 30 | Sec P.Sec. | M | F.T. F.T. | Theo | 5;2 | 1 st /2 |
| Odette Oliver | 37 38 | Tert. Tert. | M | UnEmp. F.T. | Olivia | 3;7 | 2nd /3 | Tabitha Timothy | 36 36 | Tert. Sec. | M | UnEmp. Self Emp. | Tom | 4;8 | 2 nd /3 |

*1 Education: Sec.= Secondary, P.Sec.= Post secondary, Tert.=Tertiary; *2 Status: M=Married, Coh= Cohabiting; S=Single *3 Employment: F.T.=Full time employed, P.T.=Part time employed, Par. Lv.=Parental leave from employment, UnEmp.=Unemployed, SelfEmp=Self employed, RedHrs= Working at reduced hours; *4 G1=Group1, G2=Group 2, G3=Group3, G4=Group4; *5 Birth order Eg: 2nd/2 = 2nd born of 2 siblings.

The parents

Thirty-two married couples (86.5%) lived in their own properties and one couple lived in a rented property. Out of the three cohabiting couples, two lived with the mother's extended family, and one lived on their own. Whilst one single mother lived on her own, the other single mother lived with her parents. The interviewed participants included parents who had either older children (N=14), or younger children (N=4) other than the child born with risks, whilst some parents had both older and younger children (N=3). Two out of three parents, who had both older and younger children than the affected child, insisted that their youngest was unplanned. In group 3, one couple was planning for a baby and another couple were expecting their second child.

The children

The average age of the participants' 'at risk' children was 6.7 months in group one (N=10); 2;4 years in group two (N=9); 3;4 years in group three (N=9) and 5 years in group four (N=9). The child's ID risks included conditions identified at birth or soon after for 15 participants (40.5%). These diagnoses included syndromes, congenital medical anomalies or severe complications that occurred in the immediate post-partum period.

Twenty-one children (59.5%) were either significantly premature or had VLBW. These children presented risks for the development of cerebral palsy and ID, which could become evident as the child developed. One cannot predict the intellectual ability outcome of the child, thus the focus was maintained on the birth risks recorded around the child's birth circumstances. No child was officially diagnosed solely with an ID, apart from those born with specific conditions. Parents observed some of premature/VLBW-born children as possibly manifesting developmental delay (N=4); physical developmental delay (N=2); communication delay (N=1); and feeding difficulties (N=2). Three children had received an official diagnosis of visual impairment. Ten children, who were born with risk-factors but not 'conditions', were perceived by their parents as following the typical developmental pathways.

5.3 Parenting a child born with risks for intellectual disability

The news of the birth of a child is usually associated with pleasant memories. By contrast, these parents felt literally *thrown* into a number of experiences that were *unplanned* and *unexpected* from what they considered to be typical. The unexpected turn of events marked the embarkation on a life-changing and challenging journey. Parents seemed to express both emotional and sociological interpretations for their daily lived experiences of raising their child born with risks of ID. Table 5.2 portrays the thematic hierarchical network, which will be explored in detail in this chapter.

Table 5.2 Thematic hierarchical network

| Thematic statement | Superordinate Theme | Theme | Sub-theme |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|------------------------------------|------------------------------------------|
| The experience triggered a self-protection mechanism in parents, which led to identification with similar experienced parents. This presented a multitude of life-world transformations | Experiencing is true understanding | Self-protection barrier | Rollercoaster of emotions |
| | | Identification with similar others | Lack of empathy |
| | | | Emotional comfort |
| | | Life-world transformations | Sharing of information |
| Impact was felt by all sub-systems of their family: extended family members; parenting their child/ren and parents as a couple | Family functioning | Extended family | Couple transformations |
| | | | Individual transformations |
| | | Parenthood | Practical support |
| | | | Emotional wellbeing |
| | | | Parenting with a difference |
| | | Parents as couples | Child-centred perspective |
| | | | Future concerns |
| Parents felt frustrated towards sociological issues about Malta's small size from a socio-emotional orientation. | Micro-system sociological framework | Person perspective | Older/younger siblings |
| | | Lack of choice: Trapped in Malta | Coping strategies |
| | | | Gender Roles |
| Information is perceived by parents to directly affect their emotions | Info-emotional cycle | Information balance | Enforced suppression of voicing emotions |
| | | | Social Stigma |
| | | Information channels | Availability of services |
| | | | Permanence and constancy of care |
| Service-use seemed to be affected by accessibility and suitability concerns. These do not always seem to reflect parents' needs and those of their child. | Service-needs-resource cycle | Accessibility | Quality and quantity of information |
| | | | Information seeking initiative cycle |
| | | Suitability | Communication attitude continuum |
| | | | Time allowance |
| | | | Collaborative team approach |
| Experiential changes and challenges are based on parents' experiences accordingly to child's age and individual acceptance journey | Experiential Challenges | Acceptance Journey | Awareness based on need |
| | | | Reliance on private resources |
| | | | Referral to services |
| | | Developmental challenges | Child's benefit |
| | | | Effects on parents |
| | | The 'healing' process | |
| | | Acceptance as a threshold | |
| | | Spiritual beliefs | |
| | | Hospital-home transition | |
| | | Development concerns | |
| | | Schooling challenges | |
| | | The mature expert | |

5.4 Experiencing is true understanding

All parents, to some degree or another, stated that parenting a child born with risks for ID, is ‘their new world’, a journey that began with unexpected news or events that transformed all their future plans. Table 5.3 shows three themes, which portray how parents felt emotionally alienated from the rest of the ‘inexperienced’ population.

Table 5.3 Experiencing is true understanding themes

| Thematic statement | Superordinate Theme | Theme | Sub-theme |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|------------------------------------|---------------------------|
| The experience triggers a self-protection mechanism in parents leading to identification with similar experienced parents. This presented a multitude of life-world transformations. | Experiencing is true understanding | Self-protection barrier | Rollercoaster of emotions |
| | | | Lack of empathy |
| | | Identification with similar others | Emotional comfort |
| | | | Sharing of information |
| | | Life-world transformations | Couple transformations |
| | | Individual transformations | |

Parents did not feel they could associate themselves with the typical population whose child was born under typical circumstances, discharged home with the happiness of having a healthy additional member in their family. Parents reported that their sense of belonging shifted from that of the typical parent towards an insecure temporal space, an unknown future with raised probabilities of having a child with ID. Through the themes interpreted from the interviews, I noted that parents perceived their worldviews as being thrown in limbo, an unknown situation in which they felt unprepared for having a child born ‘at risk’. The unexpected birth events were perceived to have marked a starting point towards a new life, that of parenting a child born in atypical circumstances. This situation created insecurities about their own future as a family, their child’s survival, rearing and developmental outcomes in the future.

5.4.1 Self-protection barrier theme

All parents noted that having a child born under atypical circumstances triggered a self-protection mechanism; one which instigated a barrier between the connections of their previous life-world, where all was smooth-running according to pre-established plans, versus the unexpected turmoil, unpreparedness, concerns and fears. Parents felt they were not truly understood by the significant people around them who had not passed through similar experiences.

5.4.1.1 Rollercoaster of emotions sub-theme

Shock

The birth event bestowed a shock scenario for parents when the unexpected happened: a premature birth, a succession of bad news, the child's life-threatening health state. Parents felt unprepared for the consequences. Indeed, some first-time parents would have just started to attend the parent-craft course sessions and may not have been aware that the pain that they were feeling was that of labour, such as the experience of Sergio (G4) "*I thought she (wife) was gonna die*".

The unpreparedness and unexpectedness of the birth process was a trauma for the parents. For example, Elisa (G1) and Krista (G3) attended a routine check-up and to their surprise were advised to remain in hospital as they were about to give birth. Similarly, Cathy's and Steve's father reported fear from the shock of the speed and unexpected life-changing circumstances.

"imagine, you're in a car driving 120 km an hour and then smack down right into a wall...it all came to a sudden stop right there and then when it happened" Sergio (G4)

Some parents reported the fear about mothers' life-threatening situations, such as too high or low blood pressure or unexplained blood sugar levels resulting in long pre-birth hospitalisations with guilt feelings for not being "*capable of keeping the baby in their womb*" (Carla [G1], Kyra [G3], Isabelle [G2], Hannah [G2], Rose [G4]). Such guilt feelings may be interpreted as a source of powerlessness over one's body to protect their child from being born too early, halting a full-term pregnancy in the safety of the mother's womb: a maternal protective instinct. Sarah's (G4) and Doris' (G1) saw their professional health background as an advantage to help them remain calm when their waters broke unexpectedly early.

Some mothers were aware about possible premature birth; however they still perceived their experience as traumatic due to its unexpected nature.

"it was such a shock, I know that prematurity existed, but when it hit me...it was such a trauma" Abigail (G1)

Others such as Irene (G2) and Keith (G3) perceived their reactions via abrupt physical pain during news breaking.

"at that moment in time I felt a shock inside my head, I felt it coming up through my feet and it stopped in my head...a very big shock" Keith (G3)

Parents perceived added anxiety of seeing their child in a vulnerable health state, whose size and weight was very small, and was covered with ‘pipes’, ‘drips’ and ‘monitors’. This may indicate that part of their reported shock reactions may have been triggered by the NPICU set-up which acted as an eye-opener to the child’s life-threatening state.

“there it was a real shock...I felt as if I received a blow on my head from which I could not wake up. As you see all those very small children, all of them had loads of pipes coming out of them, you feel impressed by that environment” Alan (G1)

Moreover, fathers used to see their baby on their own without the company of the mothers, due to her recovery period post-caesarean / anaesthesia which further added to their anxiety about the emergency birth, their confusion and concerns for the mother’s health state. Drover, Dean’s father (G1) felt he was prepared to see his child as his wife (a health professional), before having her Caesarean birth, showed him pictures of intubated children to ease his shock, yet, he still perceived an emotional shock on seeing his intubated child.

“F – you feel very down, you feel very down and (3 sec pause) you feel as if the world ended in reality...”

M – I gave him as much information as possible...because I know that I will not see anything but he will. I told him ‘he is going to be filled with pipes and they will do this and that...I had a picture, but he had no idea. I didn’t want him to break down when I cannot handle certain things

F – I was prepared thanks to my wife, thanks to nothing else...I would have felt a much worse shock, a much bigger shock” Doris and Drover (G1)

Some parents remembered their child’s hospitalisation as one filled with concerns for the child’s survival and negative emotional turmoil for the whole family: siblings living at grandparents’ houses, parents constantly receiving negative news and the “rollercoaster” (Ariel, G1) of emotions due to the unstable child’s health. They reported moments of extreme happiness such as the first time they were allowed to touch or hold the baby since s/he was out of intensive care period as the peaks of their rollercoaster emotions.

“the first time that I held my baby (turned eyes upwards) I was so happy that I wanted to fly with happiness, it was the DAY of MONTH...I used go there, eager to arrive there to lift her again” Elisa (G1)

Ten parents realised the child’s serious health state when staff suggested the parents should baptise the child. This acted as an eye-opener, especially, for some fathers. However, Kelly’s parents refused immediate christening as they associated christening with dying babies. Garry (G2) felt disappointed that he could not choose god-parents

from his extended family as these had just left the hospital. Timothy (G4) felt that his child's christening was the drop that spilled the bucket for him.

"That was the worst thing for me, that a one-day old baby had to be christened...at that moment in time you won't understand anything what is going on...and the anointing of the sick act really made my heart ache, it was too much for me...seeing him so small, going to be christened, plus his situation that the day after he was going to be operated on, was really hurtful, very hurtful" Timothy (G4)

Self-protection shell

A number of parents reported a self-shielding mechanism, a cover from the emotional pain as a response to the contradictory feelings from the negative news. They did not seem to deny the negative circumstances but created a safeguard for their emotions.

"Encouraging each other helped us a great deal, we supported each other to come out of the shell (she cupped her hands together – as if it's an all-round cover) that you build to protect yourself from the shock that you are in...For me as a mother, the first three weeks I wanted to love my baby but I was afraid, I felt a strong fear that I am going to lose the baby so I didn't want to feel love for the baby and it was a miserable feeling...I felt frightened that I was going to get hurt. That was part of the trauma...But then I started opening up, but when I was closed within me I felt broken down, it broke me down in fact" Ariel (G1)

Most parents seem to experience contradictory feelings from fears of losing their baby intertwined with the natural mother-child bonding process; however the emotional support from their spouse/partner helped to come out of the 'shell'. The maternal attachment process was also noted to influence mothers' behaviours in some contexts. For example Marthese (G3) noted that she disregarded her personal health in order to remain as much as possible near her child's incubator during intensive care. Moreover, Gladis (G2) discharged herself during hospital migration (patients were moved from the old hospital building to the new building) to be physically as close as possible to her child.

For some parents long daily visits near their child's incubator appeared to ease their fears as they adapted to the environment.

"As soon as we went into the ward we just said 'hello', sit near the incubator and just stare at the baby. We just stared at the chart, talked to the midwife, nurse or doctor and that's it. I mean, we didn't even have energy, we felt so shocked that we didn't have any energy to communicate." Alan (G1)

Moreover, time and improvements in the child's health assisted some parents to bridge out towards the outside world: *"as time went by we got used to it"* Drover (G1).

Most mothers, more than fathers, reported a refusal of all kinds of contact with the 'outside world'. Angela's mother, Abigail locked herself in her house.

"those first three weeks...I was always alone here, people were phoning me and I didn't want to talk. I was feeling so down all the time, when I was talking I was crying, I was worried for her. Then when she came out of intensive care they reassured me, that she was ok and only then I started communicating again"
Abigail (G1)

Mothers strongly refused to and were afraid to answer telephone calls that were from the ward. These were passed on to the father for him to answer. They used to feel threatened that they were going to receive "the" negative news: that of the child's death.

"even during the night, I was all the time pondering, 'who knows if they will call, who knows'. Sort of always expecting that phone call with that news" Krista (G3)

This situation placed fathers in a key role, that of 'news buffers' not only for news from telephone calls but also for professional negative news divulged first to the fathers and later to the mothers.

"M - the high level of stress that I had in the very beginning for example, thank God I had him (husband), as I wouldn't have answered the phone. I was afraid that it would be news from the hospital.

F - my job was to keep her level-headed, in those times especially. Sort of, if anyone would call, they used to call me first...even her friends used to message me to see if they could call...even her mother used to call me...everyone used to call me" Paola and Paul (G4)

Some fathers felt it was their duty to suppress their emotions to be able to keep calm and composed to act as the "rock for the mother" (Garry, G2). This acted as their emotional protection mechanism. Suppression of their emotional sadness was perceived as societal norm. In turn fathers received reduced emotional support; further placing fathers at risk for emotional difficulties.

"I used to pride myself that I did not know how to cry, but at the time I cried, uuh yes I used to cry alone I mean, not in front of people and especially her (wife), at the end of the day I am human as well" Manuel (G3)

Some fathers felt that as they suppressed their emotions to support their wife at the time, this was the cause of their persistent sensitivity, even during the interview.

"I tried not to cry in front of my wife...I knew that my wife was totally broken down...she went through the labour pain, I understand that as a woman she suffered...so I tried as much as possible to keep my feelings inside me and I tried to encourage her as much as I could...I always tried to remain as calm as possible, and cry as least as possible or cry alone, and keep it to myself, but then...I remained very sensitive. To date if my son does a new movement or a new word...I cry like a baby" Garry (G2)

Since mothers used to perform long daily visits at their child's ward they used to receive some emotional support from nursing staff in the form of encouragement and active

listening, whilst fathers were usually at work. Thus, fathers were the silent sufferers in this situation and the persons to receive least emotional support. They had to deal with feelings of socially expected obligation to suppress their own emotions and emotionally support the mothers.

5.4.1.2 Lack of empathy sub-theme

Following the much anticipated baby-birth, circumstances in atypical circumstances or news seemed to create an ‘us versus them’ perspective. Parents perceived a reduced level of ‘true understanding’ from the people around them, including ‘inexperienced’ significant others, who did not have or were not going through a similar experience. Some parents repeatedly mentioned that I, as a researcher, could not ‘possibly begin to understand’ the turmoil that they had encountered.

“you have to be there to understand it” Ben (G1)

“I’m truly loud mouthed but you see that’s the problem when you’re not living it. When you’re not seeing it all the time, and understanding what’s happening then you don’t get it” Gladis (G2)

The notion that *“you have to experience it to be able to truly understand it”* (Daniel, G1) further emphasised that I was an outsider in their eyes, not because I was a stranger but an ‘inexperienced person’.

“I am sure that you are not understanding, do not misunderstand it, but...do you understand what I’m telling you...you cannot understand what we felt” Pearl (G4)

“If you have not passed through this experience then you cannot possibly begin to fathom what that person is going through. Nobody can” Sergio (G4)

They seemed to have built a wall around them that only those who had a similar experience were able to filter through to their emotions. Couples transmitted an advantage of having their spouse/partner as a source of empathy since they are in the same situation; the togetherness assisted the spouses’/partner’s emotions.

“as much as he (Daniel) knows what I am going through, since he was 24 hours always with me and seeing things that I saw and it’s his son at the end of the day as much as he is mine, I think no one else can really understand. Not even my mother...as he is not their child. Ok they are going to feel sorry but, he (Daniel) is in the same situation as I am, I think no one else can.” Daniela (G1)

Parents reported frustration when significant others, including extended family members, tried to offer emotional support. They did not feel truly understood or consoled by their words. Odette and Oliver, Olivia’s parents felt torn between the love

and appreciation they felt for their extended family support, yet they did not wish to have their company during post-hospital discharge period due to lack of perceived empathy.

“it was time for me to come home with the baby, my mother decorated my house door that I had a girl...so you have to face these things that everyone is coming home to be happy for you...until this phase passed it's not easy. You really won't feel like having those moments...you won't feel like talking with the people around you...not everyone understands it, for them they are giving you support but at that moment in time your mind is elsewhere” Odette (G3)

Although the extended family was constantly present for the parents and tried to provide emotional support as much as possible, parents did not feel ‘truly understood’: *“he is not your son, you do not know what it really feels like”* (Gaia, G2). Such comments addressed to extended family members, if taken out of context, may imply a source of conflict. However, the extended family tend to care for their close kin, the parents. Yet, extended family might at times end up as the scapegoats for the parents’ venting of frustrations.

“I think sometimes I end up feeling angry at my mother, poor thing...I end up shouting at her...because I have that confidence with her and I feel too nervous and my mother ends up shouted at...but after a while all my anger burns out.” Carla (G1)

Lack of empathy was also noted to result in loss of friends as parents interpreted their relationship as *“not true”*, *“superficial”*, lack of *“sameness”* and stigma perceptions, whilst others perceived differing life-world perspectives.

“you start choosing friends, who is a friend and who is not...Unfortunately, in our case we started eliminating them like dominos...cause you start realising who truly wishes you well or for example they came just for curiosity” Naomi (G3)

*“M - at times we feel that they do not really understand us as much in the sense that, they look at our son * differently. You know? And that hurts, a lot.
F – or with a degree of pity...don't pity my son,
M –Why should you call him a ‘miskin’ (poor thing), my son is not a ‘miskin’
Maybe this time it, it happened to me, maybe the next time it will happen to you...that hurts, and it frustrates us”* Selene and Sergio (G4)

Some parents looked at their experience as an opportunity to appreciate the importance of their “true” friends.

“we found help with regards to friends, at the time when we had to go to England (for child's operation), there were some who for example wanted to accompany us, more for moral support. Sort of, you really see the support and realise who the real friends are. You realise as well, for example, may be someone to talk to, or an sms of support also helps you get back on your feet.” Thelma (G4)

Other parents reflected that the perceived lack of empathy from significant others could have originated from their skewed perceptions during their emotional ordeal.

“I think it’s useless trying to explain to others what it is, as no one can truly understand you, people start irritating you...it’s worse explaining what you are going through.” Daniela (G1)

In summary, parents appeared to build a self-protection barrier around them to protect themselves from further emotional pain. Parents reported reduced empathy and understanding from the people around them, regardless their close relationship with them. This could have been due to the ‘inexperienced’ aspect of the other person; or the lack of shared experiences from which true understanding could be drawn, from the parents’ point of view.

5.4.2 Identification with similar others theme

Parents whose child was born with biological risks for ID felt a lack of true emotional support from other ‘inexperienced’ individuals, as noted in table 5.3. Following the lack of true empathy from significant yet ‘inexperienced’ others, these parents seemed to identify with other parents who had similar experiences: the ‘experienced’ others.

5.4.2.1 Emotional comfort sub-theme

Parents’ lack of emotional comfort from the ‘inexperienced’ people prompted them to seek emotional support outside their former social circle. Some parents found support from parent-run voluntary organisations of children with similar conditions, other parents made use of non-governmental organisations (NGOs).

“once I got out of hospital, support from other parents with similar experiences as mine was very useful for me. We helped each other you see? We shared our experience...I felt that the best support we could give each other was being with parents who had children with the same condition...when Olivia was one month old, I had already met with some parents for the first time. I felt that urge to see other babies and other parents and what they are going through, you are not alone” Odette (G3)

Meeting and communicating with these parents may have provided a sense that they were not alone in this world that others are also going through an ordeal or difficult situation, reducing the feeling of loneliness.

Parents of group 1, at the time of the interview were not aware of where to meet other same-experienced parents in order to feel empathised.

“I even searched the internet as I am trying to find some communities where they talk about what they are going through, those who had similar experience...I don’t

know what help is available here, if there are any support groups or so.” Carla (G1)

This may imply that parents with small infants may lack parent-to-parent support. Indeed Brooke (G1) by coincidence had a friend who had a similar experience as hers, a very preterm birth and felt lucky to find such support.

“I believe that only a person that has passed through that same experience can actually be of support to others...as soon as it happened to me, thank God I had a friend that had a similar experience. The first person that I called was her, and she used to tell me don’t lose faith...I found support from her” Brooke (G1)

Some parents perceived support from same-experienced parents, whose child was older, via different means of communication: such as television, radio and internet blogging. For example, Odette (G3) felt the comforting veil of anonymity as an added advantage in parents and professionals forum blogs on the internet. Simultaneously, this also gave her a source of parent information-sharing network as well as professionals’ updated advice directly from internationally accredited and reliable sources.

“so here on this site they know I’m from Malta, but they do not know me, and I do not know them, from that aspect, and it is an advantage as well...I say let’s post it and I’ll see what they think or if they meet with the same issue...I feel reassured in a way or that I am moving on the right track” Odette (G3)

Parents who shared experiences noted that this not only served as a source of emotional support for both child’s development and personal emotions but also reduced social isolation. For example, Preston’s mother was given contact information through the NPICU ward staff of another mother who had similar experiences. These two mothers kept contact over the years becoming very good friends.

“she (same-experienced friend) tells me because mine is sick he has a great deal of coughing bouts and I tell her don’t lose faith he will get better...it’s like we encourage each other...knowing that there is someone else who is like him...she understands me...sort of we help each other out cause you are not alone” Pearl (G4)

Meeting other parents seemed to offer parents the opportunity to compare their experience or situation with others. This could also act as a “*consolation*” and a source of encouragement for them seeing others with children who have more severe difficulties (downward comparison). They appeared to feel relieved they are not in the other parents’ shoes, thus, seeing their situation as easier when compared to others’.

“then there is this one guy whose child seems in a worse condition than my daughter’s, and I always see him happy...as soon as I meet with this guy I already feel better because I have someone to talk to...I say to myself why shouldn’t I be like them?....So the fact that you open your heart and share your feelings with these people is one of my greatest pleasures.” Igor (G2)

“when you see certain parents that are in a worse situation than yours...at least I am petals and roses and we are content as we are...they are worse than me...sort of you appreciate what you have.” Ronnie (G4)

Meeting with other parents was interpreted as a source of support based on seeing older children who had similar conditions as their child’s. This was perceived to provide a glimpse of the child’s potential future developmental abilities and difficulties. Hence it was interpreted as a consolation and motivator for parents to continue with their efforts to stimulate their child’s development.

“If someone comes with a child with similar difficulties who has at least 10 years and you see this child, you’d feel relieved. You feel filled with encouragement because you’d say to yourself may be in 10 years’ time my daughter will be like hers” Maria (G3)

“there is this boy who is two years older than my son. As soon as I see him I feel filled with encouragement because he walks. There is one like him at school who is much older and like my son uses his walker, but now he does not use it. They really encourage me...But to meet with these people it’s a miracle, like magic...when we do, it feels like we have won the national lottery.” Tabitha (G4)

Some parents of older children (G2+) and with diagnosed disabilities seemed to have established parent-support groups through private multi-disciplinary services. However, not all parents felt the need to seek emotional support from others out of personal choice, one’s character, and unwillingness after a daily exhausting schedule.

“we’ve become so engrossed in making sure that we can find any and all avenues of support and development for our son that in this day and age with work and everyday lifestyle...you say to yourself, do I really feel like going out for a session where I will be talking about and listen to other people’s needs?” Sergio (G4)

5.4.2.2. Sharing of information sub-theme

Encountering other parents and sharing one’s experiences provided an opportunity for parents not only to receive emotional support but also as a source of information support. This helped parents to be proactive about their child’s needs and where they could seek support. As the child grew, parents seemed to become experts in accessing services to meet for their child’s developmental needs via information gathered from other parents of children with similar difficulties. For example, Olivia’s mother expressed the added benefit of learning to access services through parent-to-parent contact.

“It’s very important to find this type of support (parent-to-parent support), as you learn certain things...I got the incontinence service scheme, which was her (daughter) right because this mother kindly told me how.” Odette (G3)

For some parents, parent-to-parent information sharing was interpreted as critical in widening and understanding certain knowledge about the child's hospitalisation information or development.

"I made friends with this woman who herself had a baby in the same room as Louis...she helped me overall with everything...the way she explained these things to me I could understand her better unlike medics...if she did not explain certain things to me, given that she already had a similar experience, I would not have understood well" Lavender (G3)

Although, for some disabilities one may find local parent-run associations outside the hospital, these may not always provide a perception of support for parents. For example, Emily (G1) and Gladis (G2) did not feel that the association of their child's disability has assisted them.

"I know of one support group where parents just attend a bingo and participate in a catholic mass and the other is expensive...what I really need is a real support group, one that gives me information how to feed them, how to care for these children...really help each other not waste money in bingo" Emily (G1)

Similarly, Gladis (G2) has maintained a lone profile and kept the small number of friends she met during her child's birth hospitalisation, whose children had different difficulties, for occasional social contact. Others, such as Noel's (G3), Olivia's (G3) and Theo's (G4) parents, also created their own social circle, consisting of a small number of parents of children with similar disability as their child's, with whom they feel comfortable sharing their innermost feelings and information they have benefitted from. Some parents who are not aware of potential parent-to-parent support perceived greater distress in not knowing where to find access for the needed services.

"we don't know what to do now or where we are going to get that screening test for our child because no one tells you" Fabio (G2)

Parents themselves showed an appreciation of acquiring information from past sharing-of-experiences activities. Learning from other parents helped them become expert-navigators in accessing services that their child needed within the Maltese society. In addition, some of these parents felt they had a special *gift* that they themselves can offer support to other people with younger children under similar circumstances through advocacy.

"As soon as I called to apply for my child's summer school...I told them my child has a disability. She told me no...we do not accept them...I felt blood bubbling up in my head...And this was just sports, so ok at school we preach about inclusion even when it is to a certain extent a bit impossible for it to take place...I called loads of places for my son to be accepted...And then he got accepted...And in fact this year the policy has changed, this year they have accepted them....when certain things can be arranged, not only for me but for others as well, why not? That is my mentality" Thelma (G4)

In summary, parents felt that meeting other parents has helped them as a source of emotional comfort from sharing one's experiences and motivation towards better future. Parents also reported benefits from acquiring information that alleviated their concerns and felt guided in acquiring assistance for their child's needs.

5.4.3 Life-world transformations theme

The experience of raising a child born with biological risks for ID has left an imprint on parents' perceptions of their life-world. This resulted in a transformation in their standpoint and lifestyle both within the couple's relationship and as individual beings.

"this is a situation that is so intense...it is a life-changing experience...you go through extremely strong emotions" Rose (G4)

5.4.3.1 Couple transformations sub-theme

All the interviewed couples indicated a transformation in their relationship, triggered by having a child born with risks for ID. Some parents envisaged both negative and positive changes in their lifeworld, whilst others noted a negative change in their lifeworld.

More than half of the interviewed couples reported a positive change in their relationship, with regards to emotional support. They felt a closer bond and more mature with each other by means of mutual understanding, as they were going through the emotional turmoil together.

"our relationship is stronger...I think that the bond between the wife and a husband is strengthened...that we understand each other" Ivan (G2)

"it changes the family in a way that the certain bonding is increased because when you go through suffering together, I believe that you'll go through happiness together" Garry (G2)

In addition, some parents felt that their new found closeness increased the communication between them.

"the experience made us more mature...So we feel closer to each other...the experience brought us closer and we understand each other more...it's impressive, there comes a story in your life that changes everything for you. I see more communication between us...I have become closer in that way," Ben (G1)

"This experience has really helped us grow...because you communicate together more, maybe we took our time to communicate more but you learn more about

each other, even though one is married you won't know everything that bothers him (spouse) or everything that he likes" Paola (G4)

A significant number of parents across groups reported greater appreciation of their spouse's efforts and his/her role within the family; whether working hard to attain financial stability for the family or caring and supporting the child's development.

"she is doing most of the work with him and thank God she is taking him to therapies and running around with him, as I would not have been able to go to work because there are so many commitments with him...So I appreciate that she is doing it" Joseph (G2)

Some parents indicated an increase in respect for each other's concerns and emotions from strengthened bond of their relationship. Although, in the context of Ismelia's parents, increased mutual respect occurred concurrent with reduced intimacy, due to feelings of exhaustion from their demanding daily schedule.

"I feel it has affected us...even in our intimacy...you are closer to each other, not because you won't have feelings for each other. But you either end up sleeping, or he sleeps...not because you do not wish for these things, but we feel too tired. Because emotionally, it changes you without wanting...But we respect each other for example you feel him close to you, you feel that greater security because he is here at home with you...plus knowing what he is going through and same on me. Knowing what I did for her (child), he respects me more." Irene (G2)

A number of persons, however, reflected that their relationship did not change as they felt they were *"back to usual"* (Marthese, G3). This may also suggest that the emotional turmoil was *"left in the past"* (Krista, G3) as a coping mechanism for the parents. I noted this attitude when parents felt satisfied with their child's development, such as in the cases of Kelly's, Martha's, Kyle's (G3), Samantha's and Radcliff's (G4) parents whose child was 3;6 years and 5 years of age, respectively.

Parents pointed out that their future family plans were significantly affected. The majority of interviewed parents refused to have more children in their family, as they did not wish to pass through similar experiences.

"I already made my final decision, I told her no more children...it (experience) was a thorn and it became a rose but you can have another situation, one that can be worse than this one, as you cannot see only the survival aspect...As if he is born early he may have disabilities that are not light...it's better if I limit playing with fire...But you end up fearing pregnancy" Garry (G2)

"nowadays I see a pregnant woman, I feel fearful a bit. Believe me, believe me, it's true...phobia, phobia, as I start bringing flashbacks of what we went through, sort of, I start saying to myself, this life could have been a little better." Ronnie (G4)

It gives the impression that the birth of their child with biological risks for ID caused a fear of future pregnancies in their family, as if 'once bitten twice shy'. Parents with

older typical siblings pointed out that their family is now “full” and are not planning others for that reason. Moreover, four couples from seven, who had a younger offspring after the affected child, indicated that the younger one was unplanned.

“in fact when I realised I was pregnant with my second, I was so upset, because she could come like him” Lily (G3)

“at present I’m finding it more difficult because I have him (youngest sibling), because this one came without planning it, not because we wanted it, this came like that (shrugged)” Tabitha (G4)

Nevertheless few parents felt that with time their perception changed again. During the interview period, two parents were planning another pregnancy. Marthese and Manuel’s (G3) decision (quoted below) was based on the perceived typical development of their child, whilst Naomi and Niles’ (G3) decision was based on their positive attitude towards life. Similar perceptions were expressed by Theo’s and Samantha’s (G4) parents when talking about the arrival of their second born.

“before I said no more children, but now I do...At first I didn’t want because this happened so I said that’s it, no more, because it may happen again. But now I reason it differently, in that way.” Marthese (G3)

A number of negative changes were also noted in the couple’s relationship. Parents’ accounts described how in moments of high levels of distress they seemed to transfer their distress onto their spouse/partner.

“Most of the time the attention is focused on the children. And sometimes you neglect the partner...And most of the time we end up arguing, and sometimes I say it’s not fair everything’s on me...So thinking back, if my son did not have his difficulties we wouldn’t argue this much I think” Joanne (G2)

“we are a couple, sort of we forgot each other a bit, then although we went through these things sort of you realise that you need your husband in your life and I need him there both as a father and as my husband, but once you communicate again and you find each other again.” Rose (G4)

Parental overprotection of their child born with risks was also deemed to be a source of conflict between the couple.

“I don’t know but if we didn’t go through what we had...maybe I would be less overprotective, so certain friction between the child and I, and between the couple maybe it wouldn’t have been there....it all comes down to my overprotectiveness, I’m fixated” Paul (G4)

The two interviewed single mothers did not express transformations in their everyday lives; however, Helen (G2) noted that having a child with a disability, amongst other life-circumstances, contributed to the ending of her marriage.

“it (experience) definitely affected the relationship in the marriage...for the relationship within the family it’s quite a big strain, I do believe that it had certain impact...I do believe that the marriage problems I encountered is a summary of several things and Harrison’s health is not the sole responsibility for that. I would not take it down to that for sure, because there are a lot of different factors coming together it was just one of them” Helen (G2)

5.4.3.2 Individual transformations sub-theme

Most parents felt they have discovered a new world, that of raising a child with risks for ID resulted in positive and negative changes within oneself. This insight could have resulted from lack of prior similar experiences and the insecurities of not knowing their future steps. Parents of children with diagnosed disability conveyed an increased awareness of what it *“truly means to raise a child with disability”* (Tom, G4) as well as new world of service manoeuvring.

“That is the problem when you have children with a disability that you enter a world that is not yours...another world, one that we did not choose” Isabelle (G2)

Some parents seemed to look at the world around them from a different angle. Sergio (G4) reported feeling distanced from the world of raising a typical child, as his only child was born with difficulties. This interpretation is similar to perceptions of Harrison’s (G2), Louis’ (G2), Ronald and Pablo’s (G4) parents who are first-time parents as well. Sergio pointed out that social-policymakers and mainstream society do not prioritise the needs of the few, like his son. For him this is an act of injustice adding *“isn’t he a child in society like others as well?”* This transformation was observed to vary between one individual and another depending on their unique experiences.

In addition, seeing other children in a similar health state as their child, within the same hospital ward, created an appreciation of the fragility of life among thirty-three parents (89.2%). This had an effect on Paola (G4) regarding her future career prospects.

“we are engineers. When I saw the job satisfaction of those nurses and doctors...Nowadays I do not even consider going back to the same job. At present I wish to find something more humanitarian...maybe it touches your soft side...But you start appreciating life more...on the other hand you see too many bad things and it leaves that fear inside you. You become conscious that these things can happen, as you do not only see your baby, you see others’ too” Paola (G4)

During the child’s hospitalisation period, parents’ worlds revolved around their child’s ward with *“long daily visits”*. Selena and Paola (G4) referred to their reduced self-care; *“I stopped putting on make-up”* and *“wearing shabby clothes”*, respectively, as they gave priority to their child’s hospital visits. Marthese’ and Maria’s (G3) also reported

distressing feelings when they found themselves at home during the child's hospitalisation staring at the empty cot.

"I locked them (baby materials) all in a room to avoid looking at them as I was feeling very bad each time I used to look at them and I still don't know if my baby is going to come out of hospital" Maria (G3)

Similarly, Marthese and Manuel (G3) avoided such instances by living at the mother's extended family's residence during their child's neonatal hospitalisation. Both parents distanced themselves from sources of distress (e.g. baby materials). This may be interpreted as a high maternal-child attachment bond.

Following her child's hospitalisation experience, Daniela (G1) noted that she was more emotionally close to parents of hospitalised children and she kept them on her mind: *"I remember them in (her) prayers"*. Abigail (G1) and Marthese (G3) became emotional whenever the topic came up in a conversation. Moreover, Garry (G2) also felt vulnerable talking about his past lived-experiences. He interpreted his sensitivity as caused by his *"constant emotional suppression"* at the time, to be of support to his wife.

Parents witnessed a strong transformation in their lifeworld as a result of the birth event. Bernice's (G1), Noel's, Olivia's (G3), Theo's, Pablo's and Steve's (G4) parents felt they were stronger as they became more confident. Selene (G4) pointed out that she was less of an introvert than before, stemming from the advocating activities to meet her child's needs, similar to Noel's, Olivia's (G3) and Theo's (G4) parents. Positive transformations were interpreted by Logan's and Noel's parents (G3) who felt they have achieved a meaningful scope in their life and felt fulfilled. Isabelle (G2) accessed weekly private psychological support services and managed to come to terms with her inner fears and to be able to interact with children with disability.

"I didn't have the strength to look at them (children with disability)...this boy did nothing except talking with his eyes...he was all the time looking at me when I went there, that I lifted my eyes to look at him and smiled...it remained imprinted on my memory...because it was thanks to him that I managed to fight this fear. Nowadays, I go to special schools and look at other children as if I am seeing my older child...I love them. And that is something else that I am happy I managed to achieve." Isabelle (G2)

Prior the birth of their baby, most parents used to plan their life. Parents were advised by NPICU staff to adopt a day-by-day attitude during hospitalisation, sometimes even *"moment-by-moment"*, due to the child's unstable health-state. Some parents maintained this learnt day-to-day attitude in their home environments. They seemed to

have adopted it as a coping mechanism to help themselves feel focused in their present situation. This transformation in parents' worldview may have also acted as an umbrella protection towards their future concerns on milestone achievements.

"I used to plan 10 years in advance with great detail...now I still plan but much much less", Kyra (G3)

"even if we want to go on a holiday I'd rather just go for one next week. I do not plan anything longer, because if anything happens and we won't go, I feel very angry so that's it, I live day-by-day" Ben (G1)

Parents of children in group 1 felt satisfied that their child was achieving the typical milestones according to their 'corrected age' (the age corrected by planned-birth-date). However they still were aware of a potential delay. Some parents, such as Amanda's, Bernice's and Dean's parents (G1), appeared confused about the child's age vis-à-vis achieved milestones. This could be a coping mechanism used by parents to help them feel relieved that the child is achieving the developmental milestones according to the 'corrected age', by considering it as the virtual birth of the child. The child's small size could also contribute to a 'false age impression' that adds to the parents' confusion.

"Soon she will be 1 year...but she is not a 1year old child...she is still wearing those of 6-9 months so she still has more to grow to be able to use the 9-12 clothes. So you have to adjust your thinking. Then I sometimes tell people that she has 7 months, as approximately she is that age using the supposed-date of birth...she does everything of a 7 month of child, we're happy about her development"
Barbara (G1)

In summary, raising a child born with biological risks for ID was interpreted as life-changing for their couple's relationship and their individual selves. Both positive and negative lifeworld transformations were reported involving attitude and emotional changes.

5.5 Family functioning

Raising a child born with biological risks was perceived to impact all sub-systems in family life, table 5.4. Each level of the nuclear family was felt to be influenced deeply by this experience. This included the parents (two-parents or one-parent), their children and the immediate extended family. The extended family was perceived as a source of both support and stress via practical and emotional media. Perceptions and experiences reported by parents from a socio-emotional intra-nuclear family perspective are reported under the parenthood theme.

Table 5.4 Family functioning themes

| Thematic Statement | Superordinate theme | Theme | Sub-theme |
|--------------------------------------------------------------------------------------------------------------------------------|---------------------|--------------------|-----------------------------|
| Impact was felt by all sub-systems of their family: extended family members; parenting their child/ren and parents as a couple | Family functioning | Extended family | Practical support |
| | | Parenthood | Emotional wellbeing |
| | | | Parenting with a difference |
| | | | Child-centred perspective |
| | | | Future concerns |
| | | Parents as couples | Older/younger siblings |
| Coping strategies | | | |
| | | | Gender Roles |

5.5.1 Extended family theme

The extended family in Malta, although not residing geographically near the nuclear family as in previous decades, still plays a supportive role. The extended family was deemed by most parents to be a readily-available source of support for the affected family. Nevertheless, simultaneously parents perceived the extended family as a source of distress, despite the good intentions.

5.5.1.1 Practical support sub-theme

The extended family helped most parents in a number of practical ways and forms, one of which was care of the older sibling during the affect neonate's hospitalisation. This was interpreted as helpful by parents as they could focus more on the baby's recovery, since they feel reassured that the sibling is well cared for.

"I left my older boy with my sister, thank God he was taken care of as I had no idea what to do and this put my mind at rest" Carla (G1)

"Thank God my aunt took care of my older girl when we were at hospital so I did not have to worry about her" Camille (G1)

Grandparents were seen of significant assistance to parents' daily management. In Louis' and Theo's context the grandparents sometimes attended therapeutic appointments and health screening visits on the parents' behalf whilst they were at work. This helped parents to cope better and to 'be in two places at the same time'. Some mothers also felt that the child-minding of their child by the extended family not only assisted with their family management but also helped to maintain their work career outside the home. Those parents who did not have this opportunity on a daily basis seemed to have difficulties maintaining their job outside the parental leave period, as was the situation for Isabelle (G2), Odette, (G3) and Selene (G4).

In some other family contexts, however, grandparents could not always take up a child-minding role due to their own work schedule, as was the situation with Fabio (G2), or because they were elderly. Moreover, some grandparents felt that the added health needs of the child were intimidating and refused to mind the child born with risks, during the mother's absence.

"I cannot go to work as I do not have the type of help with whom I can leave my child. I do not have it because my mother works... and the other one is not ready to cater for Ian's needs. Or maybe they do not have enough courage or strength...so I cannot go find a job...what am I going to do with my situation?" Isabelle (G2)

"We do not have much help, before there was my mother and my aunt here but my mother lives in an old-people's home and my aunt is old now...there is only her aunt that can help us a bit and she picks up my children until she (Camille) arrives from work" Chris (G1)

Gladis (G2) felt frustrated due to the lack of child-care or practical support from her extended family when needed. She had assumed that her extended family would offer child-care support due to the cultural advantage of being close to family members.

"I need help. If I have to take one of my children to an appointment...can someone please come and take care of the others for me? Can someone phone me up and ask if I need milk and bread if I'm stuck at home? Can someone give me one night a month so that I could go out on a date with husband?...I'm not going to ask for it. I expect people to do that, that is what family is supposed to, I think that is the only perk about living in a country like Malta, where you know you can rely on your family, it is not the case in my life." Gladis (G2)

Six parents described how the support from their extended family assisted with their child's developmental stimulation activities.

"we (father and child) go in the garage to do some treadmill (for child) and then we play a bit. After that, we go to her (wife's) sister who lives right in front of us or at grandma, and we stay running, as part of his physical exercises" Niles (G3)

Similarly, Sandra's parents used to organise family get-togethers to benefit their child's socialisation as being an only child she used to suffer from loneliness.

In contexts where the extended family members had previous professional experience, such as medical professions and service administrators, this proved to be an added bonus for the parents. These were a rich source of information and service guidance.

"we used to find no one to ask for information, but then there was my uncle who used to work XXX, and he used to give me some information and we felt relieved...The few questions that I had I used to ask him, thank God I could ask him." Joanne (G2)

Marthese (G3) also found guidance from her sister's maternal experience as fruitful in learning to wash her baby. Few other parents, such as Bernice's (G1) and Kyle's (G3),

viewed support received from grandparents as a reassurance that they have access to financial aids given the parents' perceived vulnerable financial situation (still paying house mortgage). Similarly, Timothy (G4) appreciated the wishes of extended family members to buy Tom's required therapeutic equipment, interpreting this gesture as an indirect financial support.

A few parents resided with the extended family due to financial pressures since they could not afford living independently. This was a necessary and especially helpful for parents who were unmarried, such as Eliana's (G1) and Logan's parents (G3), as well as Preston's (G4) single mother. This may suggest a cultural perspective where unmarried mothers tend to live with their parents of origin until married. Although, Pearl (G4) owned a house, she said she could not afford to pay utility bills and her son's health-related expenses: she saw living with her parents (her family-of-origin) as providing both financial support and child-minding opportunities during her working hours.

5.5.1.2 Emotional wellbeing sub-theme

The first emotional support parents received was reported to be from the extended family, grandparents in particular. Emotional support from the extended family, for some parents, seemed to have compensated for lack of professional emotional support.

"I found a great deal of support from my family, had it not been the case, I do not know what would have happened to me. Cause I was really bad, I felt very down...They (relatives) were always at my mother's house...to keep me company...to help me understand and to make me feel better" Marthese (G3)

"my aunt used to spend whole days with me at hospital. She used to talk with me...As you may say, at least, even though we are the parents, they are those who help you. You are not alone" Rose (G4)

This implies the closeness of the extended family with the nuclear family. The relationship itself supported parents' emotions as they felt listened to and calmed their distressing feelings.

"my mother's support helped me a great deal...this family support was very crucial for me. I had a period of time when I felt sort of depressed...as I used to find someone to talk to, someone to say what's on mind. That was of great help for me. More than when they take care of him (child) because you are talking with someone" Joanne (G2)

"your mum helped you not to panic (to wife) she was cool about it (to me)...your mum didn't go eeheh (raised hands – over-reacting) she was very calm as if dealing with a normal routine" Kevin (G3)

Some parents reflected that the extended family's emotional support was at its peak during the child's neonatal hospitalisation and hospital-home transition periods. For some, the presence of the extended family members at hospital prompted a feeling that their shock and turmoil was shared. For example, Garry (G3) implied this may be a parental-protection perspective from the grandparents towards the parents, as the latter are still considered to be their children and grandparents tend to offer what they can to alleviate their children's emotional pain: *"I understand my parents, as for them we are their children"* Garry (G3)

The extended family was seen as a source of support during the child's development, as a protection against social stigma. They provided encouragement to help parents resist feelings of social stigma and to adjust to the new lifestyle, in the case of first-time parents. Moreover, they directly contributed towards the reduction of feelings of social isolation when mothers opted to stay at home using maternal or parental leave.

"my mum comes to my place...more for the company mainly as I am alone here and we go out with two pushchairs so she helps me go out, and we talk...she is my support system apart from the speech therapist for Florence" Farah (G2)

"my mother and his mother visit me very frequently...it's not about helping me in housework, but simply even staying here sitting down...simply their presence...the fact that you are not alone is very very important." Doris (G1)

Under certain circumstances extended family members were interpreted as intrusive. Helen, single mother of Harrison (G2), whose extended family lived overseas, interpreted the constant requests for information via telephone to the extended family as frustrating. At the time, she did not have fresh news to tell them due to the child's intensive and 'un/stable' health state. Similarly, Hannah and Isabelle (G2) felt it was also stressful re-explaining their day at the intensive ward near their child; consequently they avoided contact with 'inquisitive' extended family members.

For some parents the extended family members were observed to over-react when atypical news or events occurred, as an automatic reaction with no negative intentions. This was a source of added distress to the parents as these reactions aggravated their emotional processing.

"At first it used to be difficult, as the inner family...mum, dad...obviously we told everyone, our brothers and sisters...that he has XX and you can imagine...instead of me crying they were the ones to start crying...anyway instead of helping us to calm down they created more havoc." Joanne (G2)

This had led John's parents to consciously keep the child's diagnosis to themselves; subsequently they perceived a lack of empathy from work colleagues and uninformed extended family members.

Similar over-reactions were experienced from an over-protection perspective such as with George's parents when their child fell. This created a conflicting emotional cycle that impeded his family from maintaining their emotional independence and control.

"I burst and told him (grandfather), 'dad do not tell me again, cause you gave me a headache...he's ok' and then there will be certain arguments...'next time I will not tell you' 'so you felt offended?'...but at the same time they create certain conflicts....so without knowing, they are pressuring you continuously." Garry (G2)

The extended family's overbearingness seemed to suffocate George's parents with their constant wish to contact them, creating an inflexible daily routine.

Moreover, since Logan's parents, live with their extended family due to financial difficulties, they felt the loss of their privacy and consistency of their child's discipline.

*"M - since we live with our parents, it's as if they have every right as much as you...the company is good but opportunities to educate them as much as you want to are lost
F - I try to correct him but with them (extended family) around, sometimes they tell you 'no do not shout at him', but at the same time 'do not let him do anything'"*
Lily and Lawrence (G3)

In summary, extended family members were perceived to be a strong source of practical and emotional support by most parents, reflecting a close relationship. However, simultaneously some parents reported moments of conflict with their extended family relatives.

5.5.2 Parenthood theme

Parents noted that their parenting attitude and abilities were affected by their expectations and their child's hospitalisation experiences. Parents' concerns about the future of their affected child seemed to be a constant presence in their daily lives. They dedicated greater attention, time and priority to the needs of the 'at risk' child over-and-above the needs of other family members (including their own). Parents focused their attention and actions on the development of the child, as an investment towards the child's future.

5.5.2.1 Parenting with a difference sub-theme

Parents interpreted raising a child born with risks as different. Some participants became first-time parents: *“I became a mother”* (Helen, G2). These parents believed that they had to learn *“hard way first-time round”* (Daniel, G1) how to care for a child with difficulties, and also due to the lack of comparisons between siblings: *“this is what we know, we do not have other children”* (Lewis, G3). Theo’s parents (G4) labelled rearing their typical sibling after their affected child as *“easier”*. Other parents pointed out that raising a child with disability gave them a *“life’s scope”* (Naomi, G3) and felt *“fulfilled”* (Lily, G3) as they perceived their child to be a constant source of joy. Furthermore, they viewed their child’s survival as a gift from God and this attitude contributed to their positive life-world approach: *“today we consider ourselves as having a gift from God”* Garry (G2). All but two parents interpreted their child’s survival as a *“miracle”* and maintained the label given by NPICU staff: *“fighters”*. The negative expectations transmitted by the hospital staff as ‘against all odds’ may have further emphasised the ‘miracle’ interpretations.

Annulled past experiences

Parents, who had older children felt that their past experiences in child care were inapplicable, invalidated and annulled due to the atypical birth circumstances combined with the developmental risks, further increasing their helplessness and need of guidance. They perceived they had a *“weak”* and *“fragile baby”* (Carla, G1) due to the small size and starting life missing out a complete gestation period.

“I couldn’t wash him nor lift him like my other child because he is different, everything of his was different” Tabitha (G4)

“your mind looks at her that she’s not kind of, not a normal baby for you...she is not like the others. Like, when she got a cold, ohuh, what will happen? It will go immediately in her chest” Barbara (G1)

Some other parents, however, felt they had a ‘normal’ baby during the first few months of the child’s life, regardless of having a diagnosed condition or not.

“at first he is a normal baby...during the initial period you have a normal baby, then when he starts growing up you need to start the stimulation therapy” Joseph (G2)

‘Overprotection’

Some parents seemed to be highly concerned about the non-sterile environment of their house and self-imposed a cleanliness obsession to maintain a clean environment for their child’s protection.

“there you are in a sterile environment. When we brought her home, that was the preoccupation...checking all the time what scents there were, the dust! We are in a place where the dust is around us so, that was an enormous preoccupation about her” Ariel (G1)

“when we came here (home) with our son, for me it was a time of huge tension...we were in that environment, all sterile...alcohol wipes and rubs everywhere...I didn't want anything to happen to him under my care. So I became obsessed with everything I did” Doris (G1)

A few parents felt the need to maintain their vigilance and protection from the environment throughout the child's first five years of life due his/her weak immune system and other health complications. Pearl (G4), for example, offered me a pair of house-slippers allocated purposely for visitors upon arrival at her residence, so that I would not bring in germs from outside the house on the soles of my shoes.

Tiredness and Tension

Some parents interpreted raising a child with difficulties as a tiring experience; one that required great physical efforts on the part of the parents, especially if the child had added physical dependency.

“He tires me a great deal...he is getting heavy...have a great deal of hassle. You have to lift him here to there, to the car...even for the toilet during the night or before he sleeps” Timothy (G4)

Moreover, even the act of catering for the child's needs was physically and mentally tiring for parents.

“She tires you a great deal. Even though she is not heavy...Even washing her hair, sometimes I get a back ache...We are always catering for her...all this running around you start feeling the exhaustion taking over...but I feel weak” Irene (G2)

Two-parent families reported coping pressure due to having a hectic schedule to cater for the child's therapeutic needs. At times, parents who had a hectic schedule experienced excessive tiredness which, they in turn transferred such tension onto each other. Hence this was interpreted as a source of distress for the couple.

“sometimes...I feel very tired because of all the running around and my concerns on John and sometimes I end up arguing with him” Joanne (G2)

A few parents, regardless of their hectic schedule, planned time for themselves in order to control the daily tension by maintaining some hobbies or prior commitments. This helped their mental health and also their relationship's health.

“I do not believe that I had to change everything, in the sense that, I try to find time for myself, both of us, I mean, she has her girl-guides and I coach a sports' team, all thanks to our parents' help, but you still need some time for your own” Thornton (G4)

Similarly, Lavender (G3), regardless the tight hectic schedule, also maintained her working schedule for the benefit of her psychological health.

Milestone-achievement stimulation focus

Some parents felt that their parenting routine had an added perspective, that of helping their child's achievement of milestones. Some parents reflected that this took over their daily lives as they viewed development milestones as target deadlines of 'normality'. Stimulation of the child's development was interpreted in many forms: playing with the child in a structured or unstructured manner, and teaching the child specific educational skills such as colours amongst others. Some parents interpreted this situation as increasing their emotional bonding with their child.

"I play with her, we do puzzles, we play with blocks and run after her, we also joke with each other...she is very close to me as well because as much as possible I keep playing with her" Fabio (G2)

Other parents performed stimulation 'sessions' or structured co-operation as part of their daily routines.

"even though he was still very young...as much as possible having a stimulating environment...all the time playing with him. I tried to create a learning environment as much as possible, because I'm his mother...I have to follow him day by day." Rose (G4)

A few parents, like Naomi (G3), felt overwhelmed with the amount and intensity of stimulation exercises when their child was young:

"I felt I was all the time with that guilt that I am not working enough...All the time with this tension, which in turn reflected on our tiredness and on our relationship...the only thing that I feel bad about is that at first the therapists used to suffocate me...while you primarily realise that what he needs is someone to love him, just being his mother. Not being his therapist...forget it! First you are a parent but only today I understand that, in the past I didn't." Naomi (G3)

Some others felt guilty they were not playing with their child apart from their daily 'structured' session.

"I sometimes...I feel a bit guilty because I do not feel I am playing freely with him...I think he (Joseph) plays freely with him. I play with him in a more serious manner...with an aim in mind." Joanne (G2)

Four parents noted that they did not play with their child. They viewed child stimulation as "*interfering with nature's ways*" (Manuel, G3). These parents pointed out that they left their child to play on his/her own.

"M - I don't really bother about it, I do not really play with them, I take them out to the playground and they play there..."

F – he stays playing there with other children...I believe that nature will take its course at the end of the day” Francesca and Freddie (G2)

However, some other parents felt that their child’s stimulation and therapeutic schedule had given them a hectic life schedule.

“it’s not easy, because every day we have something, every day he has therapy, either OT physio or speech...So from that aspect plus both of us (parents) are working, it is very difficult.” Thelma (G4)

Yet, regardless some parents’ exhaustion, when their child achieved the much-stimulated milestone they felt overjoyed. This added satisfaction stemmed from the increased efforts parents invested to achieve what they previously assumed to be natural.

*“F - our experience nowadays, gave us certain satisfactions that the other siblings did not...little things
M – do not ask me when my eldest started sitting on her own cause I do not remember. But with Olivia I remember every milestone because we were onto her, we worked hard for them and even for her they were very difficult...as soon as she does one milestone you say, alright so what’s the next step?” Odette and Oliver (G3)*

Dependency on employer’s support

Single parents felt proud that they were coping with their daily lives regardless of not having a partner.

“well since I’m a single mother...I do believe that I manage everything quite well and I do cope...you simply do what needs to be done and the more often you run the checklist through your mind the easier it gets because what might have been very complicated in the beginning turns into a normality...I am lucky that my employer understands my situation” Helen (G2)

Yet, Helen (G2) and Pearl (G4) felt dependent on their employer and family, respectively as a source of management support.

Most fathers across groups also felt grateful towards their employers who showed compassion during their emergency family circumstances. They believed that the employers trusted them. Fathers treasured it as a source of strong rapport-building with their managers and enhanced their commitment towards their job. Their employers’ support to parents was evident during the times they felt most in need, especially during the birth hospitalisation. All those fathers who received employers’ support interpreted it as a source of family support.

“It (employer) prioritises family first. If something happens I could leave with permission from work...I had my mind at rest for my employment as your mind does not really function as it should” Keith (G3)

“if my manager was not so flexible maybe the experience could have affected us deeply...Imagine it could have affected us really badly if I’d had lost the job at that time” Kevin (G3)

A few parents found lack of employment support during their hospital-home transition period. For example Sarah (G4) felt she did not have the opportunity to settle at home as a family since the maternity leave started when the child was born, not when discharged from hospital.

“the maternity leave...was a big blow...That was really frustrating...since she was early the maternity leave started when she was born...that was 11 weeks prior to when she was supposed to be born...Two whole months have passed until I took her home...2 weeks later I had to start working again...My 14 weeks were up...and I was working full time then, till 5.15, so the stress of that...I felt really cheated off my maternity leave...you’re dealing with a newborn really. We had to settle at home, it was really difficult...and I hadn’t settled at all” Sarah (G4)

Thus, parents of children born with risks having long hospitalisation period, not only used up their maternity leave during the child’s neonatal hospitalisation but had reduced home-settling period, especially with parents’ intensive emotions and medicine-giving routine. This implies a lack of support for mothers should they wish to maintain their working life/career.

5.5.2.2 Child-centred perspective sub-theme

All interviewed parents appeared to give precedence to the needs of the child born with risks over the family needs, including that of the sibling. All interviewed parents willingly sacrificed their own needs to dedicate more finances and time to the affected child’s needs. Parents felt the need to constantly rebalance their financial situation to prioritise the needs of their affected child. For example Pablo’s (G4) parents felt it was necessary to dedicate the bulk of the family’s finances towards the child’s treatments in the UK. A few parents who had a high socio-economic status, also prioritised child’s expenses for therapy and operations outside Malta, such as Gabriel’s (G2) and Noel’s (G3) parents.

Some parents prioritised their child’s expenses over their own needs while others felt compelled to re-enter the world of employment for financial needs, but felt guilty at leaving their child with extended family.

“You have to cut back a great deal of things because you are not going to consider what you are going to live on only, you have to save something for when she will need an operation” Maria (G3)

“the more time passes the more expenses on these things (equipment) we will be having. It’s not easy that I say I do not want to go to work because I wouldn’t go and stay with him...I work because we need to, no doubt.” Daniela (G1)

When parents found themselves living with one pay less than before, during their times of greatest need, they interpret family financial re-balancing as a ‘must’ rather than an ‘option’ to be able to best support their child’s/children’s needs as well as cope with the daily living given the financial difficulties they may have already found themselves in. Ernst’s parents had to borrow money from extended family in order to ‘put food on the table’.

*“M – physically we are getting tired, financially in a crisis...when I receive the children’s allowance...I am going to buy two boxes of milk...we are not coping...my aunt helps me...she buys me things for example if he needs cream, shampoos
F – at times I go and borrow money from my sister” Emily and Edward (G1)*

Ernst’s parents stated that they could not claim for social benefits; since they were married and the husband had part-time job on minimum wage: resulting in distraught feelings that they were at the mercy of their relatives’ financial help. Despite this, Ernst’s needs were still prioritised over other family members’ needs.

Timetabling was identified as an effective coping mechanism for parents to manage their family lives. As previously stated, the ‘at risk’ child’s needs took precedence over the whole family’s schedule. Some parents felt that rescheduling their family routine around the child’s therapy appointments was a necessity to cope as a family. Olivia’s parents (G3) manipulated their family routine so all the family would be able to benefit as well.

“as a family we decided for example on Friday’s I know that she always has therapy...For me it’s not, I left for therapy, it’s a family outing...you have to try to use it as a reward both for the child and even for us” Odette (G3)

Theo’s parents (G4) felt that successful “*timetabling*”, coupled with child-minding assistance from the extended family, helped them enjoy one hobby each, while still prioritising their child’s needs. A similar situation was presented with Ronald’s parents (G4): Rose utilised her “*free*” time for work-preparation, whilst her husband carried out his football training on an occasional basis with child-minding help from extended family.

5.5.2.3. Future concerns sub-theme

Parents of children who manifest developmental difficulties or delays across groups, implied concerns about the child's future. Some parents who were aware of biological risks from others' experience felt concerned about their child's future, regardless of the young age and non-evident difficulties.

“it's about the future because now, you cannot do anything at the moment, what happened happened...plus we know two other preterms...One of whom the parents were finding out a lot of complications” Carlos (G1)

Some parents, such as Radcliff's (G4), based on their present observations of their child's eating difficulties and stubborn behaviour, felt concerned about the child's future behaviour.

*“F – I sometimes wonder, when he grows up to be a man how am I going to cope with him?
M – he is tiring us now...when he grows up who knows if his hard-headedness will get worse. Would I be able to cope with him?”* Riana and Rafael (G4)

Other parents seemed to be concerned about the child's future independent living status as adults in society, should they die. Their reasoning was based on the policy that in Malta adults with a disability, who cannot live independently, would be institutionalised in old-people's homes unless a close relative would care for them. This was quite worrying for parents due to potential unlearning of independent skills.

“if I can live for eternity until I know that he has a place of his own and does not end up in an institution...he will end up with old people” Emily (G1)

In addition parents seemed apprehensive as they did not wish to shift their responsibility onto their typically developing children. Some parents did indicate contradictory feelings about their typical children as future carers of their 'at risk' brother/sister. Although it was reassuring that typical children may care for the brother/sister they did not wish to burden the sibling's future family life circumstances. Parents viewed this perspective as a financial and an emotional strain to “dump” their burden on others.

“what will happen to us in the future?...maybe he'll have his own family, maybe his wife would not wish to take care of her...you cannot dump her on him...you have no idea how expensive it is to take care of these children...Maybe he'll have his own home mortgage to pay...You have to feed her and do everything for her” Irene (G3)

Other parents, such as Emily (G1), reflected on the possibility of allocating a lump-sum of money to the brother/sister who would take care of the child with disability, in order not to leave a 'financial burden' onto their children's families with today's escalating economic difficulties for families.

Some parents were hopeful and expected better services in the future for adults with ID in Malta. For example John's parents (G2) felt confident when they reflected on the progress of the Maltese society in the past 15 years. This acted as a source of encouragement, hope and positive attitude towards finding such training-needs already established when their child will be of age to use these services.

"when it comes to future jobs it's a very weak area...There is this idea of job coaching...but it is still not that structured...I worry about when he will come to that stage, but I am hoping that when John grows up...until then these things would have improved as much as the improvements that occurred within the education sector" Joanne (G2)

Some parents believed that social-policymakers should focus their attention towards adults with ID and work-related training in order to achieve employability status; to be able to care for him/herself independently in society.

5.5.2.4 Older/younger siblings sub-theme

Parents reported that the older/younger typical brothers/sisters of 'at risk' children seemed to be amongst the first to feel the impact with them, since they form part of their immediate family unit. Out of the seventeen parents who had older children than the affected child, sixteen parents noted that the older child's presence was a strong source of stimulation for the 'at risk' child, through play.

"he (Logan) is learning a great deal from his sister" Lily (G3)

"they always play together and talk non-stop, it's like the older one helped him develop his reasoning and speech quicker" Nancy (G3)

These parents constantly referred to the older child as the one who had the ideal typical development with whom they compared the development of the 'at risk' child.

Some parents observed character changes in the older child's behaviour. For example, Carol's parents interpreted the experience as beneficial to their typical sibling's behaviour, where she observed he became more mature and independent than before.

"I noted that his (sibling) character has changed since her birth...he was closer to me than now even in his way how he used to speak to me...he is more independent" Carla (G1)

Moreover, Isabelle (G2) felt reassured about the positive changes observed in her typical child and interpreted them as beneficial for her potential future caring career prospects as having learnt important inclusive life principles.

“she learned how to behave and how to give him the toys....even at school...they noticed that...she has a know-how...when she grows up, I believe that these things that she is experiencing...they are leaving a positive effect...if she chooses something like this, she will surely be good in it. Because she always had a brother with a disability...she already shows that she has certain values”

Parents dedicated a great deal of time towards stimulation activities with their affected child, so parents tried to find ways and means to spend time with their younger typical child as well as a positive way of time-management.

“I spent two hours with my daughter so I will only spend two hours with Theo, it’s not a good way because you are discriminating between children within the family, there has to be a complementary attitude...Although I spend more time with him, I tend to join them together” Thornton (G4)

Some parents viewed their first born typical older child as a “*mature assistant*”, an equal adult human being rather than a child. Parents viewed this child as maturing too quickly for his age as his is invaluable in their daily family daily management.

“he (sibling) does therapy for him (Tom)...sometimes he helps me so much with the house chores, that...when he tells me I’m hungry, I tell him ‘ow wait a bit more’ angrily...now he has to do the shopping for me, there’s no other way, as if a 12year old boy does his mother’s shopping! Poor kid...I tell him frequently to come with me to hospital for the visits instead of going out with his friends...to help me carry the walker at least...We say thank God we have him” Tabitha (G4)

However, not all parents who have a child born with difficulties wished to involve their older children in stimulation/therapeutic process. Some parents also considered giving the older children independent experiences from those of the ‘at risk’ child.

“it’s not fair that I take him (older sibling) to hospital all the time as he has his own life...he has his brother like that. But not that it becomes his life, as he has his own life and that is going to be something else.” Emily (G1)

Some parents viewed the presence of their typical older child as a source of emotional support and joy. Ian’s parents greatly appreciated the unconscious emotional support received from the typical child and through her positive “*loving*” attitude towards her affected brother as automatically uplifting.

“When he was at hospital, and they used to tell us, he is going to die...I had all that sadness, I used to come here and God bless I had her (older child)...she helped me a great deal...she had a small inflatable pool in the back garden...seeing her play, and for me I can tell you, the best thing that we had was her (older child), she helps us in a great many things...without knowing, with her ways.” Isabelle (G3)

Some parents felt that their older children, during the ‘at risk’ child’s neonatal hospitalisation, were excluded due to the constant child-minding episodes with extended family relatives. Some parents observed also a negative impact on the typical older child.

“she (sibling) found her grandfather...for her that day we were dead...she had the same shock...her coming and coming in that way...her sister was just a story behind a piece of glass far away” Kevin (G3)

“I couldn’t help him with school homework...that year he repeated the year...I used to neglect him a great deal as I used to spend a lot of time at hospital” Krista (G3)

While, Amanda’s parents (G1) reported that older child’s impact was noted from his *“rebellious behaviour”* stemming from having significant reduced parental attention during a *“sensitive”* school year.

In summary, prioritising the ‘at risk’ child’s needs affected both parents and siblings. Parental positive and negative perceptions about the impact on the sibling and on themselves as parents acted as sources of support and distress throughout their lived experiences. Participants also indicated constant concerns and anxieties about their future and that of their affected child based on their perceptions of society’s lack of adequate independent living policies towards adults with disabilities.

5.5.3. Parents as couples theme

Parents, as couples, reported the need to give importance to the quality of their relationship. Supporting each other was critical for family functioning, especially during times of crisis. Therefore parental partnerships also acted as a necessary coping mechanism to manage the needs of their child with difficulties.

5.5.3.1 Coping strategies sub-theme

The majority of two-parent families view themselves as a *“system”* needed for the benefit of the child’s upbringing. The couple viewed each other’s presence as a self-sustained strong supportive system; independent from the extended family. Both spouses felt deeply about their children as both passed through the same experience. The couple looked at themselves as the driving forces of their family, the main source of support for and of each other, they shared a bond together: *“he is my son as much as he is his”* (Joanne, G2). Since most partners in two-parent families passed through the same turmoil during the neonatal hospitalisation and remained together through ‘thick and thin’, they felt further motivated to continue their supportive cycle to function as a family. Parents treasured their deeply set family values and this was evident throughout this subtheme.

"These children need a strong family as they use up a lot of your time...in situations like these, it's easy to fall in traps of stress, where one can close within himself. You need to keep cherishing family values and say that although you are in a situation that is not easy, I have to keep going for the interests of the people around me. In the good and the bad we are a family and you have to keep it going." Rose (G4)

Some parents complemented each other's coping mechanisms; this was interpreted as a source of support to help each other adapt to their present lives. More than half of the interviewed parents also interpreted emotional balancing between the couple as supportive. This balance created by either spouse/partner to support the other: fathers' calmness affected mothers during their stressful times and vice versa. This further highlighted the couple's emotional influences on one another during their daily lives.

"we are together...we have patience with each other...when we pass through a trauma we do not process it together, that I think is very good...I am the first to feel the shock...when I recover he feels the shock and we have patience with each other...it helps us a great deal to continue to be strong" Isabelle (G2)

She interpreted the couple's character differences as complementary and helpful as they emotionally supported each other through times of ordeal.

Other parents, such as David's (G1), Tom's and Pablo's (G4) utilised emotional balancing without being conscious about it; couples were observed during the interview to encourage one another as well as themselves with their utterances: *"now things are much better we cannot keep thinking about the past"* Paul (G4). These self-help mechanisms also included self-encouragement and self-distraction in order not to focus on the negative aspects of their present situation. These tactics were interpreted as essential by parents. They felt that they helped themselves to emotionally focus on the child's development and their daily family life.

Parents perceived mutual support from couple co-operation in child care and family responsibilities, interpreting themselves as a *team*: such as taking the 'at risk' child for appointments while the other parent cares for the typical sibling.

"we work as a team...we have to co-operate to help each other, to be able to build a good relationship together or else none of us will cope on his own...unless parents have a good relationship and co-operate well, that same stress alone would be too much" Ronnie (G4)

It was also considered as advantageous to be a two-parent family to cope with the hectic schedules of children.

When both parents complemented each other's coping mechanisms, they seemed to have an attitude that daily life was smooth-running, while having differing coping mechanisms manifested itself as a source of conflict between some couples. For example, Gabriel's parents (G2) showed differing coping mechanisms which in turn resulted in some conflict. Glen assumed a distancing attitude, in order to emotionally cope with his home situation: *"I get up, I roll out to work and I stay as late as possible"*. On the other hand Gladis indicated that she felt the need to advocate for her son's needs as her way to reassure that her son achieved his developmental potential.

"We don't see, eye to eye on many issues...for him ignorance is bliss for me knowledge is power...we fight, and how! It's put a strain on our marriage...It's not a normal relationship anymore. I do feel alone...I have traded my normal family life and my relationship with my husband to be able to finance and support my son to become an independent fully fledged adult....That's the price I'm paying. I'd pay it in a heartbeat...The birds will fly the nest and may be then I will be able to work on my relationship with my husband." Gladis (G2)

In some families, divergence in the parents' coping mechanisms was a cause for conflict which *"tested their relationship"* (Paola, G4) and felt the need to make time for each other each day.

*"M - I used to feel angry and closed down further...the one up there (pointed to ceiling - God) helped us realise what was going on and we prayed...we talked to the arch-priest...we searched for help in fact we started going to a psychologist but it did not last long
F - it worked...we needed to pull the rope and sort of press on the brakes to stop and talk...in that life's circumstance how things were cropping up we didn't have much time for us"* Paola and Paul (G4)

5.5.3.2 Gender roles sub-theme

Couple co-operation in the family context involved sharing of responsibilities between the couple: a decision making process highly influenced by traditional roles. Single parent families indicated the need to act as *"both the breadwinner and the carer"* (Helen, G2) of their new family. Nevertheless, most parents did not report gender roles as a disadvantage, but as a *"partnership of sorts"* (Gladis, G2) having the advantage to care for their children in a joint manner, each parent with his/her own different contribution.

Traditional gender roles seemed to predominate in the division of responsibilities within the home. Thirty mothers, in two-parent families, cared for the child, educational stimulation and undertook all housework responsibilities, whilst fathers assumed the role of the breadwinner and seemed to be involved via free play stimulation with a focus

on physical stimulation. Some mothers indicated that their constant attendance to their child's needs acted as a hindrance for them to seek a job outside the home.

"how she (Mary) is I cannot (work)...she is not like other children you have to be with her all the time...even to go to the toilet...So you cannot go to work...because of her needs" Maria (G3)

"I want to work, I want to finish university...I have no time. That's my sacrifice, it's fine. You get one shot in being a mother you have the rest of your life to make a career." Gladis (G2)

Almost all the mothers, who returned back to their paid work soon after the child's birth, viewed their work as an added role to that within their family. Daniela (G1) felt she had two jobs, one within the home and another outside the home; she felt more exhausted when at home in comparison to her role outside the home: *"I have so much much to do especially when I am here (home)"*.

Lavender (G3), Rose and Thelma (G4) interpreted their work outside the home as advantageous regardless of their housework responsibilities within the home: advantages included psychological benefit and financial commodity.

'the fact that I left for work...you stop thinking about your concerns, you meet with people, you laugh a bit...I feel reassured that to a certain extent that he is quite well and that his grandmother is taking care of him on my behalf. I do not manage long number of days here with him (child) always sick, my temperature starts boiling' Lavender (G3)

Mothers' decision to work outside the home was highly influenced by the availability of child-minding care from extended family. Some mothers, like Ariel (G1) and Nancy (G3), felt they could not maintain their job as the mothers' parents were too old or ill to mind their young child.

Some mothers have opted to take parental leave or to terminate their career, as they felt it was their duty to give more importance to their family over their career in order to be home for the child's development during the first few years of life.

"I just had a promotion three months before my child's birth, all that I had planned is now down the drain. But that's life...I miss my career, because I have invested in it a great deal" Ariel (G1)

A few mothers like, Lavender (G3), showed instances of regret feelings that they *"had"* to step down from their career *"ladder"* to have more flexibility and maintain advantages of working outside home: *"I chose to prioritise my family...I did it with some regret"*

The culmination of gendered decision making was clear. The mother decided to remain at home for the care or upbringing of their young child: representing the family values parents wished to transmit to their child. For these mothers, this seems to reflect their way of promoting family life.

“I put him to bed late in the afternoon so that he (Dean) can stay up a little bit later and enjoy his father’s presence. And his father enjoys him as well...because you have to move together as a chain. I believe for the best of his upbringing...There is a huge difference in one’s values and in children’s attitude from how we were brought up...how can they (working mothers) transmit these values if they see their children early in morning and when they put them to bed at night?...For us it was very important to do this for our son so I stopped working”
Doris (G1)

Sharing of housework responsibilities seemed an extension of their gendered roles amongst mothers. Amanda’s, Carol’s (G1), Kyle’s (G3) and Ronald’s (G4) parents seemed to infer that the role of housekeeper is predominantly the assumed-role of the mother who stays at home, while the father was the one who helps her in her duties.

*“M – I always do the housework...sometimes he helps me...with the dishes...I mean little things
F – pfff little things!
M – sometimes he does the laundry, he takes them off the line if I am not here, or if my daughter is not well...sometimes he even does a load for me, so I do not complain.”* Carla (G1)

This was also noted to be the case where mothers worked both outside the home and through telework; these mothers felt likewise responsible for most of the housework.

“I appreciate that he gives me this (housework help) support. If it would not have been the case I would be more saddened as you need a bit of a break” Joanne (G2)

“Lewis helps me a great deal with the housework...if not I would end up doing everything on Saturday and Sunday” Lavender (G3)

Fathers commented on assisting the wife’s housework duties *“I help her”* (Simon, G4), it could have reflected their way of helping out at home, as a family.

In summary, the parents’ relationship as a couple was seen as a partnership, a team and a system where they collaborate together for the benefit of their children. The couple members/spouses appeared to care for each other in various ways. Moreover, gender differences were observed in their individual roles adopted within the family.

5.6 Micro-system sociological framework

Socio-cultural aspects were observed to influence parents' perceptions and experiences whilst raising their child born with risks within the Maltese society, see table 5.5. Parents felt frustrated with the small size of Malta; with having only one national hospital, and few private multi-disciplinary non-governmental services. Frustration was also expressed about perceived social stigma from the 'inexperienced' community.

Table 5.5 Micro-system sociological framework themes

| Thematic Statement | Superordinate theme | Theme | Sub-theme |
|------------------------------------------------------------------------------------------------------------------|-------------------------------------|----------------------------------|------------------------------------------|
| Parents felt frustrated towards sociological issues about Malta's small size from a socio-emotional orientation. | Micro-system sociological framework | Person perspective | Enforced suppression of voicing emotions |
| | | | Social Stigma |
| | | Lack of choice: Trapped in Malta | Availability of services |
| | | | Permanence and constancy of care |

5.6.1. Person perspective theme

Parental socio-emotional perceptions presented two predominantly negative perceptions. In hospital, parents felt compelled to suppress voicing their negative emotions out of fear that their child's quality of care could be affected when they were absent from the hospital ward and for the benefit of their child's future care, given that Malta has one paediatric intensive ward. Parents also experienced social isolation caused by social stigma. Parents tended to express more negative than positive thoughts based on their life's experiences when raising their child born with biological risks for ID during childhood in Malta.

5.6.1.1 Enforced suppression of voicing emotions sub-theme

More than half of the interviewed parents felt forced to suppress bursts of negative emotions for the fear of having consequences on the child's quality of care, as a result of there being only one public hospital. They were concerned about being under the care of the same professionals during possible future health care needs of their child.

*"M – just if you ask a simple question, 'what time will the X-ray result will be ready?', which I don't think I'm asking too much
F - He ATE MY FACE, he ate my face...and you have to keep calm at that point in time, cause you need his services, you cannot do scenes...as you do not know what someone might do"* Daniela and Daniel (G1) [SHOUTED]

Their protective feelings towards their ‘vulnerable’ child during hospitalisation combined with fearful feelings about the future care during potential hospitalisations acted as a barrier which further constrained parents to suppress their emotions.

Alternatively, for eight parents, it was important to voice their child’s rights but reverted to these actions as a last resort. Gladis (G2) felt that advocating for her son was a necessity, at the cost of her being labelled as “*arrogant*” by both her husband and professionals. Sergio (G4) felt trapped in a judgmental society where his desire to seek the best for his son had to be suppressed due to the medical professionals’ “*ego supremacy*” and “*lack of accountability*” on the island.

*“M – we used to hold back, due to Steve, basically
F – yeah because we were worried that whatever we say might have ramifications on how they treated him...you’re not allowed to question why certain action was being taken?...And then again it comes back to what’s happening when we’re not there near him. So you’re always on egg shells, on tenterhooks about what you’re going to say and how you’re gonna say it.”* Selene and Sergio (G4)

Some parents felt anxious when certain staff were caring for their child but could not express their emotions as there is one ward catering for all the paediatric intensive care needs in Malta.

5.6.1.2 Social stigma sub-theme

Parents reported emotions experienced during their daily lives caused by social reactions from the ‘non-experienced’ others in their community. Parents felt more sensitive and observed the non-verbal expressions of other members of their community when they went out of their house.

“at first when they (people) used to meet me, they used to give me that pity look, ‘ow poor girl (Malt: miskina), poor girl (Malt: miskina) what happened to you?’ And that used to annoy me...I am not pitiful...this was something that happened to us, we stand up again and move on. I used to appreciate those people who treated me normally...and we talk about everything, as if I had a baby and I became a mother...people treated me, as if my baby died.” Naomi (G3)

Parents perceived social isolation and alienation due to stigmatising interpretations from ‘inexperienced’ people outside their social circle. For example: Ismelia’s mother was affected to such an extent that she refused to go out with her child as she had to use an atypical feeding process and needed an intensive medication schedule, further imposing social isolation on the family. This family experienced significant social isolation as an impact of perceived social stigma.

“there was a time when she (Ismelia) had the NG tube, so when we went out, people were staring at her, quite a lot...we were also hearing comments as well...I used to go to the local traditional feast...now I think twice before going...when it is her feeding time...as soon as they (people) see the tube, or the syringe, and stuff like that, everyone stares at you...ever since she (wife) had the girl to date she has closed up in a snail’s shell...she didn’t want to know about going out with her...she is all the time anticipating it...most of the time it would be true” Igor (G2)

Social visibility, a sociological process based on the visual perceptions and interpretations of social interaction within a community, may be a cause of social stigma for the parents of children with evident physical features of congenital syndromes.

Other parents perceived stigma regardless of the child not having evident mobility difficulties but having significant visual and intellectual difficulties.

“when you’re walking in the street...at times you look at people and you see them looking at your child...in a certain way...which I don’t really like much...if my son, has a defect in his eye, don’t make it so obvious that you’re looking at it...because that hurts me as a parent” Selene (G4)

Steve’s mother implied that she has learned to avoid staring or looking at other children with disability as a respectful sign to other mothers as she felt hurt and stigmatised when others did so to her child. Moreover, some syndromes’ features are so easily recognised by community persons that parents seemed afraid of other people’s reactions.

Parents who frequently travelled abroad reported perceiving social stigma as being higher in Malta compared to the UK. For example, Gabriel’s mother reported a change in mood and emotions brought by different cultures, as greater feelings of social stigma were perceived in the Maltese culture.

“he was X years, and we’re in the UK when we picked up the wheelchair. He sat down, and starts wheeling himself...he was cheered on in the UK...you’re talking about London...everywhere he went he put a smile on everybody’s face. It was impressive!...I come to Malta...you get people whispering and going ‘miskin’ (poor boy) and what a pity. Looking at him frowning...(2sec pause)IT WAS PATHETIC...Miskin (poor boy) the stray dog, not Gabriel! It’s the wrong approach” Gladis (G2) [SHOUTED]

A few parents noted that they felt uncomfortable announcing their child’s diagnosis to friends and colleagues. John’s mother, as an example, manifested this attitude as she felt she was protecting her child from not being labelled and underestimated.

“I know that there are some who react ee!...they get a fright...They (disabled children) are linked with charity...due to too much awareness...It’s not that I want

to hide that my child has it...because I am afraid that they label him. And they underestimate his capabilities, and I do not want that. For me, he is acting like any other child.” Joanne (G2)

Her socially-built ‘charity’ interpretation was brought about by the constant advertisement on the public media of certain syndromes.

Furthermore, Igor and Joanne (G2) worked at home via teleworking to cope with their child’s health needs. They felt grateful for their employment arrangements however, this further imposed social isolation:

“my manager knows what I go through but certain people just do not show you respect” Igor (G2)

This might further create a cycle where reduced visibility at work may reduce their social rapport with colleagues adding more feelings of social isolation and stigma.

In summary, this theme highlighted the parents’ perceptions of their ‘intra-personal’ lived experiences. It has unveiled parents’ sociological perceptions of raising an ‘at risk’ child in Malta involving a protective obligation to suppress voicing their negative emotions due to the potential future hospitalisation needs of their child, given that the country has one national hospital. Parents also appeared to be significantly impacted by social stigma leading to social isolation.

5.6.2. Lack of choice: Trapped in Malta theme

Parents noted a number of emotions during their daily experiences as health care and education service users. The availability of services in Malta seemed to have affected the parents’ perceptions. Parents saw positive and negative aspects associated with permanence and constancy qualities of Maltese services assisting with their child’s development.

5.6.2.1 Availability of services sub-theme

Parents reported some positive aspects about the availability of services in Malta, regardless of its small size, when compared to other larger developed countries. Some parents were impressed that, regardless Malta’s small size, the NPICU reflected a technologically advanced ward for children’s care. This seemed to go beyond their

expectations. This could also imply that they had negative expectations of the Maltese health-care system vis-a-vis those outside Malta.

“the first question that I asked as soon as he was born...is this something that we can go abroad to solve it?...he (doctor) told me I can assure you that you are in one of the best NPICUs that there are in Europe. I am not trying to prove it; my own son can prove it...today he is with us” Garry (G2)

“Nowadays there are things as if we are abroad...Cause before they used to take them abroad, but nowadays, these are done here in Malta...the hospital is highly advanced regarding the paediatric section...there have been great advances” Bernard (G1)

Conversely, fifteen parents (40.5%) who utilised paediatric services outside hospital wards were frustrated and angry regarding the lack of availability of services. For example parents, such as Olivia’s (G3), Noel’s and Theo’s (G4), were frustrated as the occupational therapy (OT) services in schools were stopped after one year of their initiation.

“they (OT) decided to retrieve their services from government schools...that is very disappointing for me...I decided for example to send my child to a government school for this reason...that is a very serious decision, for us as parents to decide which school to send our child” Naomi (G3)

Other parents felt angry and frustrated regarding the lack of specialised professional services that could help their children’s visual impairment. These reported frustration about the lack of paediatric facilities and lack of specialised care in the national hospital’s ophthalmic wards compelled parents to seek such services outside Malta, hence incurring further expenses for the family.

“I can’t understand why a service like that of an orientation mobility specialist is not provided on the island...why do we have to go abroad ourselves many a times at our own expense, to get such a service?...if there are no professionals on the island, they (policymakers) should do something to train people or get people from abroad, so that we...can be provided with that service” Selene (G4)

Indeed, their frustration increased when the professionals that are specialised to assist their child emigrated, leaving them lost as to how to help their child’s development. Lack of specialists increased the need to seek specialised services outside the country, such as a specialised psychologist to perform a cognitive assessment for visually impaired children.

Other parents showed similar frustrations of being trapped. For example Gladis (G2) felt distressed due to a lack of professionals with current knowledge and high amount of experiences. Furthermore, some parents also pointed out that there was a lack of

available facilities to order some equipment within Malta and these had to be ordered from abroad, through private services by those who afford it as public services would take longer.

“The expense is HUGE...I was told ‘ow come on never mind he’ll stay in those shoes for another 2 months’...no because if he does he’ll develop pressure sores. And then you’ll have to treat those. Then spend another month in the hospital, and then what?...And either you give up and you leave your son wearing fancy coloured socks and slug him on a stretcher, as the advice was” Gladis (G2)

Similar frustrations were perceived by David’s, Mary’s and Tom’s parents.

This has consequently led to perceptions of disempowerment from social policy decision makers amongst a few participants, such as Sergio (G4) who vented his anger towards having little power to make their voices heard in their society.

“I don’t know of any MP who has a child with special needs, I could be wrong, but if that were the case, why aren’t they standing up for the rights of parents of children with special needs...we are too small a lobby group, we don’t have the power in terms of votes...if you had to gather all of the parents on this island who have children with special needs, it would be such a small percentage...they won’t even look at us” Sergio (G4)

All parents whose child was born prematurely and had significant low birth weight noted a lack of available materials from the national hospital ward for preterm babies. Nappies for preterm babies are not provided by the government for the hospital and parents are expected to buy them. A few months prior data collection, a non-profit parent-run organisation started to provide these preterm nappies. This organisation initiated out of personal experience of a couple and these decided to import these nappies for the benefit of other fellow parents and they are now sold from the ward. However, parents also complained of not finding clothes, bottles or dummies for preterm children on the island. They felt that society further highlighted the atypicality of their situation as these had to be ordered online from outside Malta. Dean’s, David’s (G1), George’s (G2), Louis’ (G3), Sandra’s and Preston’s (G4) parents, amongst others, experienced lack of needed preterm materials during and neonatal hospitalisation period. This posed financial and emotional distresses on all Maltese families whose child was born very prematurely or with VLBW.

“During that shock and the initial panic you find yourself in need of nappies and nappies for the size of a baby, like ours...you find yourself in a situation where I cannot buy from anywhere...no one had any in Malta...We had to get them from the UK. One packet of 24 nappies cost us 180Euros because we had to get them with the DHL” Garry (G2)

5.6.2.2 Permanence and constancy of care sub-theme

A number of parents perceived a sense of reassurance on the fact that Malta's small size offers the advantage of having a permanent and constant service in paediatric care both within the hospital and in the community. The parents' decision to maintain the same paediatrician, who cared for their child in hospital, for their out-of-hospital paediatric services was based both on trust and the positive results of their child's survival.

"under his care she did very well...so I trust him with my eyes closed" Ben (G1)

These parents felt reassured about the continuity of good quality care throughout the child's life through to adulthood. The consistency of the paediatric care both in their community via the private sector as well as the follow up within the hospital, should there be future complications, provided a sense of comfort. Some parents felt satisfied about their child's development and interpreted this as one of the advantages of living in a small island like Malta with one state hospital (Amanda, Bernice, Bernadette, G1). Similarly, Maria (G3) showed her trust in the hospital professionals due to their experience in past similar situations. All interviewed parents also manifested trust in their professionals who were assisting them in stimulation and therapeutic care by following their given advice. Furthermore, Kelly's and Kyle's parents (G3) felt the advantage that their paediatrician also lived in their home's vicinity.

"XXX is our paediatrician for both our kids...she lives very near to us and she answers her phone. She told us call me anytime, once I was very worried and I called her, poor girl she came here in the middle of the night" Kyra (G3)

Some parents seemed to trust the professionals as these felt guided and provided with sufficient reassurance about their child developing well. Certain parents with a low educational background felt dependent on the professionals for the provision of information due to their lack of information seeking abilities, opportunities or means. This could also be seen in the adoption of 'wait-and-see' attitude towards their child's development.

"M –Until now he (France) is moving on normally...for him (paediatrician) he is normal....but for me I am seeing his development slower...I think if he does not walk, I think they provide for you nowadays...I think if he needs these things, they would send for me.

F – I think he (paediatrician) would have already told us as well" Francesca and Freddie (G2)

Some parents showed their disapproval of the long-term permanence of both paediatricians and therapists alike. They felt that professionals seemed to become demotivated over time. Parents were inclined to use private services so as to have more

control over the choice of professionals’ goal setting. Some other parents however felt it was of great disadvantage towards the child if a therapist was changed frequently due staff shortages. Frequent changing of therapists affected not only rapport-building between the therapist and them as parents but also the varying therapeutic performances/ styles were interpreted as confusing for the child.

“sometimes there are not enough occupational therapists, and the speech therapists (in non-government organisation) are all the time changing...how can my child’s therapist be changed every three months...you would have just got used to the child, us and then my child started seeing another, cause you also have to understand that he is not seeing you every day for three months, but once every 2 weeks.” Naomi (G3)

In summary, the choice theme depicted parents’ perceptions of their lived experiences related to their society’s service delivery aspects. Permanence perceptions indicated appreciation towards the sense of continuity of services. Some others reported frustration due to perceived lack of guidance from their allocated professionals. Dissatisfaction was evident in their perceptions of feeling trapped in a small island when it does not cater for all their child’s needs to assist his development.

5.7 Info-emotional cycle

Information seemed to have a direct effect on parents’ emotional state, table 5.6. Nonetheless, parents did not consider all information as beneficial and helpful. Whereas some parents felt it was important for them to seek information themselves whilst others stopped seeking new information. This also included the way it was transmitted through its channels; creating a myriad of emotions based on the quality of communication attitude of the information bearer/giver.

Table 5.6 Info-emotional cycle themes

| Thematic Statement | Superordinate theme | Theme | Sub-theme |
|-----------------------------------------------------------------------|----------------------|----------------------|--------------------------------------|
| Information is perceived by parents to directly affect their emotions | Info-emotional cycle | Information balance | Quality and quantity of information |
| | | | Information seeking initiative cycle |
| | | Information channels | Communication attitude continuum |
| | | | Time allowance |
| | | | Collaborative team approach |

5.7.1 Information balance theme

The information balance cycle was based on the parents’ individual perceptions and the needs of when, from whom and how much information was considered to be helpful. Parents observed positive and/or negative effects that information itself had on their

psychological wellbeing. Consequently, parents felt the need to use an individually established balance to control their information seeking.

5.7.1.1 Quality and quantity of information sub-theme

Supportive information about child's health state or development, medical procedures and potential difficulties made parents feel prepared and guided to help their child. Nonetheless, not all information was reported to be of good quality. The amount of information needed differed between parents, suggesting individual decision-making processes for each parent. This was also reported to depend on the professionals' active listening ability, to identify the needs and wishes of the parents.

Parents were thirsty for information. They needed it to quench their emotional coping within their situation. Parents found themselves thrown in an unexpected situation, having to deal with their shock and attempting to understand the new world and medical language around them. A number of parents saw information-giving by professionals as a source of emotional support especially when this focused on orienting them in the ward during the first hours of their first visit and constant information on their child's care and health state.

“if there is someone...one that we can refer to for explanations what these monitors are for, cause at first we felt frightened of monitors, there were so many monitors, then we started asking and they started showing us...you start to understand what they are for” Ariel (G1)

The lack of immediate information increased the emotional shock of seeing one's newborn child in a life-threatening state, especially in an environment that parents are not familiar with. This was reflected in some fathers' reports of a period of abandonment and loss during the initial intensive care period of their child, during the recovery period of the mother after birth-giving.

“When my child was born...Your wife is out. You're there on your own as a father...you're left there, wondering, can I ask you a question?...There is NOTHING...the machines beeping, nobody explained what they are for...your child is there and is on machines...so what's next?...I felt alien. Like unwanted...the father doesn't care? it's his child!...I remember feeling abandoned...I had two patients now...what is going on? Is she dying? Why does she have that machine?...When will my wife be ok?...What are the chances?” Samuel (G4) [SHOUTED]

Some parents found comfort in the newspaper cuttings that were framed near their child's incubator during the intensive-care period. These provided encouragement and

were interpreted as helpful by some mothers to maintain their emotional and mental strength.

“There was a newspaper cutting stuck on the incubator that Pablo had, of a baby that lived, each time I used to go to the hospital I used to go and read it. It used to give me courage” Paola (G4)

Some interpreted the information given at the NPICU ward as one that would not have been given should their child be born in a typical context, which further helped them appreciate the positive side of their child’s circumstances.

“We received great help from the nurses, they explain everything, they show you the way cause all you see is an unlit road, but they show you the light at the end of the tunnel” Garry (G2)

While Ariel (G1) felt that the provided-information taught her “tricks” and “tips” on child care which made her a point of reference amongst her friends who needed help with their typical child care.

Most parents expressed appreciation and feelings of gratefulness for receiving information from nurses and midwives. Although some parents felt they were getting second-hand information when the hospital doctor visited their child at the hospital ward, as they felt it was their right to be present during the medical ward round. They seemed to wish the information from the ‘horse’s mouth’ (doctor/consultant).

“I used to see this as unfair. Why when the doctor comes to see my daughter, I cannot stay there to listen myself?...That bothered me...I think that I have every right to be there when the doctor comes to visit her...I sometimes had to...Leave the ward because there is the doctor? if the doctor is seeing my daughter!...I feel that I have every right to know, I know that the nurses tell me everything, but at least I will be able to listen to the doctor myself” Brooke (G1)

Some parents showed appreciation towards the training from professionals, as it helped them reduce their fears of caring for the ‘vulnerable’ child at home alone. These felt equipped to resuscitate their child thanks to their newly acquired CPR skills and felt grateful for the nurse’s initiative.

*“M - I did the CPR after a month that he was discharged...He had a fit...I went to thank her personally cause thanks to her we saved our son.
F –I said since he’s dead...I’ll try and take a chance...cause if I won’t try now I would look back and feel sorry for it...it was successful and he started breathing again” Riana and Rafael (G4)*

Yet some other parents felt that divulging information prior being confirmed, such as announcing a potential diagnosis by doctors created more distress.

“Parents who are going through enough hell as it is right now, to have them put into that unnecessary stress and tension, was that necessary?” Sergio (G4).

Barriers impeding parents from gathering new information were identified. These included the unpredictable nature of the child's life threatening situation. Some parents directly linked their added frustration of the situation with the lack of 'hope' for the child's survival given by staff. For Lawrence (G3), this frustration drove him to revert back to drug-taking for emotional relief due to "*falling to self-pity*".

"mentally tired...is he going to die is he going to live?...we used to wake up at midnight and call the ward...they tell you stable stable...you never know where you are, he may have started going downhill all of a sudden...it felt as if they were telling us, do not bond with him because anything can happen...what is left in you?" Lewis (G3)

Moreover, Ben (G1) noted that professionals should be cautioned that lack of hope could act as 'the straw that broke the camel's back': "*and you sent that human being home and he can do suicide*". Professionals seem to understand parents' anxiety; yet, they may have found themselves unable to raise parents' hopes in the event that the child dies. In hindsight, both Garry (G2) and Timothy (G4) reinterpreted their past 'lack of hope' perceptions as professionals trying to "*protect themselves from raising too much hope*".

Some parents saw professionals as a source of reliable information outside the hospital, including physiotherapists, occupational therapists, speech-language therapists, paediatricians, educational support workers and peripatetic teacher amongst others when parents were making use of such services. They provided parents with advice and activities about how to stimulate their child in the home environment.

"they (professionals) are guiding us...if speech comes in, at first she used to focus on the feeding, if he has problems in feeding, then by one year of age we moved on...I do not know these things, so thankfully she is there to tell me look do this game. As soon as she saw him advancing she gave me another. For me they are heaven on earth, sort of, cause you know that this game is for learning" Joanne (G2)

The majority of parents felt grateful for the constant information giving from professionals who helped them feel equipped and be a support system for their own child. They felt instrumental that they could provide first-hand help to their own child.

"they used to tell me what I do, and I do it here at home" Isabelle (G2)

The paediatrician was the source of medical information about the child's developmental health, particularly in relation to physical aspects. Amanda's parents, amongst others, interpreted the paediatrician's information as not only helpful to the

affected child but to the family as a whole, via email which generated trust and feelings of satisfaction.

“you feel very very much informed...a whole family kind of thing, he (paediatrician) supports not only Amanda but even us, it is very very helpful, for me it's a super service” Alan (G1)

On the other hand some parents expressed frustration that they felt more up to date than their professionals: the information provided was not deemed of good quality. They thus felt these professionals were unable to assist them with their child's development. Over time, parents learned to weigh professionals' advice and information thanks to knowledge acquired through filtering of the information on the internet.

“So nowadays we learned to evaluate whatever they tell us, I do not just do what they tell me to do...Most of the time, I am much more updated than they (professionals) are...I know a site for example the XX association of England which is updated...And when you compare what they tell you with that information from the site you say, that is what they used to advice 5 years ago...So you can learn to compare better how updated they are or not” Naomi (G3)

This further placed the parents' perceptions in the expert position. Yet parents felt they lacked guidance from allocated professionals. They felt the lack of adequate specialised knowledge needed for their child's needs leaving these parents frustrated.

“sometimes they send me teachers who were qualified in something totally different...like accounts...then they send her over here to try and teach ME about visual impairment...I was teaching her instead! So what kind of help was I getting? Nothing really” Selene (G4)

For this reason Selene felt the need to specialise in the care of children with similar difficulties as her son.

For some parents the bereavement midwife or other 'inexperienced' professionals could not answer certain questions on the real life experiences of having a child with similar circumstances. Parents felt lack of experiential information to have a picture of their journey of raising an 'at risk' child.

“what I wished was if there was someone from his personal experience, to tell me, reassure these people...there is no need to panic...once physically his heart echoes are alright...it has to be another person that says it, someone that went through this experience. Maybe they write it in a pack to tell you, I still remember...it felt like you didn't go to Italy to see the cultural heritage but to Holland...I think there should be someone that gives you a hint, look you need to start from this” Joseph (G2)

This further highlighted a strong link between information needs and emotional support required by parents whose child was still at a tender age.

5.7.1.2 Information seeking initiative cycle sub-theme

Parents valued information about their child's development at all stages. Some parents felt that initiating their information-seeking process was too great an expectation while for others it was an assumed parents' role. Parents who had the resources and access to information-seeking material including the internet, books and the knowledge about how to adequately filter acquired-information, were mostly those with post-secondary or tertiary educational level. The internet seemed to be the most sought-after source of information amongst parents who had access to such a resource. Parents also verified the information given by professionals on the internet. For example, Kevin (G3) indicated that the information given by professionals was used as a tool to filter the information.

Some parents, who were not receiving consistent information, continued asking the same questions to different professionals until consistent answers were given, to the point that some felt they were “*annoying*” (Lavender, G3) professionals. Inconsistency of advice acted as a trigger to seek a second opinion from different professionals by most parents. It was deemed as highly distressing and confusing, since they reported it created a feeling of loss.

“at times the picture is not that clear....you take him to one doctor, it's one thing, you go to hospital it's one thing, and a therapist it's another thing. I start saying to myself, but where am I? where do I stand?” Daniela (G1)

Information may also shape the parents' understanding of the child's condition, particularly after news giving process.

“The first year is the most crucial one, until you have learned on the condition, you get used to it, enter in a routine and inserted a therapeutic schedule with the rest of family life” Odette (G3)

Fifteen parents received a diagnosis soon after or before the child's birth, as having a syndrome or disability related to ID; via identification from the blood test confirmations of the newborn or before birth via ultrasound scans. Immediately after news-giving, most parents reported a strong need for information. Some indicated that they went to the extreme of reading about matrimony and bank loan rights of persons with a similar disability to their child. Some parents reported too much information-seeking “*mania*” (Odette, G2), stemming from their anxiety and lack of experience with children with disabilities. Some suggested that they should be given information according to the

child's next developmental stage rather than professionals bombard them when they are in a state of emotional upheaval: news-giving period.

"I have learned that...now when it was time for him to enter a kindergarten, I said ok let's find out about what support is offered by the learning support assistants...just before I need to take the step so that at least I will be informed as much as possible on what is going to happen soon" Naomi (G3)

Some parents reported feeling distressed as they were not given vital information, about emergency care of their child, whilst other parents were. Hence the former had to seek such information themselves. These parents showed their constant concerns and fears about the child's survival.

"There should be someone to tell you what to do in case of an emergency...I noticed there was something wrong (child had a fit)...I had no idea what it was or what to do. So there isn't that teaching enough...what she (Ismelia) has I learned from the internet, cause here in Malta I am not sure if there is another one like her...I found two associations...only from there I found out these things. Not from here in Malta!" Igor (G2)

Some parents recommended that parents themselves should take the initiative and ask questions to be able to get the required information from professionals, who were looked upon as a reliable source of information.

"when I asked the consultant, about breastfeeding, they referred me...Personnel of the breastfeeding clinic visited the ward...I found help...you have to ask...they will not know what you have on your mind, and your requests" Ariel (G1)

Similarly, Naomi (G3) felt it was her natural parental "duty" to take the initiative and search the internet to learn about updated information concerning her child's difficulties, as she did not have past experiences or familiarity with children with disabilities. Sergio (G4) was constantly on the lookout for a "medical breakthrough" to solve his son's visual difficulties. Information-seeking kept Sergio hopeful towards the future for a 'solution' to his child's difficulty. Alternatively, spending a great deal of time on constant look out for medical solutions could have acted as a barrier to emotional acceptance and quality time with their child.

Some parents felt irritated that they had to take the initiative to seek information on their child's condition and where to find emotional and service support within the hospital and especially outside hospital. Samuel (G4), for example, felt angry at being forced to seek information during the period of the child's neonatal hospitalisation where both parents were dealing with their shock emotions. He insisted that all information and emotional support should be readily-available and he should not be compelled to ask for it, or seek it himself for self-reassurance.

“if there was...a counsellor there posted in the ward...to tell you, look you are going to feel like this...instead having to find it myself...if there is on standby they come and offer you the service. Alright they have a notice board and it says that there is this voluntary organisation...It was like optional if you want it’s there”
Samuel (G4)

Some parents appeared to feel left out and betrayed once they realised medical professionals were not giving them the information they needed to assist their child’s development. This seemed to be expected from the medical professional rather than the therapist. They reported that these experiences pushed them to initiate information-seeking for their child’s benefit, so as not to miss out on potential help in his/her development.

“Thankfully then...the speech therapist told us about the P.E.G., cause you do not really get much information from hospital. You have to discover the information. WE then told the professor and he said I think the time has come yes true to do it...we did the operation for the P.E.G...We felt relieved...we really really felt the difference.” Igor (G2) [SHOUTED]

Some parents felt the need to stop finding new information due to the negative effects on their psychological wellbeing. For example, Rose’s (G4) fears pushed her to halt the vicious cycle of information-seeking in order to feel calmer regarding her child’s developmental stimulation needs and to maintain a serene relationship with her husband. Similarly, Oliver (G3) made sense of his information-seeking choice cycle as part of a car-repair analogy: attempting to repair a car on your own from knowledge gained from the internet, creating even more queries and frustrations than solutions.

“the things that you start to find will create even more questions and you start saying look she may have this she may have that, then after all she may have nothing of the sort but may have something completely different. It may fire back as you start building up more thoughts and these in turn will create more pressure on you”

In summary, the information balance theme included parents’ need for adequate information as a source of emotional support and guidance to help their child’s development. An individualised balance and timely information was reported as essential so as not to experience distressing side-effects. The quality of information and information sources was considered to be vital for parents.

5.7.2 Information channels theme

Information channels refer to the manner how information was communicated to and perceived by the parents rather than the content of information itself. This included the communication attitude of the information bearer and how this was perceived by the parents at the time of transmission. This theme also look at the time allocated for such communications both between parents and professionals as well as team collaboration perspectives.

5.7.2.1 Communication attitude continuum sub-theme

Supportive communication attitude

A professional's communication attitude was interpreted as supportive when s/he followed the needs of the parents by using active listening to their concerns and questions during any news- or information-giving processes. Some parents interpreted the communication attitude of some specialist medical professionals as supportive. Both Bernice's (G1) and Martha's (G3) parents, amongst a few others, felt privileged that their specialist doctor had a supportive communication attitude.

"he told me...not the baby and not even you, we are going to do it (operation) all three of us. Cause if this is successful all three of us are going to be happy, if it is not successful all three of us are going to suffer" Manuel (G3)

These parents felt supported when the professional explained in simple detail so that they could understand the medical/ surgical process and post-surgical care. It made them feel involved as part of the medical team. These parents highly recommended that all medical professionals should use hopeful and empathetic communication attitudes.

The importance of having shared spiritual beliefs with those of the medical profession assisted in providing 'a silver ray of hope' or encouragement. Some parents interpreted this as a source of emotional support through their faith during times of turbulence.

*"M –he (surgeon) told us these things are controlled by God...
F – we filled up with encouragement...the baby was at the very end...from the way he talked to us regarding his way to operate on her...he told us 'but do not lose faith, because I am going to do my best'"* Ben (G1)

Ben suggested that medical professionals' communication attitude should carry a small message of hope to which parents try to "grab at" during times of despair or anguish without giving too much false hopes.

Nursing professionals, including midwives, were seen as highly supportive by most parents. Parents felt grateful for the small, seemingly insignificant but supportive gestures from hospital staff, such as a hug or their silent presence.

“some were really really helpful and they're very friendly...they did not expect you to say anything they just took you, they hugged you for a minute and say, if you need something just let me know” Helen (G2)

“I was really distraught, literally sitting by his incubator and extremely emotional and this nurse didn't say anything she just came and she sat down next to me. Didn't say anything just was there. A BIG difference, you know.” Sergio (G4) [SHOUTED]

Moreover, parents felt that most of the professionals were supportive, helpful and attempted to fill the void of emotional support to parents during their emotional upheaval and hospitalisation period.

*“M – most of the doctors they are not like that (unsupportive)...David's professor...honestly, I have never met a person so nice.
F – sweet, incredible, you'd say this is a professor? Because he was really a very nice person.”* Daniela and Daniel (G1)

“I met with specialists...you'd say wow. I'll say a prayer for him every evening...cause you feel it in the way how he speaks with you, the way he calmed you.” Oliver (G3)

Insensitive communication attitude

Throughout their experience of upbringing their child all the parents perceived, to a certain degree, that insensitive communication attitudes were addressed to them. Most parents commented that only few professionals were insensitive, and yet these left most mark on them. Insensitivity was an individually-described state of communication attitude that aggravated their emotional turmoil.

News-giving of the child's diagnosis at birth was a highly distressing event that remained imprinted on the parents' minds. All fifteen parents, who received a diagnosis during the birth-giving period, reported differing news-giving experiences. Fourteen parents agreed that professionals' communicative attitude could have been more sensitive towards their emotions during news-giving moments. These indicated that a lack of emotional support combined with language-use or pessimistic approach of professionals made their situation worse:

“my gynae cried with me...But certain words weren't appropriate...she told me 'look everyone has a burden to carry' ...at that point in time...I did not realise, yet, that I have a burden...BOOM another hit on the face” Naomi (G3) [SHOUTED]

Some parents continued feeling long-term anger about the news-giving process. For example, Odette (G3) felt abandoned just after birth-giving as all the professionals left her alone and she felt hurt by the insensitivity that a trusted person displayed.

“the midwife came in to give me the news herself, and the news was really cruel, it wasn't humane...She told me ‘your baby will have a deformity for her life but the paediatrician will tell you’...left me alone facing upwards and she left the room.”

Odette (G3)

Parents' strong focus on professionals' non-verbal communication seemed to create a realisation that they were in an atypical situation.

“they were talking amongst each other, and how they took him and stayed looking at him...something not normal...yet they still told me that there's nothing wrong.”

Edward (G1)

Emily (G1) saw her news-breaking as insensitive since she was informed on her own, with the expectation that she would be her husband's news breaker. At the time of interview Edward still showed signs of disbelief (denial) as the doctor told him that his son was a *“freak, a joke of nature”*. Only, Theo's parents (G4) did not report excessive news-giving distress: the professionals placed the baby in the mother's hands she realised herself, as she professionally worked with children with disabilities.

The bearers of negative news, particularly medical professionals, were negatively looked upon. They interpreted these professionals as lacking sensitivity, especially during news-giving, be it child's life threatening state or diagnosis-giving, which made some parents feel as if *“going off a cliff”* (Helen, G2). One might also infer that parents' distress indicated a lack of awareness or provision of other sources of emotional support, such as parent-to-parent support. Parents described incidences when their medical professionals' communication attitude during the child's birth hospitalisation was not considered as adequate. For example Florence's parents (G2) were made to believe that they asked too many questions and were blamed for the child's breathing difficulties; when a few weeks later the child was diagnosed with congenital heart disease.

“in the very beginning...they (midwives) were making me feel as if I am an encumbrance because I called them when I had a difficulty...that attitude is really horrible. That they get angry at you because you do not know how to breastfeed and I am calling them to help me...it made me feel very disheartened.” Farah (G2)

Insensitivity was also perceived from the administrators' attitude whilst applying for the disability pension soon after news-breaking. Administrators wished to see the child's face as a diagnostic verification process, perhaps to control for fraud. The bureaucratic

procedure could have been emotionally-demanding and it was seen as unnecessary by parents, since at the time of experience parents were still dealing with their diagnosis shock.

“they have everything on computers nowadays...The way how they just wanted to see his (Ernst) face, as if it’s a confirmation, was painful” Emily (G1)

Patronising communication attitude

A frustrating mode of communication, as reported by all parents, was the patronising attitude of some medical professionals where parents felt added oppression over-and-above their child’s situation. Difficult vocabulary seemed to reduce parents’ understanding of the communicated message of the speaker, forcing parents to seek explanations from nurses or junior doctors.

“it’s useless you came here telling me a great many words, terminology that I cannot understand, you blew my mind and you left me there, and that’s it! Might as well not tell me anything....I didn’t understand what he told me” Daniela (G1)

Some parents also interpreted it as portraying a detached attitude. It was not welcomed by parents, especially by those who had tertiary educational levels as they felt they were treated as “*a number*”. Similarly, Oliver (G3) felt hurt and interpreted the paediatrician’s follow up questions as insensitive when they asked routine developmental questions.

“doctors, like seeing my child as a XX case, not another child with XX. No this is a XX case (slamming hand on table with each word) so BOOM and things start coming out associated with it... before all that he is a boy, before the condition he is a boy...That at least you owe it to the child” Naomi (G3) [SHOUTED]

This attitude was reported by some parents in groups 3 and 4, when these appeared to have a more mature and accepting stance. It made parents angry and reduced the clarity of parent-professional communication. For example, Ronnie (G4) felt angry towards the “*end of line*” attitude, where specialists told them that they were the only specialised person in the country and whatever they say goes.

Portraying a detached attitude also seemed to diminish trust in the medical professionals. For example, John’s parents (G2) felt frustrated about the medic’s apparent superiority and detached attitude, as they felt as qualified as the professional who was addressing them.

“F- Certain doctors are so cold, in their approach...sometimes they don’t even tell you their name just their surname...nowadays you are not speaking with...that idiot who does not have any schooling, nowadays you are speaking with an architect, with a lawyer, with an engineer...Do not underestimate other people!

M – it feels like talking to a wall...what is needed may be there would a more personal touch to it...Trying to make it less challenging, less of a burden feeling”
Joanne and Joseph (G2)

Some parents observed a difference between the communication attitudes of therapists and those of medical professionals. Igor (G2) felt that medical professionals seemed to reduce their ‘hope’ for their child’s prognosis:

“doctors are not like therapists...it’s true that no one wants to commit himself if she is going to walk or not in the future, and they are right...However, I believe that with the physiotherapy and speech therapy there is still hope for progress...but doctors they dishearten you a great deal from these things” Igor (G2)

It may be the case that for children with severe difficulties, hope is a crucial tool for parents in order to ‘keep going’, while doctors tend to portray a pessimistic perspective to help them remain realistic.

5.7.2.2 Time allowance sub-theme

Professionals, paediatricians and therapists who dedicated time to answer parents’ questions were viewed as supporting parents’ concerns and distress. A number of paediatricians dedicated time to some parents’ “*list of questions*” (Abigail, G1) resulting in diminished concerns. Others like, Bernice’s (G1), Martha’s and Kyle’s (G3) parents, felt emotionally supported and worthy of the specialist’s time when the child’s paediatrician showed patience through time dedication.

Time allocated to each patient by medical professionals during outpatient appointment was interpreted as quite limited (5-10 minutes per patient). Some parents did not blame the professionals entirely. They indicated the need to update the medical outpatient policy ‘system’ of time allocations towards a more person-centred perspective.

“The relationship (of doctor) with the parents should be different than that with another patient...they should be aware that you, as a parent, are going to be sensitive to the news, and they have to be careful how they talk to you...be more sensitive...it’s true, doctors have a great deal of pressure cause there are loads of people waiting...I do understand that it’s borne from the system.” Oliver (G3)

Some parents felt that reduced communication with paediatricians was interpreted that these were keeping them uninformed. Sergio (G4), for example, interpreted the lack of time dedicated by paediatric specialists during hospitalisation as a lack of respect for parents’ emotions.

“If you have a parent who is literally, emotional, crying and needs support, you stop what you’re doing you get out of your office and you go over there and you try

and talk to them and listen to them...You're dealing with people's children, take the time and go out" Sergio (G4)

Dedication of individual time by the specialist paediatricians was interpreted as supportive for parents. Kyle's parents felt they truly understood their child's difficulties when they sat at a meeting with their doctor who explained in detail and used simple drawings. This improved their emotional state and relieved a number of concerns originally caused by the lack of understanding of certain terminology.

5.7.2.3 Collaborative team approach sub-theme

Close collaboration between parents and professionals was judged as highly supportive and felt as part of their child's team. John's parents (G2) felt dependent and grateful to their team of therapists for guidance on their child's stimulation and therapeutic programme, similar to Amanda's, David's (G1), Ian's (G2), Noel's (G3) and Theo's (G4) parents, amongst others. This perception enhanced the feeling of parents being part of their child's therapeutic team as they felt they were doing their share in helping their child's development, including decision making.

Some parents appreciated and felt responsible and empowered when collaborating with the medical consultant's decision making process. For example, Kyle's father felt empowered and greatly appreciated the opportunity to participate in the decision making about his child's survival.

"I lived the experience where I had to take the decision myself. When the professor approached me...he told me 'either we give him this dose...or else there may be complications like ulcers and brain damage'...it had its side effects but I took the risk, I told him now right now, give it to him right now. I told him!...but I appreciated the fact that he asked me." Keith (G3)

Some parents noted lack of collaboration between departments both within the hospital as well as between the hospital and other major departments in the public sector. This pushed parents to collate the information themselves and adopted a team communicator's role. Collaboration was considered essential, to provide holistic care for the child's development. Some parents felt they were the only communication link between hospital services and educational services.

"here there are like small institutions, and when you come to the link (between institutions), now there is the ACTU (education special needs services section) and it has a good link with schools because they have peripatetic teachers but not with hospital...when you mention education, the educational aspects are tied together,

it's like hospital has nothing to do with it, because it's health, but I think it is all tied together.” Paola (G4)

A collaborative approach may take place between the school personnel and parents. Some parents felt guided by their child's teacher or education support worker (LSA) where s/he sent teaching guidance plans for parents to continue teaching their child in the home environment. For example, Rose (G4) felt her collaboration with her child's LSA was crucial to further stimulate her child for better educational potential from the home environment.

“he has the LSA with him because of his mobility restrictions...she writes to me every day what they do at school and I move on with her step-by-step. Sometimes I even do extra hand-outs myself, for him to do them here at home. For example, before he started school we met, (LSA name)...she told me what they are going to cover in kinder two and we started preparing him beforehand.” Rose (G4)

Similarly, Pearl (G4) felt that collaboration with her child's teacher was essential due to his considerable absenteeism caused by health risks. Thus such a collaborative attitude helped her child to be home-taught by his mother after her working hours. It also helped to keep education-attainment concerns at bay.

“he has such a sweet teacher...as soon as I send him for two days he comes back feeling sick...I go to school, she gives me the papers...until now, he did not complete all like the other children, so we will do them slowly now during the holidays when the other children are not working on them, we have to work so that hopefully until January we reach to the same level of other children” Pearl (G4)

Few parents, like Louis' (G3), felt concerned and “stuck” (Lewis, G3) about their child's education due to frequent absenteeism from school. They expressed a need to collaborate more with their child's teacher and speech therapist in order to perform some educational activities at home.

“because he is sick, he loses a great deal...if he is going to miss speech therapy and I am not going with him I cannot work on certain things or continuation that the speech therapist tells me about...At school it's the same thing...all he had was 3 complete weeks in total (in 3 months)...he was VERY sick...For him a cold means after two days we are going to hospital, always, it always happens like that” Lavender (G3)

Some parents felt that professionals trained and/or working outside the Maltese islands had better teamwork attitudes. Some parents also noted significant differences in terms of collaborations with staff as well as feelings of inclusion in the team of health professionals who worked outside Malta. These parents reported that they felt lucky to be helped by the latter medical professionals who were trained outside Malta.

“What was good for us, now it could also be that Mr XXX saw things from England, and so has a different mentality...he gathered us twice in his room to

explain everything to us...It wasn't that he just took it for granted, but they consulted us as parents what is going to happen on my child. That is very important." Marthese (G3)

Other parents suggested that professionals' working attitudes in Malta should shift towards greater open-mindedness and teamwork attitude they perceived existed outside of Malta. They felt more warmth, collaboration, greater sense of belonging to their child's team and better rapport with professionals outside Malta.

"Abroad, it's different...Ivan shared his innermost feelings with him, he (surgeon) stayed there to listen to him, he did not chuck him out or embarrass you...when they noticed the least bit of movement they called him (surgeon) and he was eating out with his family...and he came...He was all the time coming to talk to the nursing staff...I think there should be more teamwork...here in Malta I think there so many loose ends." Isabelle (G3)

"when we go abroad, you meet with doctors...you feel good talking to them...he was a consultant in a hospital...with a large amount of experience. And you feel as if you are talking to someone like you. And here in Malta...everyone tries to step on everyone's toes to show off how good they are...that irritates me." Naomi (G3)

The information channels theme placed the professionals in a unique position where their communication attitude had the capacity to provide emotional support for parents. Parents reported professionals' insensitive communication attitude as hurtful and led to long-term anger. Parents showed appreciation when professionals allowed more time to answer their questions and involved them during the child's interventions and medical treatment decisions. This enhanced the parents' empowerment feelings.

5.8 Service-needs-resource cycle

All parents sought after-hospital services in both public and private sectors. After-hospital service use seemed to have an effect on and was affected by the family's available resources. Accessibility and suitability of services did not seem to reflect their family's needs at all times.

Table 5.7 Service-needs-resources cycle themes

| Thematic Statement | Superordinate theme | Theme | Sub-theme |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|---------------|-------------------------------|
| Service-use seemed to be affected by accessibility and suitability concerns. These do not always seem to reflect parents' needs and those of their child. | Service-needs-resource cycle | Accessibility | Awareness based on need |
| | | | Reliance on private resources |
| | | | Referral to services |
| | | Suitability | Child's benefit |
| | | | Effects on parents |

Table 5.7 indicates the ramifications of service-needs-resources cycle to accessibility and suitability themes. In both themes there were positive and negative influences, praise and complaints, satisfactions and frustrations. The accessibility theme explored how parents came to make use of the services they felt they required, whilst suitability covered parents' perceptions of the services that they have made use of in order to support their child's development.

5.8.1 Accessibility theme

Access to certain services was not open to all who wished to self-refer, but was accessed only by a *referral* from the patient's medical specialist or family doctor. Moreover, parents did not access certain services due to lack of *awareness* of available services in their community based on their child's immediate needs. Parents' financial *resources* acted as a means to access private services should they feel the need for urgent support or as an alternative to public services. A slight overlap between the sub-themes could be observed as these seem to 'go hand-in-hand' in the parents' daily lives.

5.8.1.1 Awareness based on need sub-theme

Parents seemed to seek services based on the child's present needs or as guided by the paediatrician or teacher when they start school. Fourteen parents across groups did not feel the need to access services: such as physiotherapy and/or specialist services. These viewed their child as developing within perceived typical standards (or as advised by paediatrician or teacher).

"I have the book that they gave me before they discharged me from hospital and if I need, I will search from there. If I see that my child is not developing as she should, I will start searching for services" Brooke (G1)

"She (Samantha) seems ok, her teacher says she is fine, if she tells me something then I will look for help" Shanaia (G4)

Some parents interpreted their unexpected birth experience as an opportunity to learn about paediatric services and intervention procedures. Parents implied a 'realisation' and a lack of prior awareness of these services in Malta.

"I really learned from this experience, how could I have imagined that I have to learn how to do massages on my son's feet...I learned a great deal" Hannah (G2)

The professional background of some parents provided them with knowledge about services that may help them in the future if needed. This was viewed as a helpful tool

and a reassurance within itself that they were equipped to assist their child in his/her future development and education.

“Thank God that I chose my career in education...if my boy feels stuck in a certain aspect, I feel that I am capable to rack my brain and find another way how to help him cope...the fact that I am a teacher is an advantage for him” Rose (G4)

Other mothers such as Doris (G1), Helen (G2) and Sarah (G4), who worked in the health sector, were also aware of how they could support their child’s development from a health-related perspective. Parents whose professional or educational background was not within the health or educational services seemed dependent on the paediatrician, family doctors or internet for information about services.

5.8.1.2 Reliance on private resources sub-theme

Private resources include the family’s finances whilst raising a child born with biological risks for ID. After neonatal hospital discharge, parents reported a dependence on their personal financial resources to access private paediatric services. These were accessed in parallel to public services, which are free for all Maltese citizens. Parents described their frustration at having to wait for a significant amount of time for an appointment with a specialist professional at outpatients department. This also seemed to have affected some fathers’ involvement in children’s services since they said that their work annual leave was being “*wasted in outpatients’ waiting rooms*” (Oliver, G3; Ronnie, G4).

A combination of public and private services was commonly reported to cater for the child’s developmental needs based on their financial status. Some felt that their finances were a key to freedom to revert for private services when in urgent need of this support, increased frequency of therapeutic sessions, or for a second opinion. For these parents, their family finances were crucial to overcome limitations of public services. Indeed, the ‘wait’ for an appointment in private services was much shorter and service quality was perceived as better.

“I called hospital and requested another appointment...They told me in 3 months’ time...I want it much nearer. They told me you can go privately...the day after...I used to show these same papers at hospital...He spent three quarters of an hour studying these notes and comes out with a diagnosis...Did I have to visit you privately and pay 60 Euros...to give me a chance?...Ian was suffering for 6 months, apart from us feeling stressed...headaches and sadness because my child was suffering...few professionals at hospital and outside work on the same level” Isabelle (G3)

Most parents saw their experience raising their ‘at risk’ child as creating added financial expenses, especially when parents were on one wage (due to gender roles) whilst still paying their mortgage fees.

“financially we were highly affected...Cause just to go to London for treatment, we ended up broke...last year, we went to London six times. It’s true that the government helps us but taking off the government financial help, we were still left with a hole in our pockets. We are talking on the bare necessities here” Paul (G4)

Although they felt grateful to the government for providing some refunds for added expenditure, when using referred services abroad, parents still felt a financial burden that do not help two-parent families.

“When you go the UK...they paid for my flight ticket...I needed my husband...my father and his sister came with us...they wished to support us, emotionally. I am not expecting their flight tickets to be paid as well, but at least pay for the parents as a couple” Thelma (G4)

Moreover, additional incidents as a consequence of the miscommunications between hospitals proved to add financial burdens for some parents.

Some parents’ reported that the lack of a LSA in nursery schools and/or during optional summer schools caused added family financial instability, since mothers could not seek paid employment. These reported that they had to live as a one-pay family regardless of their financial challenges. This gap in the government services was seen as an impediment to re-starting work and re-balancing their family’s financial state: thus they felt trapped in this cycle.

“during the summer I cannot send Olivia to school...Because if I send her to summer school I have to pay an LSA, plus the school fees. I cannot afford that...I cannot go to work, unless I find something that I am off during the summer. It has significantly affected our financial life...even on my employment opportunities and types of jobs as well.” Odette (G3)

Additionally, mothers like Irene and Isabelle (G2), also felt that the added health needs of their child could impede them from trusting child-care centres as they felt that their staff were not trained for similar children’s needs and emergency eventualities.

A few parents felt financially stable enough to use only private paediatric services to assist their child’s development, due to dissatisfaction with public services. Yet, they still perceived it as a financial burden. These parents believed that it was worth the strain as they had more control on their therapeutic goals, frequency of sessions, choice of professionals and received home service delivery.

“I used to feel that I had no say in my son’s upbringing, sort of there was a bible and I have to do everything accordingly...but now we are completely private and not with a non-governmental organisation, it is still a financial strain...But now I noted that I have more of a say, I can state what things should be done. If I do not like something, you can point it out” Naomi (G3)

However, Gladis (G2) was not happy about using only private services as their available funds were “*not a bottomless pit*”, regardless of her child’s insurance assistance. While some parents like Newton (G3), saw their private physiotherapy service as an “*imposed*” financial burden since Neville was emotionally distressed during hospital visits. Nancy (G3) felt they had “*no other choice*”, as public physiotherapy services do not perform home-visits.

A few parents pointed out that their finances were too limited to access private services, including non-governmental multidisciplinary organisations.

*“M - Three thousand pounds a year for our family are too much...the NGOs asked us a great deal of money. So that is out of the question...to use a private pool it’s 80Euros a month...it’s too much
F – I know he needs it but with my pay alone we cannot afford it” Emily and Edward (G1)*

This further reflected Timothy’s (G4) attitude towards using finances to achieve one’s needs as “*with money you can build a road in the middle of the sea*”. However, few others like John’s parents (G2) felt constant guilt feelings for not using private services as they preferred saving their child’s disability pension in order to utilise private services for him in the future, such as employment training. They felt equipped enough to cater for their child’s needs via public services only and home stimulation by the mother.

Some parents reported that their daily parking fees during their child’s neonatal hospitalisation at the NPICU ward, for an average of 4 months, created another financial stress. Parents commented that it was necessary to be with their new baby who was in a life-threatening situation. This could indicate strong parental bonding.

*“M –that (parking) greatly affected us...7 weeks it’s not a short period, and you spend every day there you have to use the parking...
F – at times...it was about 10 Euros every day, only for the parking” Carla and Carlos (G1) (emphasised)*

5.8.1.3 Referral to services sub-theme

Referral by the child's paediatrician or medical doctor is necessary to access certain health services for parents to acquire professional guidance, such as physiotherapy and occupational therapy services or other specialised medical, neurological and MRI amongst others. Speech therapy services are amongst the few that work on an open-referral system; yet none of the participants showed this knowledge further highlighting limited service awareness (as in section 5.8.1.1).

Some parents felt annoyed for “*going the extra mile*” (Joanne, G2) due to insisting on a referral to certain public services from their paediatrician, rather than it being an automatic procedure. This was interpreted as lack of the professional's ‘diligence’ by these parents since they felt lack of “*mental energy*” (Igor) to explore and learn about other options at the time when needed.

*“M –we had to be the ones to suggest it! (physiotherapy referral)
F –at hospital...they (outpatients doctors) won't tell you look it's now time to start the physio...and if we were not the ones to insist about it, it wouldn't have happened...I had to insist and ask to send me for physio because we asked this person about another three times” Irene and Igor (G2)*

Some parents felt the need to ‘shop-around’ in order to obtain their required referral, either from the public or private services. Parents believed they needed a referral out of intuition or acquired information. For example, Lavender (G3) felt “*lucky*” that Louis was referred soon after neonatal hospitalisation discharge as they found his needed the educational support worker at school entry, while this was not the case for those who were not referred. Indeed, some parents felt their child missed out on certain services as they were not referred earlier in the child's life by professionals at the time.

*“M –I know that my child was very short sighted...we were never approached...the school headmistress, told me all the information...then we needed to access all the services...we had to go to a private psychologist cause the waiting list of the public services was huge and my child would have lost a year...As soon as we went to the headmistress...we started a rat-race...the headmistress referred us...we discovered that it was a whole process
F – a very very large and huge process (both tensely smiled)” Paola and Paul (G4)*

Referral is a necessary tool to gain access for services abroad that are not delivered in Malta. Consequently, they would be eligible for funding assistance from charities. For example, Gladis (G2) felt frustrated that professionals viewed her as financially stable enough to provide for her child's needs via private services in or outside Malta.

*“I owe 2 or 3 doctors, I can count them on one hand, my children’s lives...I’ll be forever grateful. But then, understand your limitations as well, if you don’t understand it, then refer me, refer me and allow me to go to doctors abroad who see dozens of these cases in 1 week and not who happen to see 2 or 3 in 5 years. Give my son the best, he **DESERVES** the best” Gladis (G2) [emphasised] [SHOUTED]*

Lack of referral was also experienced by other parents whose specialists refused a referral for certain tests for their child. Some parents seemed to see a referral to other services or tests as a source of hope to help their child’s development.

“M – that they allow space for referral so that you can always get diverse help...as parents we won’t know...it’s already a difficult situation for us and when you see professionals who are trying to help you and who takes your situation seriously is a great relief for us.

F – these professional people should not feel...big-heads, and they’d feel they are the last stage...there were certain traumas that we had to go to private services because of this issue...these professionals should ask themselves ‘can I refer this child somewhere for his benefit?’ If they ask themselves this question before cutting a line, I think they would find an answer” Rose and Ronnie (G4)

In summary, accessibility for parents was understood to be directly related to the family’s resources, to navigate effectively both private and public services. The parents saw this process as essential to support their child’s needs. Accessibility to services was also based on the parents’ awareness of their child’s immediate needs or awareness of services. Professionals also played a vital role in referring these parents to services; given it was a necessary process to access services in Malta. Parents seemed to view referral to other services or professionals as a sign of professionalism, the key to access services and funding as well as hope for potentially a better future for their child.

5.8.2 Suitability theme

Paediatric services such as those offered in schools and health sectors may not always be perceived, by the parents, as actually catering for their child’s specific needs. Available services may prove to be difficult for parents to use them due to their inflexible schedule and problems in service execution/delivery which may deprive them of being able to provide for their child’s needs.

5.8.2.1 Child’s benefit sub-theme

The in-patient hospital services were praised and appreciated by parents. Parents greatly appreciated that the hospital services were ‘free’ for Maltese citizens. Indeed, they saw

it as a source of financial assistance that was supporting their family from further expenditure during times of emotional ordeal, when they reflected how in other countries parents have to pay for their hospital services, such as in the USA. However, long waits (months) to receive an outpatients or screening appointment contributed to dissatisfaction with services, since they felt their child was missing out of his/her needed support. The crowded outpatient waiting room was also considered to be detrimental to their child's health.

“as we were going in the room where the professor was, there was a woman, and she coughed...the professor told me that he's doing fine and he's better. Two days later he started coughing, and three days later he was going to die. Because of that woman's cough, I am sure, cause I did not have a cough” Pearl (G4)

Similarly, Olivia's parents (G3) felt it was a risk for the infants' health given that she was more vulnerable to illnesses than other people, including elderly who also *“go to hospital because they are feeling unwell”* and wait *“half a day in the same room”* (Oliver, G3).

Unlike the NPICU ward, which was situated in the new hospital building, the Child Development Assessment Unit (CDAU) remained in the old hospital building. This was interpreted by few parents as giving less importance to paediatric services and its environment was perceived as one that *“makes disability more bold”* (Naomi, G3); an observation that took place when the child was very young, possibly these may have been more sensitive at the time of this experience. While, few others expressed gratitude for the therapists' guidance as these felt reassured that the therapists' advice was backed by research, unlike some non-governmental organisation services that were performed by volunteers.

“I had a concern at first, whether we should start services of an NGO, are they specialised? Are they qualified?...they (NGO) send us people at home, and these are volunteers, there is a possibility that they won't even be qualified...that's not acceptable for me, I expect services from qualified and updated people. We have this brilliant public service!” Joanne (G2)

John's parents felt that the projected image of the non-governmental organisations seemed to exploit parents during their weakest emotional period, soon after their news-giving shock. However, this opinion was not shared by non-government service users, like Odette and Naomi (G3), regardless of their full weekly schedule.

The lack of frequent therapeutic appointments by the public paediatric services was noted by a number of parents, across groups. It seemed that dissatisfaction with

physiotherapy and occupational therapy (OT) support quality was attributed to the low frequency of sessions, by some parents. Indeed, the low frequency of professional sessions in the public sector was interpreted as low man-power of the respective professionals, leaving parents lost.

“it’s has been ages since he started attending there (public services), since he had a few months...the physio and OT are really really bad...they see you when they feel like it, let’s say it like that. Physio she sees him once every six months.”
Thelma (G4)

The professionals’ transfer routine was interpreted as reducing opportunities to create adequate child-professional and parent-professional rapport. It seemed to create a vicious cycle where the child’s learning was seen as ‘at risk’ due to time wasted in rebuilding rapport with each new professional and readjusting the intervention programme.

“F - there are physiotherapists who change very frequently, a great many of them are student workers...I did a whole month with one and then the month afterwards they tell you it is going to change...a drawback for the child...they told us there are only three (fixed physiotherapists)...So you cannot stick with one” Igor (G2)

This was not welcomed by parents as they felt half of each session was being wasted re-explaining previous goals and intervention. Parents from group one did not seem to express similar interpretations, possibly due to their limited service-use.

Some parents also expressed other aspects of dissatisfaction with the quality of services they were offered, such as flexibility of the professionals, logistical errors such as over-booking mistakes, lack of available services and the communication attitudes of the professional.

“I remember we had quite a number of cases where...somebody else comes in because of overbooking...they separate the room by a curtain divider...How can you feel comfortable to discuss...what your son has been doing...It’s everybody’s right to have a certain degree of privacy” Sergio (G4)

In addition some parents noted that although parents pay for private services especially with non-governmental organisations, they still did not get a tailor-made service according to their child’s individual needs, as publicised.

“the services is not tailor-made how they picture it, for the individual, it is just a service that is generalised for everyone...and they feel that they are providing the best service...that is how they portray it” Naomi (G3)

Parents of children who manifested physical difficulties, felt lack of services in both private and public sector, particularly regarding required physical independence

equipment, such as specialised shoes and KAFOs (knee-ankle-foot-orthotics). These parents highlighted the lack of frequent measurements and the lack of production of KAFOs or specialised shoes in Malta; all of which parents felt were damaging to their child's development.

"look his shoes are too tight now. He (Tom) has to wait six months to be able to get another one...I am forced to depend on them...It's already two months since I have ordered them for him from hospital...another month and they send for him...and see if they fit...he is growing fast...how am I going to tell him 'you cannot walk anymore Tom because you do not have the callipers'" Tabitha (G4)

Tabitha felt torn between gratitude for such a service and anger at the lack of frequency this service to update Tom's equipment as frequently as required by the child's natural growth spurts. The lack of this professional expertise in Malta was seen as a barrier for these children's physical independence that could also hinder the progress and be a cause of distress for the child.

5.8.2.2 Effects on parents sub-theme

A consensus among parents indicated that public services were inflexible and focused solely on the physical health of the patients (adult or child). Parents felt their needs, as carers of dependent patients (their children), were not taken into consideration. They also had to modify their work-life balance and daily schedules around the public fixed service system and interpreted it as a hindrance rather than a facilitative process to attain the required child's service needs.

During the postnatal period some mothers were hospitalised near other mothers who were passing through 'typical postnatal period'. This situation resulted in an exacerbation of their emotional distress, a constant reminder of what their experience should have been. They also felt unable to share feelings with the neighbouring mothers. Most mothers suggested that parents going through similar experiences should be placed together in the ward if there are no available single bedrooms in order to provide emotional support to each other through sharing their experiences.

"I didn't have my baby with me, so why do they place you in the same room with others who have babies? That really hurt me...at that time you would have just had that experience...You have nothing. It makes your experience feels even worse" Nancy (G3)

Only the few felt "lucky" (Helen, G2) as they were placed in a single room. They were aware that this was based on availability. Some mothers like Joanne (G2) Odette (G3)

and Thelma (G4) assumed that it would be the case since their child was born with congenital difficulties and were diagnosed at birth.

Moreover, a few mothers reported feeling emotional pain each time they saw other mothers' happiness whilst being discharged from hospital. This too was reported as a structural ward-organisation issue, which showed insensitivity towards these mothers' emotions.

"I think that it is a massive issue...you have to wait in the common waiting area and seeing parents going out with their babies for home...Your son is dying and you are seeing another going out...you are all the time facing these things for 4 months and your son is dying and most probably he will not go out of that hospital alive, it's not a joke" Daniela (G1)

Some parents felt distressed that they had to turn to private services as paediatric public hospital services function only during morning and early afternoon hours. Morning appointments could not be used by working parents; this could have further pushed parents towards using private services more. This finding may also be linked with the accessibility theme (5.8.1). Parents understood that their fixed working hours and financial needs could not to be blamed on the public sector yet they felt it was like 'a blade cutting from both ends'.

"I cannot just not go to work, at the same time I want what is important for him...so I feel I have to get somebody so that I will make sure that he does not miss the session...these sessions that are very important for him...First and foremost his health is the most important. Maybe there would be more appointment times available so that, maybe I can attend them more" Daniela (G1)

This also applied to parents' perceptions about hospital pharmaceutical services that had limited opening times (mornings only) for controlled medicine. Parents, who work, have only one car for the whole family or who do not have extend family members to pick up the needed-medicine, felt it was difficult to adhere to these times. This further added distress to parents' already tight schedules to make ends meet.

"well you got the 'pharmacy of your choice' scheme...I had to try and get some medication because we forgot something...we were on the south side of the island...I was even prepared to pay for it...I was told by 2 different pharmacists that the whole scheme hasn't come to the south end of the island yet...Again more red tape, more bureaucracy more frustration and stress" Sergio (G4)

In summary, services were not considered as supportive to assist the affected child's needs in conjunction with their parents' needs. They were aware of the importance of paediatric services for their child's development and yet they could not make full use of such services due to their family and employment commitments.

5.9 Experiential challenges

A number of experiential differences were observed among the participants across the four groups, table 5.8. Acceptance seemed to be an individual journey that was not related to their child's age but to the parents' attitudes and un/met needs, while, their worldview interpretations depended on their experiences related to the child's age. As the child was discharged from hospital parents seemed to face a number of challenges related to the hospital-home transition. When the child was about 2 years of age developmental expectations raised a number of concerns. The families whose child was 3;6 years of age experienced schooling influences on their child's development and daily lives. Parents of 5 year old children seemed to have assumed an expert role, and showed a style of maturity about their personal and social experiences that was not seen in the other groups. Interestingly, when interviewed, almost all parents, of each age-group reported that they "*now feel settled*", thus reflecting step-wise developmental challenges as the child grew. Overall, parents' experiential changes were observed in a cumulative perspective; the experiences reported by parents whose children were aged 6 months were more limited than those by parents whose children were 5 years of age.

Table 5.8 Experiential challenges themes

| Thematic Statement | Superordinate theme | Theme | Sub-theme |
|------------------------------------------------------------------------------------------------------------------------------------|-------------------------|--------------------------|---------------------------|
| Experiential changes and challenges are based on parents' experiences accordingly to child's age and individual acceptance journey | Experiential Challenges | Acceptance Journey | The 'healing' process |
| | | | Acceptance as a threshold |
| | | Developmental challenges | Spiritual beliefs |
| | | | Hospital-home transition |
| | | | Development concerns |
| | | | Schooling challenges |
| | | The mature expert | |

5.9.1 Acceptance journey theme

Parents' emotional journey towards acceptance of their new life-world seemed to progress based on an individual basis. Acceptance was also interpreted as being a 'threshold' perspective; parents had to take courage to move forward, so as they could assist their child. The parents' spiritual beliefs seem to contribute, on an individual basis, towards their adaptation and acceptance process.

5.9.1.1 The 'healing' process sub-theme

Apart from experiencing shock at having an unexpected birth event, they felt fearful for the child's survival, the potential consequences for the child's future development and quality of life. Ruminations in the form of self-questioning first reactions and reflections mixed with concerns towards the child's future and self-doubt acted as negative reminders of the fragility of life; these were reported by almost all participants. This hindered parents from advancing towards acceptance of their current situation directing them towards a negative emotional cycle; with feelings of exhaustion when lost in their thoughts, which further worsened their state of mind. Through ruminating they seemed to re-live their past experiences and these seemed to peak when parents found themselves alone, particularly during the first months of their child's life.

"I don't think my mind is 100% settled...if you are alone you go back where you were...it's useless that I keep on saying 'ow because I was unlucky, and why did it happen to me and why me...and why everything to me'" Daniela (G1)

Nonetheless, a majority of parents felt the need to constantly "*fight off*" (Timothy, G4) ruminative thoughts in order to move on and come out of this negative cycle: "*fight with life*" (Newton, G3). This attitude seemed to be a self-help mechanism to help them move-on in their acceptance journey.

Some mothers noted that their constant ruminations about the child, negatively influenced their relationship as a couple in the past, acting as a cause of conflict.

"you are morally so so down...Why me? And why my child?...so I used to leave this influence on him (spouse) that if he is going to work he is leaving with sadness from here...you end up, looking towards each other...he ends up being blamed for everything...You'd feel even more pressured and tired because you have been thinking about it so much." Odette (G3)

Mothers also seemed to express greater rumination than fathers, maybe because they stayed for longer daily hours in hospital and were also alone at home with the baby more than fathers, who were the sole bread-winners at the time. Ruminations also seemed to change over time for almost all parents who reported them. Steve's parents seemed to be the only couple who continued ruminating when their child was 5 years old, possibly reflecting their sustained anger towards society for the lack of perceived service-support.

Time was considered by thirty-one parents (83.8%) to be a healer that helped them to adapt in everyday life: "*now I'm used to it, I feel settled*" (Carol, G1); "*it's a thing of the past now*" (Ariel, G1). Yet, this seemed to be a unique process for each parent.

“if you came to talk to me last year, it would have been a different situation...it’s until you settle what you should do with him...I cannot say I am feeling depressed ...like I was at that time. Now, it’s literally normal...cause now we got used to it”
Joanne (G2)

While some parents reflected that although time helped them to accept their situation, they were still in ‘healing’ due to their constant developmental concerns.

“this issue that she does not talk. I still feel hurt as I know that I am taking her for therapy...seeing them (peers) talk, that puts me backwards...you always continue carrying them to heal...but you start accepting it totally” Odette (G3)

Moreover, some parents indicated that they did not see the disability anymore, as they focus on the child.

“before we used to mention it...everyday...nowadays we rarely talk about it...when I look at my son I do not see the condition, when he was a baby I used to look at him and only see the condition” Naomi (G3)

Similarly, some parents indicated that their child was a source of joy in their life and that these reported a “difficulty” (Ivan, G2) imagining their child as a typical child.

“Her joyous character is amazing...I wouldn’t change her for any other, should I be given the opportunity” Maria (G3).

Routine making and maintaining was considered as critical to cope, by parents, with their schedules around their child’s therapeutic appointments. Time-tabling was not only considered as important across groups but also used as a source of adaptation process. It seemed to inspire a concept of ‘normalcy’ which was individually defined. Following one’s own time-table as a routine helped them to perceive that they led a ‘normal’ life regardless of how much appointments or commitments were managed by parents. This also helped them feel secure in terms of knowing what the next step is.

“once at home then you start getting used to everything and sort of everything becomes normal...now we feel back to normal...we feel as if we have settled in our daily routine” Freddie (G2)

“we are completely back to normal now...we follow our daily routine” Simon (G4)

All parents across groups referred to their daily routine as “normal” but all their routines were unique and varied pertaining to their life circumstances and their children’s needs.

A number of parents, whose child had significant difficulties, interpreted seeing other typical children of the same age as their ‘at risk’ child, as heart breaking. These perceptions also contributed to their social isolation due to avoidance of such instances that brought about emotional pain.

“we cannot go to the playground...Even though I have two other children, but I feel it, I feel it, both me and my wife...I feel a heartache going to the playground.”
Timothy (G2)

“his (Glen) passion was skiing, he won't go on mountains ever again...cause he knows that it's not the kind of holiday that Gabriel can enjoy. He's very hurt...It upsets him to see children of Gabriel's age running around...It hurts me as well, but, I take pleasure out of the other achievements Gabriel made.” Gladis (G2)

Emotional support is not readily-available during news-breaking but at times staff offered parents contact with a bereavement midwife or brought an outside-hospital counsellor during the child's hospitalisation period. When these professionals were provided to a few parents, some considered it to be helpful but in a few cases this was interpreted as even more distressing, due to lack of perceived sensitivity towards parents' emotions.

“this person (bereavement midwife) came and asked us how we were...I told her how do you expect us to be one (baby) is dead and the other is in and out...I told her we are going to do his funeral and bury him...She told us no don't bury him for now...so that when the other one dies you can bury them together...I had another shock 'I told them this one is going to die?'...The pain was unbearable and she made it worse.” Isabelle (G2)

Some parents recounted a refusal of professional emotional support during their child's hospitalisation due to their strong focus on the child's recovery or due to already perceiving emotional support from extended family.

“at the time (during hospitalisation) I did not have the mind to talk to the bereavement midwife, I was too focused on her (Martha)...but at home I felt surrounded with my family's help” Marthese (G3)

Upon finding themselves alone at home after hospital discharge the majority of parents felt most in need of support since the child had survived the ordeal and they were dealing with their emotional baggage.

Self-help mechanisms such as resilience skills and a positive world-view attitude were observed to help parents in reducing ruminations on their child's condition. For example, Naomi (G3) reported her positive outlook when interacting with other people:

“when I meet with someone I never try to raise the situation...if I meet with someone and the topic turned on it (child's condition), well and good. If not I will not mention it myself...I won't say 'because my son has a condition'. No I'll say 'Noel has XXX and he is doing well.'...If I am positive they are going to be positive with me, that plays a very important role.”

Her decision to transmit a positive attitude was interpreted as not only helping her in social situations, but may have also acted as a positive reinforcement for her personal outlook to be a more positive and determined person.

5.9.1.2 Acceptance as a threshold sub-theme

Acceptance was also viewed as a compulsory step or a state to help oneself face the situation while also assisting their child. Some parents depicted such an achievement as a compulsory process that parents “*need*” to experience in order to emotionally “*move on*” as well as for the benefit of the child’s development:

“you need to accept the situation to be able to move on” Thornton (G4).

Acceptance, for some parents, was interpreted as a goal that they should ‘achieve’ as soon as possible after news-giving in order to stimulate their child as early as possible. Ronald’s parents (G4) saw their acceptance as a decision-point, set towards a more positive lifeworld for the benefit of their child.

“It’s important that emotionally you come to the point that you accept the situation, you have to battle with life on a daily basis...I felt the need to for example stop being sensitive for certain things...that is why you have to strengthen your character so as the things in your environment won’t break you down...and I am happy as I am...if you do not accept the situation you’d suffer including the child and your husband” Rose (G4)

Similarly, Noel’s parents (G3) perceived acceptance as the end of the “*negative emotional era*”, in order to focus on helping the child in his development acquisition. Oliver (G3) also noted that when they, as parents, accepted their situation they worked more constructively with their child and with each family member.

“you have to work for it (acceptance)...you have to see how to move on with the situation...once you accept the situation, you are going to work in a positive way...then you’d give yourself targets, so that things will start improving. But that is very important...as soon as you accept the situation you feel lighter, you start working for it (child’s development) and you change your way of life” Thornton (G4)

These parents implied that acceptance helps not only oneself to feel better, but is interpreted in terms of positivity achievement.

Some parents noted that they felt it was a “*must*” (Harrison, Ian [G2], Pablo and Theo [G4]) to acquire their acceptance goal in their daily routine. Parents interpreted their acceptance as a “*compulsory*” process, without having a choice, in order to move on for the benefit of their child. Few fathers specified that being involved during the initial

therapeutic sessions helped them overcome their emotional upheaval and negative thoughts at the time.

“at first yes it is difficult, you’d think that everything stopped...The quicker you accept the situation the quicker you will start working with your child...when you seek help and start finding the help you need, you will start realising that it’s not your fault...The more you start working with your child and you gain knowledge...you start feeling relieved...the very first day that her private tutor came and started doing some activities and she starts explaining you start feeling better.” Oliver (G3)

A few other parents noted that becoming skilled to help their child also helped them to accept their situation; a positive cycle to support their child to lead as ‘normal’ a life as much as possible.

5.9.1.3 Spiritual beliefs sub-theme

For the majority of parents, spiritual beliefs played a significant role in their acceptance journey. It acted as a source of emotional support both for the individual parents and for the whole family. The importance each parent gave to his/her religious beliefs was quite individual. Few parents, such as Kelly’s (G3), did not consider it as important in their lifeworld but most parents talked spontaneously about it during the interview. Meanwhile, others drew positivity and encouragement from their spiritual beliefs in their daily lives.

“I saw that God helped a great deal as well so that we could see the positive side of it” Rose (G4)

“my philosophy is that it is a ‘nature’ aspect...my son had to be born with that condition, as a consequence of nature, as it has its own defects. Now in God I find the strength to cope with the situation but not that God sent him like that...Sort of everyone finds his way how to heal...this way is helpful to me...I found out that through this way of thinking I healed and I still maintain a good relationship with God.” Naomi (G3)

The awareness that significant others were dedicating their prayers to the parents’ needs transmitted a sense of supportiveness: *“we had a lot of people who supported us...prayed for us”* (Farah, G2). Some parents felt emotional support through their spiritual leader (clergy) who was their friend: such as Ronald’s and Sarah’s parents (G4) felt that their clergy friends helped them strengthen their couple’s relationship during times of ordeal.

Some others used to pray as individuals and as a whole family to assist themselves and their older children’s acceptance, respectively, particularly during the child’s neonatal

hospitalisation. This helped parents to emotionally cope and maintain the older children's life's routine.

"If we didn't have God helping us...we would have driven the other three (children) crazy, because we used to return here, remain normal, calm...we didn't tell them the seriousness of her situation in hospital...we used to tell them 'pray because we do not know if we are going to keep Bernice here, because if Jesus tells us she is suffering, he will have to take her back so that she will not suffer'" Barbara (G2)

Some parents felt grateful to God for the child's survival and development. These parents used their belief system to rationalise their child's survival: "God-sent life's mission" (Igor, G2), or 'pre-destined' life-route "you have to accept the situation from God...it had to happen" (Newton, G3). This may also be the case as they, as parents, felt powerless about their life's circumstances. Indeed, most parents labelled their child's survival as a miracle.

"The day arrived to be taken out in a cot, and he got the infection...for hours, he went with God...They got him back...he did about 3 weeks playing with death...Nothing was working...When the situation was at an edge, it was at the very end, something always happened to twist the story round...it happened about 3 times...I can say it's a miracle...Even the doctors said it...it's as if God wanted to show me that he is over and above everything" Daniela (G1) [emphasised]

On the other hand, a few parents felt that they turned 'against God' when the situation took a negative turn.

"During that time (child's hospitalisation) I felt against God...why me?...but then it's like you need His help so prayers and so on, but at the time I felt very bad" Marthese (G3)

Gladis (G2) and Sergio (G4) reported that they rejected God. This could also reflect their angry state of mind towards the lack of service support to help their child's development.

"I lost a lot of spirituality...There was a time and to a certain degree I still feel it, that I don't even wanna see a priest...I couldn't and I still can't believe...a merciful God would allow a child to be born like this, than they would counter 'ow no but that's nature' ...On the one hand you're saying we are supposed to believe in a God that creates everything so when things are good...woohoo team God. When then something goes wrong like this, we put it on nature and science. That's a big contradiction in my book...I can't believe in a God who allows something like this to happen." Sergio (G4)

In summary, the acceptance journey seemed to project an individual journey observed by all the interviewed parents. This was interpreted as a healing process, a target to be achieved by both parents' and to be able to assist their child's development. Most parents indicated that their spiritual beliefs played a crucial role in their acceptance

journey; as a source of emotional support and strength. A few parents conveyed persistent anger towards prior religious beliefs.

5.9.2 Developmental challenges theme

Parents' experiences and perceptions seemed to change as the child grew. Parents of children who were 5 years of age had more experiences when compared with those whose child is 6 months of age. This cumulative effect of experiences also created hindsight re-interpretations of what parents considered as essential periods while raising their child born with risks. Interestingly at every age-group parents seemed to be passing through a period of settlement. It felt as if parents passed through a spurt of change or growth and they re-settled at each explored child's age.

5.9.2.1 Hospital-home transition sub-theme

Hospital discharge

Children born very preterm, with VLBW and/or complex health complications (N=31) were hospitalised due to life-threatening health state for a period ranging from 1 to 9 months from birth (4 months average). Parents appeared to welcome their child's discharge news as if their child was born on the day of discharge; the birth of their child into their community, they could take the child back home with them and hence felt a sense of family completeness. The majority of parents reported feeling happiness of having their baby at home.

“when we went home with the baby, it was the XX of XX, it was a Friday. I felt as if, as if he was born that day, that happiness that a mother feels when she comes out of the hospital...and she takes her baby with her and felt proud of it” Hannah (G2)

Yet, for the majority of parents hospital discharge brought about fears of re-hospitalising their child and “going back in there” (Daniela [G1], Selene [G4]). Professionals however did anticipate such fears and offered the ‘rooming-in’ training where parents were invited to sleep over at the NPICU.

Prior to discharge, parents were given information, training and advice about potential cot death and some parents were also trained in CPR. This brought about another wave of contradictory feelings, where parents felt grateful for such training, whilst reported feeling shocked about the continued vulnerability of their child outside hospital.

"I felt VERY frightened...because over there (hospital)...they taught us the course of CPR...you start saying to yourself, 'maaa what will happen if this happens to our child when I am at home alone?'...carrying out CPR a doll, is one thing, and doing it with some force on your own child is another...I told him (spouse)...I am not going to spend the first few days at home alone, because if anything happens to her, maa!...you panic." Ariel (G1)

Some, more than others, felt lost upon discharge without guidance and not knowing where to go for help regardless of being monitored by outpatient paediatric follow-up appointments. For example, Gladis (G2) interpreted discharge as an abandonment of medical staff: *"they wave you off with a booklet"*. Some other parents felt unprepared at the discharge to care for their child on their own expressing fears of the unknown leading to the creation of insecurities how to help their child's development. This seemed to have affected their self-confidence until they felt fully settled at home in their daily routine.

"the first year is the worst, as during the first year everything is new...until you do the first step. Everything, sort of insecurity or fear of unknown, that is part of it" Odette (G3)

Technology/Equipment dependency

During their child's hospitalisation parents, especially mothers, became dependent on the monitors and immediate professionals' assistance in emergencies. They were afraid of being alone at home, stripped of the safety of having professional support within easy reach.

"when you come home all of a sudden you realise that you do not have that warm blanket of the professionals' presence and all those monitors anymore" Garry (G2)

'when you come here you're alone, over there you can quickly go out of the room and call someone for help' Drover (G1)

A community midwife visits all mothers for three times after discharge. However, these mothers, in particular, did not feel this was enough, given their child's added health risks and insecurities.

Some felt the shock of being 'thrown into the lion's den' until the parents felt fully settled at home. Rapidly moving out of hospital's 'safe' environment, together with the warnings of cot-death risks, led to a dependency on technology. The apnoea mattress monitor acted as a reassurance to parents, thanks to a hiring service from a voluntary organisation, which was interpreted as an emotional support by twenty-nine parents. However, some constantly kept checking their child's breathing by waking up at night due to concern that the monitor may not work.

“you feel concerned because of the breathing...during the night you cannot sleep properly, as your mind wakes you and sometimes I touch her to see if she is still breathing...as if your mind takes time to settle.” Ben (G1)

This was commonly reported by both mothers and fathers alike inferring initial distrust towards the hired apnoea mattress-monitor, with excessive tiredness as a consequence. Yet, some parents were justified for not trusting the apnoea mattress-monitor as there were occasions when it would raise false alarms.

“at hospital it (apnoea mattress) never used to ring...here during the first night it was non-stop...I really felt panicky...then I realised that the alarm went off because she moved...it drove us crazy, I really wanted to throw this monitor out of the window” Elisa (G1)

Few others, like Dean’s parents (G1), also placed a micro-camera on the child’s cot in order to feel reassured that the child was breathing. While Sandra’s parents (G4) continued using it as audio-monitor even though the child was 5 years old: *“I do not know why we still keep using it” Sarah (G4).*

Avoiding social contact

Following hospital-discharge some parents reported avoiding social contact as much as possible for the protection of their child’s health. Contradictory feelings were perceived by other parents in varying degrees.

“I became very careful...if I was going to my aunt’s ‘look is everyone well, is anyone sick’, as soon as I hear someone throat clearing, I tell her, ‘sorry I am not coming’ I had to draw a line for his sake” Gaia (G2)

Other parents, like Paola (G4) experienced *“panic-attacks”* and *“post-natal blues”* as she felt too lonely at home and *“miserable”* due to *“loss of new friends from ward staff”*. Parents felt that this was brought about by the imposed social isolation to protect their baby’s health. In contrast, some parents noted that contact with extended family members created added distress due to news-breaking of child’s disability, and re-experiencing negative emotions caused by relatives’ over-reactions: *“they start crying, and I end up crying with them” Joanne (G2).*

Some parents, especially mothers, became fixated on cleanliness during hospital-home transition as they feared their home environment was not as sterile as hospital environment; further intensifying their cleaning routines as they became *“more aware of the dust in the air”* (Ariel, G1) in her house. This further contributed to extreme tiredness together with sleepless nights.

When some parents found themselves caring for a smaller-than-usual child, they felt concerned for the child's health and unprepared: *"I barely wanted to touch her, she was really really small"* (Carla, G1). However these concerns were naturally reduced for most parents once they saw their child significantly grow in size: *"I feel better, because she's gaining weight, even her clothes show"* Camille (G1).

Medicine-giving routine

Upon discharge most parents were given an intensive medicine-giving routine to improve the child's weight, which was indicative for the baby's health. The medicine-giving schedule resulted in initial fears of the unknown and feelings of lack of confidence in administering medicine to 'small' babies. The majority of participants had a prescribed medicine-giving routine; these perceived it as *"out of the ordinary"* (Krista, G3) and an *"extra"* (Raina, G4) aspect to what they considered as the typical baby-care routine. This situation further raised their alert levels and maintained a high level of anxiety.

"when he was discharged he had eleven medicines and I used to give him an injection myself twice a week...I really lost hope when they told me on the day that I was going to leave...I said 'ow my all these!'...there my kitchen corner was covered with medicines." Hannah (G2)

Simultaneously, this child-care aspect associated with hospital-discharge could have also acted as a motivator for settling at home.

"at first...it was difficult until we got used to the idea of administering all the medications ourselves...But at the same time I felt very confident that I could do it...there was the risk of him getting the MRSA...I couldn't wait to get the go ahead to take him home, so although I was very apprehensive...but at the same time yes I knew that I could do it" Selene (G4) [emphasised]

The child's early intensive care at home was also interpreted as restricting the freedom of most parents to go out or visit places.

"when he (Preston) came home he had the oxygen tank, so we couldn't go out...later on this voluntary organisation bought two small cylinders and gave me one, as the one that I had was massive and we couldn't go out" Pearl (G4)

The child's medicine-giving routine also provided a constant daily home-care schedule where parents felt satisfied at following it well. Parents were advised not to maintain the rigorous hospital-care and note-taking routine at home, so as not to intensify the already-filled child-care schedule for the parents. However, four mothers maintained this note-taking routine on their initiative. These parents offered a health monitoring system for medical professionals to identify potential complications in future care.

“when he (Louis) was at hospital...As we go along we write it down. There were cases when I realised that there was a mistake...he was just given an antibiotic and someone did not write it down in his chart and after two hours, someone else came to give him another intravenous shot...I want to know, so as to avoid mistakes like that one, it would be better for Louis” Lewis (G3)

After completion of the interview Garry (G2) confided his dreams of publishing his diaries as a source of support to other parents who pass through similar experiences.

5.9.2.2 Development concerns sub-theme

Parents were highly concerned if their child failed to achieve the expected major milestones by 2 years of age. These included independent walking, toilet training and expressive communication, in the eyes of parents. Some parents felt that when the 2nd year has passed without manifesting developmental delays, they felt relieved that all was well.

“during the first year and a half I used to feel scared that in the future there’s gonna be something. I felt it because you feel worried until he actually grows. But now...he is 3 years of age...God bless he seems alright...I feel satisfied now.” Keith (G3)

Some parents of children who were born with diagnosed or evident difficulties (such as congenital anomalies) did not manifest such expectations but they still felt concerned on the child’s future developmental prognosis.

“we are not too exigent...if there is a milestone and he achieved it...we’re happy with it. But we are not determined that if he is meant to achieve it in six months, he will achieve it in six months. If he achieved it in one year and six months for us it’s not a problem...I think it may be controlled by their condition.” Joseph (G2)

Although these parents did not feel pressured about their child’s timely development of milestones, they still indicated a strong will to help their child achieve them through daily stimulation. However, other parents felt quite concerned about their child’s general delayed development; in the absence of an official diagnosis at the time of interview.

The perceived ‘delay’ in the above-mentioned milestones did not seem to concern the paediatrician; consequently there was a lack of referral to the respective health or educational services. These parents relied on and were partly reassured by the paediatrician’s calmness in the absence of a diagnosis. Nonetheless, parents maintained a degree of concern regardless the medical professionals’ encouragement.

“his development...seems longer than usual...even regarding his speech, he doesn’t say everything. He doesn’t want to know...even his toilet training but the

professor was happy...there isn't that communication between us (mother and child)...It's not easy to accept it...the professor said that I should be more patient...I have been trying the whole summer (toilet training)" Francesca (G2)

The paediatrician seemed to reassure parents' anxiety that the child was still 'on time' to develop his/her milestones; presumably as a compensation period due to the very-preterm birth of some children. Hence, they might not have considered the child as 'sufficiently' delayed to be referred to other services, suggesting a 'wait-and-see' attitude to these parents.

Some parents' concerns seem to have originated from their comparisons of their 'at risk' child with their older typical siblings or reduced knowledge of typical development milestones. Henry's parents (G2) seemed confident that their child understood "*everything*" based on the child's repetition skills.

"he plays with his sister, he communicates a lot with her...she tells him give me this, give me that, he does everything...so the problem is not in his brain...he understands everything...do you want the bottle? Bottle? You want the bottle? (to child holding bottle, he pointed)...look did you see (to me)" Hannah (G2)

Preparing for School

According to some parents, the child was school-ready when s/he has achieved the needed developmental skills to physically cope independently at school: independent walking, toilet training and socio-communication skills. Failure to achieve these milestones by the child was a cause for parental concern, not only for the child's development but also for future school-achievement. It helped parents to decide if their child should start school by the 3rd year of life or delay it by another year. Parents such as France's, Henry's and George's (G2) preferred to wait for the school initiation period in order to receive guidance from teacher's feedback.

"If he needs help in the future I'll take him, sometimes it passes through my mind if he needs a facilitator, but we'll see the teacher has to guide us" Francesca (G2).

Some felt hopeful that when their child would start school it would eventually transpire that all their concerns were in vain, confirming the paediatrician's predictions. However, some parents reported a shock about their child's delay identification at two years of age; one which acted as an eye opener regarding the child's developmental impairment.

"I felt traumatised...I felt the trauma rather than in the very beginning, I felt it more when he was about 2 years of age and when you start seeing things that should be developing and did not yet occur." Ronnie (G4)

Parents also reflected on school-choice decision making processes; where to send their children to start their educational life. A few parents showed concern regarding child-care centre or school-choice based on satisfying the child's developmental needs such as specialised nursing services and occupational therapy services.

“regarding her school, if we take her in the future, you have at least half-a-day, you have to know that who is caring for her and that at least there are enough personnel specially trained...something serious should be organised in the first place not providing a temporary solution” Igor (G2)

Terrible-tvos or not?

Many parents saw their two year old child's increase in energy as a natural part of development (terrible-tvos). Gaia (G2), amongst others, interpreted her child's short attention as a *“pleasure to tease”*, yet, felt concerned that George does not know yet *“how to play on his own”*. Some other parents felt that since the child went through a neonatal health ordeal, they reported that pity over-rode their will to discipline their child when the need called.

“sometimes when she does something wrong we get angry with her, but then we say ‘ow no poor girl...considering from what she had to go through’...It's not that I let her to whatever she wants” Marthese (G3)

Moreover, few parents in group 3 and 4 interpreted similar behaviours that initiated at around 2 years of their child's age. Kyle's parents (G3) interpreted their child's behaviours as highly stubborn and found themselves controlled by their child's 'teasing' and feared for his safety: such as locking himself in the garage whilst flooding it with water. To a certain degree, they still interpreted their child's limited 'role-play imitative activities' as *“intelligence”* (Riana, G4) and his teasing as *“cunningness”* (Keith, G3).

5.9.2.3 Schooling challenges sub-theme

Pre-school education in Malta starts at 3 years of age in order to prepare the children for formal education. This educational period (3-5 years of age) is not compulsory in Malta, thus not all parents felt the need to send their child to school at 3 years of age. For example Neville's and Logan's parents (G3) decided not to send their children at 3 years to allow more time for development.

During the third year of the child's life some parents experienced a positive change in the child's development and behaviour: *“ever since she started school her behaviour started improving a great deal”* Odette (G3). They attributed school initiation period as the source

of developmental progress observed in their child. Some parents attributed their child's developmental spurt to the sudden exposure to other peers in a playful school environment. For example, Kyle's mother (G3) noted that her child was becoming more expressive. However, Pablo's parents (G4) felt concerned, at the time, about potential bullying from other class peers, due to his non-evident visual impairment.

A few parents felt that since their child suffered from significant health needs their child was advised by the doctor to delay attendance at school. They still accredited school initiation for his learning spurt and their child's intellectual skills.

"he only attended (school) about 3 weeks...He is absorbing whatever we tell him...when he arrives to school he goes directly to get his favourite toys and he knows where are those that he prefers playing with...Here we do not play with him...we do not sit down and play for half an hour with him with cars as he gets fed up easily" Lewis (G3)

Kelly's, Martha's (G3) and Samantha's (G4) parents maintained that their child had developed in a typical manner and did not observe a change in their behaviour following school attendance.

Other parents reported a number of concerns during the first few weeks of the child's schooling: the child's acceptance at school by their peers, the parents' acceptance by other parents and the child's teacher. Besides, some parents felt "*apprehension*" (Selene, G4) and fears of "*letting go*" (Shanaia, G4) of their child when their child started school. Their concerns were perceived to be reduced upon seeing their child returning happily from school. Yet, few parents also felt satisfied in sharing her knowledge when mothers of typical children asked her for developmental advice.

"I felt very sad until she started school. I used to feel concerned on whether she is going to behave, if she was going to be accepted at school?...What will other parents say?...Now I got used to it...the other parents talk to me and ask ME things...a mother asked me about certain developmental milestones and I told her" Odette (G3)

5.9.2.4 The mature expert sub-theme

The attitude of parents as 'experts' about child's development and about services started to emerge among parents of 2 year old 'at risk' children (Gabriel's, Ian's and John's parents, G2) from their early experiences in accessing services. This subtheme seemed to peak in group 4 as they displayed a distinctive attitude towards their past with hindsight re-interpretations and their gained-knowledge of rearing their child with risks. The majority of parents, of 5 year old children, seem to have an expert attitude towards

accessing services to cater for their child's needs. They also actively provided support or sought to provide support to other parents who had similar experiences.

Parents felt they had sufficient experience to be of support to other parents. For example, Tom's father (G4) insisted that professionals should consider his family as a source of emotional support to other families whose child is born in similar circumstances, as he did not find such support when he needed it. It may also reflect a positive attitude of parents 'acceptance' of their life-world.

*"M – I wish I can be of help, not only for him (Tom)
F – I am ready to show him to others...those who are expecting a child and they know that they may have one like him...because I know what it feels like...There should be an association or group...if someone showed us a child with similar disability, we could have never known...I found nothing"* Timothy (G4)

These parents conveyed a wish to be the providers of emotional support to other newly 'experienced' parents in the future since they had found none.

Some parents did not feel influenced by the birth circumstances of their child as they perceived their child was growing in a typical manner. However, Sandra's (G4) parents felt that their experience equipped them with an added skill that could be of support to other parents with similar experience. Preston's mother (G4) also offered support to other parents on a voluntary basis.

"I had a colleague whose baby came early...automatically, I sent her a message and I told her 'listen if you need anything or you need any support just contact me' and in fact she phoned to talk to me and I gave her a book that I bought at the time...the nurses asked me, they said 'listen can we keep your number just in case, if there are parents sort of who need to talk to somebody who's been through, would you be ready? Of course I told them, yes, with all my heart...I think once you've been through it, then you can sort of...help in that way" Sarah (G4)

Some parents perceived their lifeworld in a more positive manner. Thornton (G4) related his positivity with acceptance of their child's difficulties and context. While Ronald's and Preston's parents (G4) felt strengthened as they maintained a positive outlook towards life even though they continue to feel different from 'inexperienced' people. They perceived that they had stronger character and were more "mature" since they lived more difficult experiences, which they assumed to be 'out of the norm' for other persons who had typical children.

"I think that as a mother I needed more strength in my character to be able to move on in this situation and move accordingly to my son's needs...Maybe other parents that do not have children with problems...they didn't feel the need to build up their character as much because everything happened as they planned. But us,

as parents who had these experiences...I had to adapt my character to make it stronger so that the things around me do not break me.” Rose (G4)

In summary, developmental challenges appeared to change as the child grows. Parents’ emotions were predominated by loss and insecurity feelings during the hospital-home transition at the child’s 0;6 years of age. They reported feeling concerned on the child’s development at 2 years of age and school-related issues were expressed when children had 3;6 years of age. Whilst, parents of 5year old children reported feeling more mature and willing to be of help to others who are passing through similar circumstances.

5.10 Conclusion

The parents (fathers and mothers) of 37 children have embarked on a journey that initiated with an atypical birth situation that bestowed an unexpected emotional shock: the birth of their child with biological risks for ID. While all children were born with biological risks, not all manifested difficulties. However the ‘risk’ itself profoundly influenced the participants’ child rearing experiences. Parents shared a number of perceptions stemming from the emotional and sociological circumstances of their experiences. Parents looked upon their experiences as different and life changing where added challenges presented themselves as the child grew. The findings are discussed in light of available literature and theoretical underpinnings in the following chapter.

Chapter 6 Discussion

6.1 Introduction

The current investigation aimed to explore the experiences and perceptions of Maltese parents in raising their children born with a biological risk of ID during the children's first five years of life. This study focused on the perceived physical, emotional, psychosocial and communication needs of these parents in promoting their child's development. Differences and similarities in these parents' experiences were explored when their child was 0;6, 2;0, 3;6 and 5;0 years old. This chapter discusses the results in relation to the above mentioned aim of the study, the theoretical framework and previous research, including methodological strengths and limitations.

6.2 Study contributions overview

Understanding parental experiences can assist professionals in supporting parents in their care-giving responsibilities as the child grows (Dunst 2007). This study was prompted by the concern that there was a research gap regarding the lived experiences and needs of Maltese parents whose child was born with biological risks for ID throughout the first five years of life (see section 1.4). This study's findings confirmed a service void in the Maltese islands and could be used as the foundation stone for family-centred multidisciplinary early intervention services. This study was the first of its kind with the Maltese population and it provides contributions to literature about the experiences of Maltese parents. The study was an opportunity for Maltese parents to voice their stories, which were marked by:

- cultural influences,
- living with risks: family impact and adjustment,
- child age-related parental experiential differences.
- addressing parents' needs

These contributions may have implications for other parents in similar situations and could be of support in their journey. These are discussed in detail in sections 6.3 and 6.4.

Cultural influences

The Maltese culture was a constant presence in the parents' interpretations of their experiences when compared to other countries (Abela et al., 2005). The interconnectedness of family relationships is clear in the data confirming it as a Maltese cultural feature. Grandparents and close family members were reported to be the first support network. For this reason grand-parenting played a critically supportive role during this extra-ordinary life-circumstance that assisted family emotional, practical and financial coping. Grandparents seemed to function as close collaborators in child-rearing for most parents in this study. Such close-knit characteristic may also be the case in similar small-state cultures or some ethnic groups who also manifest close family ties.

In Malta, there is one national hospital with one neonatal and paediatric intensive care unit (NPICU). This appeared to trigger fears among parents about expressing negative feelings so as to protect their child during potential future hospitalisations. Given the high population density (1,261 persons/km², Eurostat, 2009) and 'face-to-face' community characteristics of the Maltese culture, social stigma was perceived to be highly stressful and frequently reported by the parents as a primary cause for reported social isolation. The combination of these factors is considered to be unique to this study.

Religiosity and spirituality is strongly intertwined with the Maltese culture. This was reflected in the findings of this study. Most parents expressed the use of their religiosity or spirituality as part of their process of emotional acceptance of their new lifestyle. Some parents identified similar shared-beliefs as part of emotional support from professionals.

Living with risks: Family impact and adjustment

Following the birth of their child, parents seemed to have entered the world of living with risks. A long-lasting impact was reported by most Maltese parents where they felt constantly apprehensive as they were continuously treading on unfamiliar ground. Rearing a child born with biological risks for ID was interpreted as atypical, with the unexpected shock of being thrown in a different world from what was expected and of being unprepared for the subsequent circumstances. Golish and Powell (2003) also

reported similar shock due to the unexpected turnout of events regardless of prior preparation, among American parents. Yet, the Maltese parents' shock reactions from birth throughout the first five years of the child's life seem unique (see section 6.3.2). The Maltese parents highlighted the need for parent-to-parent support, which does not exist as an organised service on the archipelago. Prior studies have highlighted the perceived usefulness of parent-to-parent support (e.g. Ainbinder et al., 1998; Kerr and McIntosh, 2000; Farmer et al., 2004). This study shows evidence that Maltese parents need such a service from the birth of their affected child or soon after receiving the negative news, preferably throughout the child's first five years of life or more.

Parents constantly reported the need to accept and adjust to their child's circumstances and 'normalise' their daily lives, by using various coping mechanisms. The majority of two-parent couples felt they had complementary coping styles which assisted their daily family management. This finding may be explained by the previously-reported high marital satisfaction level of the Maltese population (Abela et al., 2005). It may suggest the strength and endurance of the Maltese marriage in extraordinary circumstances such as rearing an 'at risk' child. Furthermore, Maltese couples expressed the advantage of having a spouse/partner by their side; a finding that may point towards the need for more support to single-parent families. Parents expressed both positive than negative changes in their lives. The positive transformations were perceived to mitigate but not eliminate the negative aspects. Although some of these findings were reported in prior research, these are critical for social policy, education and practice given that this was the first Maltese study of its kind.

Child age-related parental experiential differences

Not all research performed with similar populations identified child's age-related differences in parents' experiences and perceptions. One of the contributions of this study focused on the necessity for Maltese professionals to regularly re-evaluate parents' needs as the child grows, in order to provide holistic developmental care for the benefit of the child and the family as a whole. This study agreed with prior international literature showing that the needs of parents change as the child grows. This study focused on changes of Maltese parents from birth to five years of their child's age covering the following phases: hospital-home transition, development concerns, schooling challenges and mature expert. This study highlighted that professionals have a crucial role in assisting Maltese parents' changing needs, via periodical re-evaluation.

Addressing parents' needs

Findings from the current study highlighted the met and unmet needs of Maltese parents. Maltese parents felt that their needs were given less importance even though they represented their child's best interests. This calls for the incorporation of the parents' needs in the child-focused Maltese services and initiating a shift towards more family-centred principles in service delivery. In the subsequent chapter, I propose a number of recommendations about how Maltese policymakers may implement changes to the current services, so as to incorporate the needs of Maltese parents. Maltese parents' expressed needs should be addressed accordingly in early intervention services, as well as through health and education support services provided hand-in-hand with paediatric services. Although these findings may not, in their entirety, be applicable to other countries, this study may still act as a catalyst for similar studies in other societies, in order to explore parents' voices.

6.3 Parents' experiences

A number of similar experiences were reported by Maltese parents whilst raising their child born with ID risks, from birth during the first five years of life. Cultural influences were observed in all life-experiences, including family closeness, problem-solving methods, social stigma and frustration about the lack of choice of services offered. The impact seemed to be experienced by the whole family: one which brought about a number of transformations to their lives. Parents emphasised the importance of acceptance and adjustment in order to '*normalise*' their lives as much as possible. Socio-cultural, family impact and adjustment, together with age-related experiential differences, are discussed below.

6.3.1 Cultural influences

This study indicated that participants felt the need to suppress negative outbursts of emotion arising from their desire to protect their child's future receipt of hospital services. Following Sultana and Baldacchino's (1994) *savoir-faire* claims, suppression of angry outbursts may be a way to deal with conflict and avoid repercussions for their child's potential future needs, given that Malta has only one national hospital. Similar interpretations have not been observed in prior literature performed in other countries.

Some parents reported the need to be advocates for their child's needs. This finding is similar to Goldbart and Marshall's (2004, p.207) British parents' lived experiences with their child in need of augmentative communication who also felt the necessity to become 'pushy' due to feeling they had no other 'option' to address their child's needs. Perhaps Maltese parents also reverted to advocacy actions to push for their child's needs to be addressed, similar to Goldbart and Marshall's sample. Arguably, the need for advocacy may come from the lack of integration of parents' lifeworlds in service delivery (Todres et al., 2007; Dahlberg et al., 2009), hence creating frustrations towards services. This may also imply stigmatisation from professionals. Azzopardi (2000) agrees with this explanation in his study with Maltese parents of adults with disability.

Social stigma from other community members seemed to create distress amongst parents of children born 'at risk', especially those who manifest a physically-evident disability. The participants commonly pinpointed the word '*miskin*' (Eng.: pity, wretched, poor girl/boy/thing) as evidence of social stigmatisation when heard from the general public. Even though community members may mean no harm, the use of '*miskin*' seemed to be an ungracious way to manifest sympathy. In fact, these comments may be classified as gossip, which is considered as a means of normalcy control (O'Reilly-Mizzi, 1994); what is not 'normal' is identified as different and highlighted as such. This 'invisible oppression' may be perceived from the 'inexperienced' population further increasing the 'us-them phenomenon'. This finding could, thus, be uniquely tied with the 'face-to-face' Maltese culture. It may also amplify the high degree of social visibility due to its small size and highly dense population (Sultana and Baldacchino, 1994; Abela et al., 2005). One may argue that methodological choices of exploration in this study may have contributed to the divulgence of parents' deep feelings. Indeed, Erickson and Kurz-Riemer (1999) indicated that stigmatisation was ever-present among parents of children with disability across cultures. Nevertheless, it was not as constantly and overtly perceived as in this study with Maltese parents. This emphasises the importance of sensitising the general population about such issues (see section 7.2.1).

Parents in the current study reported a degree of social isolation resulting from perceptions of stigmatisation, similar to Callus and Bezzina's (2004) and Borg's (2006) findings. Callus and Bezzina (2004) observed similar feelings of being devalued by stigma among parents of children with disability. It follows that stigma could have triggered social isolation, as a defence mechanism. Hence, marginalisation (exclusion

from society and feeling devalued by community members) were at times reported, even from close relatives. This may also become a negative vicious cycle as once the parents feel hurt and isolated it could impede them from progressing in their acceptance process (cf. Trute et al., 2007). Davis et al.'s (2009) Australian participants indicated the presence of both social isolation and social stigma, yet these authors did not relate stigma as a cause of isolation. Findings in this study show that stigma was a direct cause of social isolation for Maltese parents whose child was born with ID risks; where isolation may be considered as a solution by participants to avoid being hurt by others' stigmatising of them and their child. Further exploration on this phenomenon in the future is needed to better understand effects of social stigma.

Research in other countries has associated social isolation with friendship losses (Tracey 2000; Gray 2002). From a sociological perspective, Barton (1996) saw perceptions of pity as a possible cause for loss of friends. In this study, pity from friends did create feelings of stigmatisation, which ultimately led to loss of friends. This marginalisation seems to be accentuated even though Malta is a small community. The present study's participants also interpreted these experiences as an eye-opener to identifying 'true' friends, given that they had loss of friends, similar to findings in Ainbinder et al. (1998) and Davis et al. (2009). This finding could be explained from lack of perceived sameness or perceptions of stigma. Minde (2000) and Singer et al. (2003) also reported stigma rationales for loss of friendships.

Living in a small 'face-to-face' community, however, was not always interpreted as negative. Some parents felt reassured and relied on the trust in having the same professionals who followed their child's successful discharge from hospital, perhaps due to positive associations of child's survival. Despite this, 40.5% (N=15) of the current study's participants expressed frustration and/or anger about the lack of locally available services such as occupational therapy in schools, paediatric ophthalmic services, specialist services for visually impaired children and infrequent orthotic services. These experiences led to perceptions of lack of control and feelings of loss among the participants, which surfaced as feelings of being 'trapped'. Maltese parents might have felt this frustration due to the lack of timely guidance and professional assistance leading to feelings of disempowerment, since they felt responsible to support their child's development. Perceptions of disempowerment were also observed in Runswick-Cole's (2007) UK research where 'power-relations' of professionals saw

parents as passive partners. Such an explanation may remain unresolved unless comparative studies are performed in future research across countries.

Malta's cultural feature of family interconnectedness was evident when parents turned to the grandparents or families-of-origin as the first source of support. This finding has been reported in prior literature in different cultures (e.g. Green, 2001; Blacher et al., 2007; Chang and McConkey, 2008). This study also found, similar to Woodbridge et al.'s (2009) and Green's (2001) findings, that grandparents seemed to assist family management and practical aspects. There may be an element of trust based on the closeness of the parents and their families-of-origin, given that the latter seemed to be the preferred alternative child-care choice over child-care centres (see section 5.5.1.1). This preference may reflect cultural family closeness rather than lack of trust towards the institution of child-care centres, as expressed in Borg (2003). Other factors also influenced this decision including lack of catering for child's special needs in these centres (see section 6.4.3). Maltese families give great importance to children (Abela et al., 2005) and this cultural feature may also explain the close involvement of grandparents or extended family with the parents' child rearing experiences in this study.

Despite this, some grandparents may not be physically strong, may still be working or not feel capable to care for the young child with special needs. Participants reported some conflict or feelings of overbearingness upon their family lives and similar conflict has also been reported amongst British parents (Hastings et al., 2002b). However, for the Maltese parents the close family relationship seemed stronger than the reported conflict as almost all participants maintained a good relationship and frequent contact with their families-of-origin. This context places the grandparent as a 'second parent' role, where, with the parents' permissions, they may be educated and involved in the child's intervention scheme; depending on the family constructs and limitations, such as old age and working duties of grandparents (see section 7.2).

The role of religion and spirituality

Most participants' spiritual and religious beliefs in this study provided emotional support for most couples' emotional coping, enhanced acceptance of child's condition, marital support and some parents reported increased family communication levels. Clergy, who were perceived as friends, also acted as an emotional support for some

couples during difficult times in this study. Similar enrichment and growth has been reported by prior literature as enhancing the family's well-being (Lin, 2000; Hastings and Taunt, 2002; Howart et al., 2008; King et al., 2009), positive attitude (Kashdan et al., 2002) and personal emotional strength (Stainton and Besser, 1998). Such enrichment associated with religious beliefs may indicate cultural influences where religion and culture in Malta are intertwined (Abela, 1994). Even though Montebello (2009) pointed out that religio-cultural supremacy was decreasing in Malta, this does not seem to be the case among the lifeworld interpretations of most Maltese parents of 'at risk' children under study.

Some parents explained their child's circumstances through their spiritual beliefs, such as perceptions of pre-destined life-plan and life's mission, similar to Pelchat et al.'s (2009) findings amongst Canadian parents. In agreement with Pelchat et al.'s findings some parents in this study also reported spiritual transformation. Some parents also spoke of gratitude to God for their child's survival, seeing it as a miracle or a gift from God similar to the Latino parents in Shapiro and Simonsen's (1994) study. Although, such religious connectedness and value system seem to vary on an individual basis, prior studies acknowledged that cultural differences could influence such reactions (Heller et al., 1994; Triandis, 1995). The religious or spiritual beliefs of most Maltese participants seemed to be part of their acceptance journey and in creating optimism in their daily emotional coping, possibly indicating a cultural influence. When optimism and positive-thinking were expressed, parents noted reduced negative ruminations, further agreeing with Bostrom et al.'s (2010a) views that acceptance upheld a balance between positive and negative perceptions.

In summary, Maltese cultural influences are evident in the various aspects of the participants' lives: living on a small densely populated island, religion, stigma and family closeness, amongst others. Although these findings about cultural influences may be unique to the Maltese culture, they may be applied in other small-state cultures or ethnic group whose attitudes are similar to Malta. Spirituality was reported as a source of support, yet it would be interesting to explore spiritual coping with other parents with similar circumstances.

6.3.2 Living with risks: Family impact and adjustment

This study highlighted what it feels like to rear a child born with risks for ID during the first five years of life. Not all children manifested ID or were diagnosed as such: the majority of children in groups 2, 3 and 4 manifested delays in various developmental aspects (see Charkaluk et al., 2010) while some parents felt their child had a typical development. All parents in this study felt the impact of having a child at risk for ID as a family. Parents' adjustment and acceptance in this study showed how participants coped and settled in their daily lives. These also implied the transformations from their way-of-life before they had their child.

Family impact

All participants reported that the impact of having an 'at risk' child affected their lives and their relationships within their family (including other typical children) and with extended family members. The majority of siblings in this study were viewed to have adapted well, by their parents (N=21), possibly due to good communication levels within the family (see Giallo and Gavidia-Payne, 2006). This shared impact may be explained by the ripple effect of family systems theory (Friedman et al., 2003), whereby each family member influences the other through their behaviour and life events (Casey, 1996). Although Hay and Nash (2002) criticised the family systems theory due to its assumptions about the 'traditional' nuclear family, the Maltese single parent families in this study also implied a shared impact with their extended family members.

Participants in this study saw parenting an 'at risk' child as resulting in a life-style change; one which erased their previous child-rearing experiences and had a lasting impact. This does not seem to agree with Veddovi et al.'s (2004) findings that past child-rearing experiences were considered as helpful. Yet, for first-time Maltese parents, rearing a typically-born child was also a life-changing experience (Borg Xuereb, 2008). The parents' new life-style seemed to carry a significant emphasis on achievement of developmental milestones: with added satisfaction when their child reached them, which further motivated them to stimulate their child's development. This finding coincided with Power et al.'s (2009) results, where their three Irish mothers of children with cerebral palsy, expressed similar added satisfaction resulting from the high emotional investment in their child's successful developmental progress.

Parents in the present study reported that tight schedules, concerns and advocacy exhausted them. Concerns about the child's behaviour and exhaustion seem to agree with prior literature regarding parents of children with disability (Baker et al., 2005; Raina et al., 2005). These perceptions can also be considered as part of the ripple effect of rearing a child with special needs (see Friedman et al., 2003). Similar to Graungaard and Skov's (2006) findings, participants in this study pointed out that exhaustion was increased due to excessive outpatients appointments, hospitalisations and therapy visits, added to their child-care routine. Additionally, Mitchell's (1997) study also reported perceptions of exhaustion, while Davis et al. (2009) noted limited freedom and disrupted sleep patterns in parents of children with cerebral palsy. As parents, they may have felt responsible to strive for and prioritise their child's developmental needs regardless of their personal schedule.

Shock reactions

Parents of the affected child perceived themselves as being thrown into an unexpected crisis: reactions included apparent shock, frustration, guilt, powerlessness and unpreparedness. Parents of typically born infants in Malta were also reported to remain distressed at 6 months postnatally (Borg Xuereb, 2008). Nevertheless, shock has been reported in other overseas studies when children are born in perceived atypical circumstances, within different cultures and using different methodologies (Golish and Powell, 2003; Green, 2007; Maul and Singer, 2009; Fonseca et al., 2011). Similarly, Tracey (2000) also noted participants felt unprepared and considered it as a crisis, despite some parents being informed before the birth.

Maltese participants reported that shock was dominated by contradictory feelings: happiness about having a new child and concern about their child's life-threatening state. These findings concurred with prior researchers (e.g. Goldberg and Divitto, 2002; Golish and Powell, 2003; Fonseca et al., 2011) who also identified shock, sadness and anxiety amongst parents of 'at risk' children. Arguably, the reduced familiarity with the environment may have aggravated their shock, further highlighting the lack of knowledge about their immediate environment, such as NPICU ward equipment (Rosetti, 2001).

Contradictory feelings were also reported by Padden and Glenn (1997) who noted both positive and negative reactions to the news of having a child born 'at risk': relief and

happiness combined with fear and concern. In the current study, these seem to be perceived in a similar time-frame to Padden and Glenn's (1997) participants who reported both positive and negative feelings as early as a few weeks after their child's birth. Moreover, similar to Padden and Glenn's findings, the Maltese parents' shock reactions in this study gave more weight to the negative than positive feelings around the birth period. Golish and Powell (2003) labelled similar findings as the joy-grief contradiction, when their American participants had children with life-threatening conditions at birth. They further described their participants' emotional process as a roller-coaster journey. This was similar to the feelings expressed by some parents in this study. Such ups-and-downs of emotions may be explained from the highs and lows of the new-born baby's health state during hospitalisation. Moreover, some mothers in the current study reported guilt feelings and powerlessness as well as self-blame, similar to Golish and Powell (2003). These mothers may have felt responsible for their baby's incomplete gestation period, similar to Gueron-Sela et al.'s (2013) whose Bedouin mothers saw premature birth-giving as a failure-related event.

The Maltese parents' reactions seemed to have triggered a self-protective mechanism as the experience seems to have shocked them to their 'core' around the birth period. This protective mechanism has not been reported in prior literature, perhaps it may be attributed to the depth of the method of inquiry or different cultural characteristics. Self-shielding in this study, including an inability to communicate with the outside world amongst some parents, seemed to result from the aforementioned contradictory emotions so as not to become further distressed. Such a reaction could also be explained as self-preservation attitude or a denial of their new unexpected experience (Atkinson, Atkinson and Hilgard, 1993).

Nevertheless, the reported self-shielding shock reaction could be explained from a cultural perspective. Callus and Bezzina (2004) and Borg (2006) indicated that Maltese parents of children with disabilities felt they were different from the rest of society (the 'inexperienced'). This may further agree with O'Reilly-Mizzi's (1994) 'invisible oppression' by community gossip, which leads to perceptions of stigma (see section 2.4.1 and 5.6.1.2). This interpretation may also be similar to Rolph's (2006, p.178) outcome who noted that parents' '*initial silences*', triggered by avoiding to express their fears, led to the need to '*hide from the outside world*'. It is vital that health professionals assisting affected parents are aware about such a reaction, in order to provide effective

and tailored emotional support, to help them share and acknowledge their emotional state (see recommendations 7.2.1).

The mothers' lack of communication with the outside world during the immediate postnatal period seems to have given the fathers a socially constructed 'sense of duty' to protect the mother's emotional well-being. This could be associated with the male protective role (Powers, 2001). Arguably, fathers could have also been unconsciously pressurised by the mothers to adopt such behaviour. Since the birth was highly taxing for the mother, perhaps she was still perceived to be in a physically vulnerable state. Their spouse/partner could have attempted to act as emotional protectors for the mothers regardless of their own suffering: the silent sufferers. Consequently, fathers perceived it was their 'duty' to act as 'news-buffers' for mothers and the communication bridge between what was happening to the hospitalised child and the extended family. This may also be another example of Family System Theory's ripple effect and circular causality notion (Friedman et al., 2003): the behaviour of one individual (the mother's lack of communication) influences and is influenced by other members (the father). Golish and Powell (2003, p.324) also observed an 'unemotional reaction' to their participants' child's premature birth. This reaction may be similar to but not the same as in this study, as fathers in this study interpreted feelings of 'duty'. This may be attributed to the depth of analysis in this study or traditional gender roles (see Borg Xuereb, 2008).

Hollywood and Hollywood (2011, p.37), whose Irish fathers were reported trying to stay 'out of the way', visited their preterm babies less often than the mother. Although in the Maltese context, fathers visited less often too, they did not report a similar rationale. They felt the need to maintain their job as the main breadwinners of the family. Suppression of feelings (Pelchat et al., 2009) and distancing (Gray, 2003) were reported by fathers of children with varied disabilities. Contrarily, in this study the majority of fathers did not seem to manifest distancing as a coping mechanism, but felt the obligation to take over a protective role during the birth period over and above their work routine to preserve their job. It was after the physical recovery of the mother and after the child's hospital discharge that the mother seemed to take over responsibility for the child. Only a few fathers in this study, when compared to Gray (2003), reported distancing, using the 'bread-winner' role as an excuse; going away from the home

environment helped with their emotional coping. However, there is a paucity of literature on fathers' reactions to having a child born with ID risks.

Attitude change

The interviewed Maltese parents interpreted raising an 'at risk' child as a life-changing experience. Most of the couples' perceived transformations were positive: growth and strengthened relationship, greater appreciation of spouse/partner and greater mutual respect. Such findings were also observed in prior research with parents of disabled children (Hastings et al., 2002; Pelchat et al., 2009). Similarly, prior literature has indicated that raising a child with disability was reported to strengthen family cohesion (Chang and McConkey, 2008) and family congruence over time (Mazer et al., 2008). Increased respect towards their spouse/partner was also observed while raising a typical child (Mulsow et al., 2002). These lifeworld transformations as a couple are thus similar to other parents in different countries. Few participants in this study viewed their relationship as unchanged, agreeing with Risdal and Singer's (2004) and Wieland and Baker's (2010) findings.

The positive changes were not universal as most participants in the present study also observed increased marital conflict during moments of exhaustion and concern. Such findings coincided with Stoneman and Gavidia-Payne's (2006, p.1) reports of reduced marital adjustment due to excessive 'daily hassles'. The early years of rearing a child with a disability was especially marked with perceptions of impact on their lifestyle (Davis et al., 2009) and potential marriage breakage (Urbano et al., 2007; Clarke and MacKay, 2008). One of the two interviewed single mothers did interpret the experience of having an 'at risk' child as a contributing factor to her marriage breakdown. Similarly, Golish and Powell (2003) noted that 2 of 47 couples in their sample separated partly due to the strain on their marriage from having a child born very preterm. This may indicate that raising a child with disability in Malta may pose a risk for marital conflict as in other countries. Yet, Abela et al.'s (2005) survey identified that a high level of marital satisfaction in the general Maltese population was a culturally embedded characteristic, regardless of the opportunity for legal separation. There may be a cultural influence on the marital satisfaction of parents rearing an 'at risk' child. However, given that divorce was legalised soon after completion of data collection, changes in the marital status may vary in future investigations.

Some parents across groups reported reduced sexual intimacy. Mulsow et al. (2002) showed that parents raising a typically developing 6 month-old child gave more importance to intimacy than other forms of social support, whilst by 2 years of the child's age this was inverted. Reduced intimacy expressed by parents in this study could be commonly experienced by all parents raising young children.

Other factors might also be at play in reduced intimacy, such as the reported fear of seeing other pregnant women or fear of future pregnancies. Padden and Glenn (1997) reported that half of their interviewed mothers showed concerns about future pregnancies during the early weeks after the birth of their 'at risk' child. 'Concern' is an individually attributed term that may have cultural ramifications (Kiing et al., 2012). Yet, participants in this study expressed 'fears' that altered their future family plans (see section 5.4.3.1). This situation could be attributed to the fact that in Malta abortion or termination of pregnancy is illegal. There is no prenatal screening for abnormalities apart from ultrasound tests. Consequently, perceptions of reduced intimacy could be explained as avoiding future opportunities for having a child with disability by some parents. Indeed, half of the parents who had more children after this experience reported them as 'unplanned', while only two couples were planning a future child perhaps due to their optimistic life outlook or their positive outcome of the child's development. Some parents spoke of how they stopped planning on a long term basis and adopted a day-to-day attitude, perhaps due to their child's life-threatening state during hospitalisation. Clinging to day-to-day attitude was likewise observed by Golish and Powell (2003) whose participants parented preterm-born children.

Despite these concerns, almost all parents indicated that they had discovered a new world. This could have occurred as a result of being 'thrown' into an unexpected and unfamiliar situation (Golish and Powell, 2003). Thirty-three parents (89.2%) reported greater appreciation of life and that their experience had helped them to become stronger persons, whilst six parents added an increased confidence to speak for their rights. This finding was also reported by Green (2007) where advocacy over a period of time assisted American parents to enhance their confidence. Hastings et al. (2002b) also observed reports of personal growth and maturity amongst mothers who had a strong informal support network. Similar interpretations were reported by most participants in the current study regardless of the absence of professional emotional support; spousal/partner support contributed to their growth as a couple. It could further reflect

cultural marital influences as reported by Abela et al. (2005). These individual and couple positive changes could be considered as positive growth towards adjustment to parenting a child with disability. Following Resch et al.'s (2010) work, these could play an important role in parents' wellbeing. It is vital that professionals, who collaborate with these parents, are aware of such attitude changes for the benefit of rapport building and intervention to support holistic family well-being.

Acceptance process

In the current research, an acceptance process seemed similar to findings by Kandel and Merrick (2007) and Vermaes et al. (2008), where acceptance of their child's situation was influenced by parents' personality traits, support system, education of parents and spousal relationship. Kandel and Merrick (2007) added that financial resources assisted acceptance, but in the current study most parents did not feel themselves to have a financially stable situation, yet they still manifested acceptance of their child's condition. Financial resources of the families in the current study seemed to act as a tool to access services rather than influencing emotional acceptance.

Parents expressed their acceptance as an individually-established change in their emotional process. Such interpretations did not agree with Lloyd and Hastings' (2008) acceptance perceptions, in which study acceptance had a bi-directional relationship with anxiety and depression. This disagreement could be evident as most parents in the current study, gave more importance to their positive transformations than the negative ones during their child's early years. Bostrom et al. (2010a) also indicated that even within the first 6 months of being diagnosed with ID, parents gave a balanced picture of both positive and negative descriptions of their child (0-5 years of age). However, Bostrom et al. did not specify whether their ID was developmental or due to biological risks at birth.

Hope was associated with feelings of wellbeing and is a known predictor of positive perspective in the adaptation process (Lloyd and Hastings, 2009b). The parents' optimism, hope and realism seem to be strong regarding the child's future, similar to Heiman's (2002) findings. Additional concerns for the child's future independent life status within the Maltese society were however commonly observed amongst interviewed parents. These seem to result from the lack of adult independent living services and opportunities on the island (Azzopardi, 2000). Some parents in this study

have reverted to advocacy actions when they felt concerned about their child's unmet development needs. This finding agreed with Inkelas et al.'s (2007) and Jackson et al.'s (2011) results. Advocacy activities by the parents in this study were negatively looked-upon as these increased tiredness and stress, similar to Mitchell (1997). Some of this study's participants regarded advocacy actions as necessary to address their child's needs, similar to Goldbart and Mashall (2004). However, the parents in this study did not report prioritising advocacy actions as in King et al.'s (2009) parents of young children with autism, when these were compared to parents of high-school children.

The majority of parents (83.8%, N=31) agreed that time seemed to be a healer. Time seemed to have assisted the adjustment of parents, similar to Green's study (2007) with American parents. Time could have helped them distance the atypical birth experience from their current lifestyle in the present study. Others viewed time as a source of maturity that gave them experience, learned skills, a positive worldview and resilience skills as self-help mechanisms. This could be explained using Sartre's existential philosophy (1948) that the individual sees him/herself in a process of becoming. Some parents also saw time as an opportunity to look back and re-interpret their past experiences. This agreed with Gadamer (1989), who argued that time was of essence as an interpretation in one moment could be different in another.

Parents saw acceptance as a window of opportunity to reduce their negative thoughts and maintain their daily routines (section 5.9.1.2) and was also interpreted as a practical coping mechanism (see section 6.4.3), perhaps to create feelings of 'normalisation' in their lives. Pelchat et al.'s (2009) participants also expressed a similar need to adjust to the parents' daily routines. Additionally, the interplay of hope and optimism perceived when their child achieved a milestone might have further encouraged parents to use goal-oriented thinking regarding their child's development as part of their emotional acceptance process (see Erickson and Kurz-Reimer, 1999). This might also explain why almost all parents recommended such an attitude to other parents in order to '*heal*' whilst being active with their child's stimulation for development.

Constant reflections on the negative aspect of parents' experiences seemed to take place soon after they settled at home, impeding them to 'move on'. This seemed to correspond with the process of post-traumatic stress growth (Calhoun and Tedeschi, 1998), where such negative ruminations might be overcome by the individuals' coping

strategies. For a few parents, however, such thoughts persisted throughout the first five years of the child's life, attributing them to feelings of disempowerment due to their child's unmet service needs. It may be possible that those few parents in this study could have remained in the anger phase of acceptance process (see Atkinson et al., 1993). This finding may also adhere to Barnett et al.'s (1993) finding that mothers manifested greater stress related to infant-related difficulties than mothers of typically developing children. Bartlett et al. (2011) indicated that parents' perceptions of vulnerability about their child's development were statistically different in their explored cultures: Netherlands, Norwegian and Canadian. Although the current study found sociological influences on parents' perceptions of their child's vulnerability, these cannot be compared to Bartlett et al.'s (2011) study due to methodology differences.

6.3.3 Age-related experiential differences

There was inconsistency in prior literature regarding changes in parents' experiences over time; mainly due to the varying methodologies used for exploration and wide age ranges explored. This study's findings provide support to prior literature that the more the child grew the more the parents adapted to their situation. Although this notion was also reported by Lin (2000), the ages of the children with disability differed from the explored age-range in the current study. The present study shows evidence of experiential differences in parents' experiences based on the child's developmental transitions during the first five years of life. These included hospital-home transition period, development concerns, schooling challenges and the mature expert. Jackson et al. (2003) also showed the presence of changes in perceptions among parents rearing their young 'at risk' child (0-18 months). Findings in the current study did not concur with Davis et al. (2009), as the latter observed no changes in perceptions specifically on 'child-care' amongst parents of children with cerebral palsy regardless of the differences in experiential events, perhaps due to wide age-gap between explored groups (childhood and adolescence).

MacDonald and Callery (2008) also observed that parents' experiential changes over time were based on the hindsight recollection of experiences. They noted parents' experiential changes based on the child's major educational transitions: such as infancy, starting school, infant-junior school and high-school. However, unlike MacDonald and Callery's (2008) study that was only based on retrospective accounts, age-related

differences in the current study were based on both current lived experiences and retrospective perceptions. Following Sartre's (1948) philosophical thinking, time is of essence in one's interpretations of experiences and might influence the re-interpretations of past experiences. If a longitudinal methodology had been employed perceptual shifts could have been explored with the same cohort, where both retrospective and current interpretations of lived experiences could be compared. This merits further research using different methods of inquiry.

Participants regarded the hospital-home transition period as the most difficult period of their explored child-rearing experiences. This was marked with contradictory emotions, re-creating a daily schedule, fears of re-hospitalisation and apprehension towards an intensive-medicine-giving routine. The transition of Russian parents with premature children was influenced by the health of the infant, discharge readiness of the parent, timeliness of discharge and appropriateness of post-hospital care (Boykova and Kenner, 2012). Parents, in the current study, saw the hospital discharge news as the child's official birth into society, yet they felt fearful of being away from the safe technological and professionally-supported hospital environment. This could indicate lack of discharge readiness, as labelled in Boykova and Kenner (2012). Olshtain-Mann and Auslander (2008) argued that insecurities persisted even two months after postnatal discharge among Israeli parents' premature newborns. Re-hospitalisation fears and insecurities together with parents' protectiveness could explain the adopted compensations by the Maltese parents: excessive cleaning in order to acquire hospital-perceived sterile environment and over-checking of child's breathing. Prior literature labelled these as over-vigilant actions to protect their child (Holditch-Davis et al., 2003).

Nicolaou et al. (2009) highlighted the need for information, in the UK, from professionals due to reported concerns for their child's development during hospital discharge period. Indeed, interviewed Maltese parents also reported concern and feelings of abandonment and loss upon hospital discharge with a perceived lack of guidance, despite the 3 postnatal home visits of the community midwife. Borg Xuereb (2008) had already recommended a re-organisation of Maltese community midwifery care system for parents whose child is born in typical circumstances. Lopez et al.'s (2012) review specified the need for nurses' home-visits as crucial during NICU-home transition. Findings in this study agree with Lopez et al.'s and Borg Xuereb's

recommendations as Maltese parents considered their child to be born in atypical circumstances, feeling insecure how to care for a ‘smaller’ or ‘different’ baby as their past child-rearing experiences have been annulled. Thus these parents have a more immediate need for this family-focused service which explicitly incorporates their needs as carers.

Professionals advised parents to avoid social contact soon after hospital discharge due to the low immune system of the child. Simultaneously, the birth of a new child is culturally marked by increased social contact to share the parents’ happiness and welcome their child into society. This conflict, between cultural expectations, child’s health concerns and sadness due to self-imposed isolation to protect their child’s health, created tension in parents. It further highlighted their atypical birth circumstance even outside the hospital environment. McKim (1993) acknowledged that the first few weeks after being discharged from hospital were perceived as the hardest by parents of premature infants. Such cross-cultural agreement suggests the need for further in-depth exploration concerning specialised professional interventions involving psychologists and social workers, which could be required by parents in similar circumstances during their hospital-home transition period.

During the second year of the child’s life, participants were particularly stressed due to suspicions about their child’s developmental delay. Likewise in Graungaard and Skov’s (2006) study parents also expressed distress, frustration and helplessness due to lack of diagnosis across the first five years of their child’s life. In the current study, some parents who expressed trust in professionals’ judgement and had no diagnosis seemed to interpret their child’s behavioural problems in a positive manner, as part of his/her typical development. A possibility exists that even though the child was born with ID risks, their development may follow typical milestones (see section 2.2), in which case their trust in professionals is justified. Yet, parent’s concerns may also imply lack of awareness of potential developmental difficulties, hence an increased possibility of missing out on formal support (see section 6.4.1). Indeed, some parents in this study felt concerned about both the child’s developmental delay and their increased need for support. This disagreed with Hodapp et al. (2003), who were uncertain if their participants’ stresses were solely related to either their child’s developmental delay or to increased support needs. This disagreement could be due to their use of quantitative measures with reduced depth of parents’ individual voices. Thus, it is vital to educate

parents on typical developmental milestones and potential child's developmental difficulties in order to feel empowered and not blindly rely solely on the professional's advice (see section 7.2.1). Educating professionals about the importance of early intervention cannot be overlooked.

Parents visualised school attendance as an important step both for developmental readiness among 2 year olds but also upon starting pre-school education in children aged about 3-3;6 years. This was seen as a transition for both child and parents with 'letting-go' apprehensions, fears of child's acceptance in the school environment and positive changes in child's behaviour attributed to school initiation. Parents' concerns may be explained by McIntyre et al.'s (2006) findings, that children with ID could manifest early school-settling difficulties due to the child's low self-regulative behaviours rather than the disability itself. In the current study not all the children were sent to pre-school education by 3 years of age, due to delayed development. The parents' concerns about lack of developmental readiness for school may be explained by Schendel et al.'s (1997) and Charkaluk et al.'s (2010) association of biological risks with developmental delay: one which may have impact on educational achievement possibly due to mal-adaptive behaviours (Foster-Cohen et al., 2010; Larroque et al., 2011).

The experience accumulation of parents whose child was about 5 years of age seem to have equipped them with tools such as ability to offer support and advice to other parents with younger children. Such an altruistic interpretation may also be associated with the individual parents' acceptance process. This may be similar to Green's (2007) outcome, where positive perceptions may increase over time. Comparable perceptions were not associated specifically with parents of children aged 5 years of age in prior literature; however they have been reported amongst mothers of children with varied ID aetiologies and with wider age range in Lloyd and Hastings (2008). Interestingly, perceptual shifts based on the child's age were shared by most parents of 5 year old children in this study. Although this study set out to explore experiences of parents based on these age-groups, parents in group 4 themselves identified the child's age as a trigger for perception changes. This may call for regular re-evaluation of parents' needs during the observed transition periods by professionals and social policymakers, in order to delivery individualised approach to support (see section 7.2.3).

6.4 Needs of parents in promoting their ‘at risk’ child’s development

Professionals and policymakers as the organisers of services need be aware and address affected parents’ needs in order deliver early intervention services to enhance the whole family’s strengths. What could be the needs of Maltese parents whose 0-5 year old child is born with biological risks for ID? This study identified a number of needs from these parents’ experiences in order assist their child’s development. Since parents constitute the immediate environment of the dependent young child (Bronfenbrenner, 1994; Guralnick, 1998, 2008a; Roush and McWilliam, 1994) their needs are as important as their child’s (Dunst, 2007). Thus, their experiences also affect the rest of the family (Casey, 1996; Friedman et al., 2003). Addressing these needs might assist in creating more family-friendly services and initiate a service-shift towards family-centred principles. It follows that this study has shown that most of the unmet parents’ needs are directly affecting the children’s development. This gives strength to Brinker’s (1992) concept that early intervention needs to be embedded within family-centred values rather than child-centred principles. Parents’ needs are discussed according to the four defined needs (section 4.3), in the light of prior literature and theoretical frameworks: namely physical, emotional, psychosocial and communication needs.

6.4.1 Physical needs

Physical needs, in section 4.3, are defined as needs perceived by parents arising from the physical and corporeal environment within their society throughout their experience in promoting their child’s development such as needs related to services (e.g. service awareness, referral, helpfulness of services) and the immediate environment (needed materials).

Services awareness

Parents commented that their search for services was based on awareness of services, including awareness of the child’s present and potential future difficulties. This was also observed in other countries, such as in Asscher et al.’s (2006) work, whose participants sought services based on their awareness of child’s risk factors, behavioural difficulties and delayed development. Wakimizu et al. (2011) also found that reduced awareness of social support was associated with reduced empowerment perceptions among Japanese parents of children with developmental disorders. Such an argument may explain a potential negative cycle among those participants in the current study who manifested

reduced awareness of services resulting in reduced access to services. Consequently, there could be deprivation of preventive early intervention for the child's development.

Maltese parents reported perceptions of passivity or feeling lost, possibly due to lack of information about typical developmental milestones. Those parents, who reported information sharing from parent-to-parent support for accessing services, seemed to feel at an advantage and consequently felt more empowered. This agreed with prior literature stating that parents who are informed about typical child development or about available services perceive themselves as being more prepared to assist their child's development (Popich, 2003; Ertem et al., 2007). Likewise those parents who reported awareness of services and accessed services for preventive measures reported positive appreciation of their child's need for stimulation of milestone development, unlike those who lacked service awareness.

Referral to access services

Referral from the medical professionals (general practitioner, family doctor or paediatrician) was viewed as key to accessing public services and financial assistance in Malta, similar to findings in some other counties (Rosetti 2001). Bailey et al. (2003) pointed out that diagnosis was the key to obtaining access to support networks. In the context of Maltese society, referral was more important to access services than diagnosis, thus lack of referral made parents feel unable to help their child. If parents' awareness of services and their child's development are low, the professionals' referral is critical to the child's progress. It follows that lack of referral may deprive parents access to services, thus compromising the development of the child. This may explain the participants' subsequent frustrations.

Frustration due to lack of referral has been expressed by parents in different societies (Bailey et al., 2003; Davis et al., 2009). A referral from a doctor is needed in Malta for almost all health services, although not for SLT services, which uses an open-referral system. Yet parents seemed to be unaware of such information. This seems to agree with Davis et al.'s (2009) recommendations on the necessity to improve service access in order to improve parents' quality of life. Maltese parents' frustration could also reflect that lack of referral itself act as a barrier to access EI services unlike the barriers identified by Jimenez et al. (2012). The current study emphasised that in Malta a referral is not only important to give access to the paediatric services for these parents, but also

vital to the child's future development; and ultimately may influence children's potential educational achievement and eventual adult independence (see Foster-Cohen et al., 2010; Larroque et al., 2011).

Referral, in the current investigation, also carried a hidden meaning for parents. It provided a ray of hope to improve their child's development. As noted in earlier section, retaining hope was a coping strategy used by Danish parents during the process of obtaining a diagnosis for their young child born at risk (Graungaard and Skov, 2006). Lack of referral seemed to add to the family's concerns about added financial expenditure, as without a referral this excludes all possibility of obtaining financial assistance. Some parents felt that referral was not obtained due to the professionals' lack of sensitivity, which added feelings of powerlessness and helplessness (further discussed in section 6.4.4). Added financial hardship and insensitive communication attitudes of some professionals may further explain parents' frustrations and demoralisations when their child was not referred to his/her needed paediatric service. Insensitive communication attitude was not reported to act as a barrier in prior literature. Contrarily, Jimenez et al. (2012, p. 553) noted that sometimes parents misinterpreted the professionals' 'reassuring' communication attitude as lack of need for referral. This requires further investigation on the perspectives of professionals and parents on the process of referral to better understand and overcome potential barriers.

Helpfulness of services

Maltese parents saw services' suitability as important to meet their child's developmental needs. They had pride and high regard for the hospital's intensive paediatric ward, seeing it as technologically well-equipped. This was also replicated in prior literature amongst parents of children needing 'elective surgery' in Malta (Portelli, 2006). Nevertheless, parents seem to perceive certain inadequacies in the suitability of service facilities that, in their opinion, could be improved for the child's benefit: for example using a separate paediatric waiting-room. Likewise, Davis et al. (2009) reported that Australian parents of children with disability identified the need to improve the environment in ways that are conducive to the child's needs.

Additionally it seemed that, for parents, the low-frequency of certain therapeutic sessions meant insufficient human resources and reduced adequacy of services. This was in contrast to private practice which offered more frequent sessions. A similar

finding was not identified in prior literature, perhaps because parents did not meet with similar challenges or lack of direct comparison between public and private services. While medical practitioners are usually in post over the time needed by families, other service personnel are not. The frequent turnover of some professionals, such as physiotherapists and occupational therapists, in Maltese paediatric public services does not help in rapport-building between the professional, the parent and the child. It was also identified as a barrier that may impede child's developmental progress due to lack of therapy continuity. There is a great need in Malta to introduce continuity of such care services for early intervention professionals. This suggestion was also put forward by MacDonald and Callery (2008).

Some fathers showed a desire to be involved in their child's intervention. Perhaps they felt they were missing out on their child's life or not contributing to their child's development. This finding may be similar to Huang et al. (2012), where Taiwanese fathers valued any opportunity with their child to incorporate rehabilitation techniques and assist their child's development. A paucity in the literature exists on fathers' involvement in child's intervention, one which merits attention in future research. However, as Maltese fathers felt it was their 'duty' to maintain a full-time job, they could not always participate in their child's sessions and pinned frustration on lack of flexibility of public services. Fathers seemed to be aware of their spouse's sacrifices in supporting their child, and wished to be part of their child's upbringing. This agrees with the cultural notion that child-oriented family values are embedded in the Maltese culture (Abela et al., 2005; Borg Xuereb, 2008; Abela, 2009a, 2009b). Perhaps they may also have felt they were missing out the added milestone satisfactions and father-child bond.

Those fathers who wanted to be involved in their child's services reported that most of their annual leave was spent waiting to be called for the outpatient appointments. This may have further repercussions on mothers' decisions to seek employment outside the house, similar to Cuskelly et al. (1998). This may also provide a practical explanation of the reduced paternal involvement during therapeutic sessions in clinics. Dyer, McBride, Santos and Jeans (2009) found high paternal involvement when a diagnosis was received before 9 months of child's age; however, they noted a decline in paternal involvement as the child grows older. In the present study wishes of paternal involvement were expressed by some fathers across all groups. Added leave benefits for

affected fathers may prove helpful in reducing frustrations and better family and financial coping (see section 7.2.3).

Although public services are available and free for all Maltese citizens, mothers and fathers may not benefit fully, unless changes in service-times are implemented. The uniqueness of parents' experiences also pointed towards the need for an individualistic approach in service planning and delivery (see section 7.2.3).

Material needs

Twenty-nine parents in this study praised and appreciated the provision of apnoea monitors by a parent-run voluntary organisation for home-use during hospital-home transition period. Prior literature did not have a similar finding, perhaps such information may be taken for granted or these materials can be easily purchased in other countries. Many parents also reported difficulties in finding other essential materials for their child, including very small nappies, clothes, bottles and pacifiers, given the small size of some 'at risk' children. Such a lack of material left parents feeling distressed and lost, further highlighted their atypical circumstances as they did not find where to buy such items in Malta.

Prior literature did not identify similar material needs from parent reports regardless of the methodology used. Arguably, it might be the case that outside Malta such materials are easily provided or bought. This might also create what Runswick-Cole (2007) called perceptions of disempowerment amongst parents of these children, due to lack of needed resource allocation. There is still the lack of available preterm new-born clothing on the island. This is also considered as an unmet need by these parents, who are obliged to order such basic materials from the internet. Parents argue that being a 'minority' population the market does not see these issues as a profitable investment. Nevertheless, there is a need for retailers to invest in this population in order to reduce frustrations which may ultimately affect child's development (see Zelkowitz et al., 2009).

6.4.2 Emotional needs

Emotional needs, in section 4.3, are identified as needs related to feelings within-the-person including emotional support perspectives, support systems as well as factors that affect parents' emotions when raising a child born with risks for ID. Parents' emotional needs during the child's early years cannot be overlooked due to their potential influence on later child social-emotional development (Zelkowitz et al., 2009; Glazebrook, 2011; Ramchandani, 2012).

Us-them perspective

The majority of Maltese mothers were hospitalised during their post-partum period beside other mothers whose child had typical birth-circumstances. This highlighted their atypical context and they felt hurt, isolated and unable to share their grief with other mothers. Five mothers said that the fact that they were given a single bedroom during their postnatal recovery was beneficial to their emotional wellbeing. Having single bedrooms at an NICU is understood to be conducive to facilitating effective communication between hospital staff and parents (Cone, 2007). In Malta the NPICU does not have single rooms and not all mothers were accommodated in single bedrooms in postnatal wards, perhaps due the limited availability. If structural alterations of the national hospital are too costly, an alternative solution includes placing similar-experienced mothers together in shared bedrooms, providing an opportunity for emotional support through sharing of experiences (see recommendations 7.2.3).

Most Maltese parents of 'at risk' children, who participated in the current research, consider themselves as different from other 'inexperienced' parents: 'us versus them' perspective. These parents seemed to view others as 'inexperienced' and unequipped with similar real-life knowledge; hence interpreted as unable to give them emotional support. It is possible that parents in the current study did not feel belonging to the rest of the community who, as they perceive, have had typical experiences, but felt they had an experience that marked them as different. By extension it may also be attributed to stigma perceptions. Arguably, following Merleau-Ponty's (1958) reasoning, one can empathise but not fully understand another person's experience, due to the embodiment of one's own experience. Prior researchers did not report a similar finding with parents of 0-5 year old 'at risk' children. Kralik et al. (2006) review indicated that transitions in the health status of individuals could create a loss of self and a shift in one's self-identity, while, Helitzer et al. (2002) found a perceived loss of identity by the parents of

children with special needs. MacDonald and Callery (2008) also observed a loss of identity when children attended formal education; however they associated it with acceptance and confirmation of lost dreams rather than a constantly present feeling. Different interpretations of such a finding may be attributed to the nature of qualitative method used for investigating parents' perceptions. This finding highlights that Maltese parents feel isolated and are in need of emotional support from similar-experienced others (see recommendations 7.2.3).

Parent-to-parent support

The majority of parents reported meeting with others who had similar experiences; most of whom considered it as a source of emotional support and reduced social isolation. Such a perception is reported to be an effective coping strategy, similar to Graungaard and Skov's (2006) findings. Parents seemed to feel understood by 'experienced' others due to perceived sameness (Ainbinder et al., 1998) and feel emotionally uplifted from the sharing of experiences, where parents felt listened to and supported (Taunt and Hastings, 2002). Kerr and McIntosh (2000) interviewed parents with upper limb deficiencies unlike the current study. Nevertheless, similar perceived-sameness on meeting same-experienced others assisted in reducing social isolation similar to the sample in this study. Parents across groups, in the present study interpreted such encounters as an emotional relief using downward comparisons; such as interpretations of emotional support via consolation feelings (section 5.4.2.1). Such a phenomenon concurred with Ainbinder et al. (1998) and Davis et al.'s (2009) observations who also found that downward comparisons, when possible, were a source of emotional support, regardless the different study population and wider children's age range.

Additionally, parent-to-parent support via meeting other parents whose older child had a similar condition, also acted as visualisation of their child's future potential, highly similar to Kerr and McIntosh's (2000) findings. Interestingly, in this study few parents felt distressed or did not feel the need to seek contact with same-experienced-parents: barriers included tight schedules and lack of awareness of this kind of support. Such logistical barriers were also observed by Kerr and McIntosh (2000), who also added loss of contact numbers. Arguably, the act of seeking support for some may be perceived as an admission of failure (Brett, 2004) but this interpretation for lack of support-seeking was not expressed in the current study. Sharing experiences was also seen as an opportunity to learn about service-accessing information that their child may

need. This is similar to Kerr and McIntosh's (2000) sample who expressed benefits in gaining information about service access. Some parents who did not have parent-to-parent support, in the current study, felt more distressed as they were unaware of services that could assist them to meet their child's needs. Such unawareness may also explain why Abela et al. (2012) found lack of access to required services by Maltese families. This suggests the urgent need of promoting and emphasising the establishment of parent-to-parent support groups in Malta.

Parents in this study expressed that the available parent-run voluntary organisations lacked organised emotional support when parents felt most in need: during their child's birth-hospitalisation period and immediate post-hospital discharge. This suggests that the provision of an organised parent-to-parent support service could also be set up under the umbrella of public services to assist the emotional needs of these parents (see recommendations 7.2.3). Although, there are initial costs to set up this service, it would be an investment for affected families' wellbeing if organised well.

Spousal/partner support

Emotional support from the spouse or partner seemed strong among parents in this study: almost all couples saw themselves as advantaged over single-parent contexts. Spousal/partner support is recognised to reduce parenting stress whilst raising a typical child (Mulsow et al., 2002) and when having an 'at risk' child (Golish and Powell, 2003). It might be the case that since their spouse/partner was sharing the same experience they felt these were equipped to understand them, via shared experiential knowledge and interconnectedness. The two single mothers in the sample reported support from extended family and friends; however, they perceived themselves as filling the roles of both the father and mother for the child and their need to remain strong to support their child. This may further confirm the 'advantage' expressed by couples.

Maltese two-parent families in this study seemed to give significant importance to the couple's relationship as crucial for emotional well-being and family functioning. Such perceptions may be borne from the cultural family characteristics (Abela et al., 2005, Abela, 2009a, 2009b). The participants in this study viewed themselves as a self-supporting system; regardless of marital or parenting state. This finding could be influenced by the use of constructive style of communication as conflict resolution

method (Abela et al., 2005). This also seems to agree with the family system's theory perspective (Casey, 1996; Friedman et al., 2003), where the family unit adapts according to each member's experiences and needs reflecting their interconnectedness. Such couple team co-operation also agreed with Golish and Powell's (2003), Green's (2007) and Maul and Singer's (2009) research outcomes as part of emotional and practical coping. Consequently, there is a need to facilitate spousal/partner support to strengthen this source of emotional support between couples. While affected single-parent families may need to be followed up more closely as it seems that they may be at an increased risk for emotional distress, unless they have support from their families-of-origin.

Extended family emotional support

Grandparents were seen as a source of emotional wellbeing to the parents of affected children, similar to prior research (e.g. Younger, Kendell and Pickler, 1997; Golish and Powell, 2003; Nachshen and Minnes, 2005). This seemed to be perceived as providing a compensatory mechanism in the absence of professional emotional support, by most participants in this study. This finding agreed with Heiman (2002), where initial support was received from family members, however, the support from Maltese grandparents endured throughout the child's five years of life for most participants. Some parents' perceptions in this study seemed to reflect those of Swedish parents in Lindblad et al. (2007), indicating that their relationship with grandparents seemed to have strengthened whilst rearing their child with disability.

On the other hand, some parents experienced contradictory feelings about grandparents' support, which seemed to have troubled them. The grandparents' emotional support was greatly appreciated, yet they did not feel empathised by them, given that they did not share similar past experiences. Golish and Powell (2003) also observed conflicting issues with the extended family of parents with premature children. However the latter's 'conflict' was managed by educating family members on the premature child's development. In the present study some grandparents were also interpreted as over-bearing, over-reacting to news, over-protective or disregarding parents' disciplining of their child. This finding seem to agree with Mirfin-Veitch, Bray and Watson's (1997) UK study, yet it differs from Woodbridge et al.'s (2009) study who reported that their Australian grandparents avoided overstepping parents' boundaries.

Grandparents' emotional support may be explained by the Maltese cultural influences and relationship closeness with the extended families (Tabone, 1995). However, interpretations of overbearingness may also result from parents' attempts to assert boundaries of their nuclear family. A few parents expressed hindsight reflections on the grandparents' potential concerns, which seem to agree with Hall's (2004) the 'double concern' and Woodbridge et al.'s (2009) 'double grief' research with grandparents. There is a need to study the involvement and experiences of grandparents of 'at risk' children both from a national and international perspective. Findings also suggest the need for grandparents' education and support, so that they in turn can support the new parents.

6.4.3 Psychosocial needs

Psychosocial needs, in this study (section 4.3) refer to factors related to such issues as resources (financial and work related needs) and management (family coping) needs.

Financial needs

Financial burden

Interviewed participants saw service access as partly relying on the family's available resources, besides referral (see section 6.4.1), particularly to access specialist services within and outside Malta. Such perceptions agree with Resch et al. (2010) whose participants felt that their financial state acted as a barrier to access and obtaining services for their child. Almost all parents in this study felt the need to use a combination of government and non-government services due to limitations in public services: the 'double-edged blade' nature of the fixed time availability of public services and more immediate or frequent appointments in private services (see section 5.8.1.2, 5.8.2.2). These barriers pushed the majority of Maltese parents to interpret raising an 'at risk' child as a financial burden on their family's resources due to increased expenses. Moreover, the lack of specialist services in Malta, such as paediatric orthotic and frequent ophthalmic services, increased perceptions of financial burden amongst parents. This financial burden perception was also evident in other countries such as Canada (Davis et al., 2009), Israel (Heiman, 2002), USA (Shannon et al., 2003) and Ireland (Greer et al., 2006).

Abela et al. (2012) reported that lack of family resources affected parents' use of required services from professionals' viewpoint. However, these authors did not link this finding with fixed-time limitations of the public services or the lack of specialist services in Malta, as identified by Maltese parents in the current study. This may also indicate that parents' needs are better voiced by experienced parents themselves rather than by professionals (see Merleau-Ponty, 1958).

Other financial stresses were reported such as urgent neonatal operations in the UK. Given that only the flight ticket of one parent was funded during neonatal hospitalisation, this was interpreted as going against family values, which indeed does not reflect the Maltese cultural values (Abela et al., 2005). The decision to pay the extra flight and face their child's surgery outside Malta together seemed to reflect the strong inter-connectedness of the couple (Borg Xuereb, 2008; Abela, 2009a) as a source of spousal/partner support. Hence, lack of financial support to both spouses/partners parenting a child with urgent health-care needs in the UK does not support the relationship of already-distressed parents (see section 7.2.3).

Most mothers spent a significant amount of time each day near their 'at risk' child's incubator or cot until s/he was discharged home. This also resulted in added financial stress, such as daily long hospital parking fees (see results 5.8.1.2). Such financial burdens resulted in a significant reduction of the family's quality of life. Similar findings were reported by Davis et al. (2009) regarding financial difficulties related to infant care. However no other research identified hospital parking-costs as a financial burden, perhaps due to their focus on emotional impacts or broader financial impacts expressed by parents whose child's ages varied between childhood to adolescence, while this study focused on the early years of the 'at risk' child's life.

Parents, whose child had a congenital syndrome diagnosis, were advised to apply for a disability pension to assist their child's service needs and expenses (Callus and Bezzina, 2004). Although, the national disability pension was appreciated as a financial help for the affected child, not all who received it saw it as equivalent to their actual costs; particularly due to dependence on private services. This seems to agree with other countries such as USA where financial difficulties were also reported despite federal and state programmes as well as private insurance financial assistance (Shannon et al., 2003). Moreover, the application process was seen as hurtful by these parents, possibly

due to their sensitive emotional state at the time of application. This disagrees with Epley et al.'s (2010) findings, that administrative staff saw their role as empowering these parents. Consequently, this may call for a re-evaluation of the amount of disability pension fees for the child's and the family's benefit as a whole in the light of state expenditure and the application process (see recommendations 7.2.3).

Maternal employment

Interviewed mothers experienced difficulties returning to the world of employment after having a child born 'at risk'; due to lack of specialist child-care services, lack of family child-minding support, fixed-time limitations of public services and lack of provision of learning support assistant (LSA) during summer schools for children with special needs. Abela et al. (2012) also found that the lack of child-care services for young children with disability could limit parents' opportunities for another source of income, since mothers could not work. Thus, given that mothers felt that they had no other option but to stay at home to care for their child, the majority of parents ended up with 'one-pay', increasing their financial concerns.

Previous literature also reported that families with greater needs for resources may not receive more support (Mahoney and Bella, 1998; Allen, 2007). Maltese mothers felt that inflexible working hours and the lack of LSA service during summer schools acted as barriers to seek paid employment and improve their family's financial state. Prior literature also associated lack of maternal re-employment with gendered decisions and caregiver burden perceptions (Cuskelly et al., 1998, Davis et al., 2009; Oh and Lee, 2009). Although lack of LSA barrier was not reported in prior literature, as it could be tied to Maltese service limitations, it created a persistent impediment for mothers to seek employment during the child's preschool years. Thus, barriers identified in the current study could have further augmented women's decisions to opt out of their prior-birth employment in favour of caring for their child or forced to change their profession to one with school holidays.

Interviewed mothers showed a desire to work outside the home to improve their family's financial state, similar to Gordon et al.'s (2007) Australian participants. The fact that mothers did not have the option of flexible working hours added to their financial burden perceptions. Some suspended or downgraded their career prospects to allow greater flexibility in the event of potential child health emergencies. This seems to

concur with Hieman's (2002) claims that mothers of children with disabilities had lower career expectations. A few mothers and fathers experienced the advantages of tele-working, in order to maintain their child's public services and still earn income for the family. But the tele-working option was not offered to all parents; perhaps due to the nature of their jobs or the absence of such a policy at their workplace. This may further confirm the need for policy improvements possible to support families of children at risk for ID (see recommendations 7.2.3).

Support needs from employer

Maltese employers were perceived to support family values by interviewed participants, as fathers felt supported when their new-born was in a life-threatening situation. Permission to leave work and visit their child in an emergency and other work arrangements offered during that time were interpreted as invaluable. Although there is no current public policy to assist these fathers, employers were seen to support in a reasonable manner. Prior literature did not indicate similar support. Perhaps Maltese employers may be more family-oriented or informal work arrangements were made.

Some mothers felt compelled to extend their parental leave to cater for their child's health needs. Findings of the present study concurred with Leijon et al.'s (2003), where Swedish mothers of preterm-born children reported using parental leave more than term-born children. Galtry and Callister's (2005) and Earle et al.'s (2011) added that there are limited opportunities for adequate parental leave for mothers to maintain prior-birth jobs, let alone for fathers. Indeed, one mother in the current study felt "*cheated*" out of her maternity leave, given that this started when the child was born and was spent on daily hospital visits to her child at the NPICU. Added leave benefits could be made available to enable both parents to participate in their child's care or allow adequate time for hospital-home transition/settling. This may also encourage sharing of child-care responsibilities within their family and add opportunities for maternal employment which would in turn improve the family's financial stability (see section 7.2.3).

Coping needs

Child care

Support in child care such as child-minding, offered by grandparents or other close extended family members were highly appreciated by the parents. This concurred with

Borg Xuereb's (2008) findings on Maltese first-time parents of typically-born infants. Such practical help was interpreted as a contribution towards the new family's daily management, but not all parents who felt in need for this help received this support. Arguably, parents may make use of child-care centres, yet this decision did not seem to be the first choice of the interviewed parents. The choice of child-care may be influenced by inter-generational choices (Mirfin-Veitch et al., 1997; Shpancer and Bennet-Murphy, 2006). Such inter-generational influences may also further intensify gendered decision making.

Additionally, Borg (2003) also found that his participants parenting typically-born Maltese children would not consider sending their child to child-care centres, due to lack of trust. Child-care centres are a relatively new concept in Malta where the number of centres opened is still small (Sollars et al., 2006). Moreover, those who wished to make use of child-care centre services, in the absence of extended families' child-minding, were disappointed with available fixed-day cost rates and the lack of specialist care. Although European Agency (2009b) specified that child-care services in Malta follow Equal Opportunities Act, this may be confined to building premises rather than professionals' care training. Indeed, the available child-care centres were seen as being available only for typically-developing children, by those parents whose children needed intensive medical interventions. This may be an added reason why such services may not have been considered for child-care. Consequently, child-care centres need to have professionals trained adequately to care for children with special needs to assist these families' daily management needs (see section 7.2.2)

Coping mechanisms

Parents felt that routine-maintaining and constant health vigilance helped them to cope and adjust to their situation as a family, similar to Pelchat et al.'s (2009) findings (section 6.3.2). Maltese parents reported that they managed to 'normalise' their daily lives by strict adherence to their routine. This mechanism might have helped them to focus on their schedule rather than the child's disability, via goal-oriented thinking (Erickson and Kurz-Reimer, 1999; Lloyd and Hastings, 2009b). Tway, Connolly and Novak (2007, p.258) recommended routine-maintaining as a coping strategy for American parents of children with autism in order to create 'normalcy', preventing the disorder from disrupting family life. A shift of focus was also noted amongst first-time Maltese parents, from meeting their needs as individuals or a couple to meeting their

child's needs, similar to Borg Xuereb's (2008) parents of typically developing children. Indeed, such a focus was observed over and above those of other family members, including siblings.

The majority of interviewed parents considered themselves as constantly vigilant due to the awareness of their child's low immune system, seeing them as fragile. The majority of Holditch-Davis et al.'s (2003) sample, likewise, showed overprotection and over-vigilant actions, such as protecting the child from germs. However, unlike Holditch-Davis et al., the Maltese parents themselves in this study did not consider these actions as over-protection; 'inexperienced' people may interpret such actions as over-protection, possibly due to lack of awareness of low-immune system consequences.

The experience as a couple raising an 'at risk' child adopted mutual understanding and appreciation, and mutual emotional-balancing to protect each other's emotional health. Such team dynamics were interpreted as co-operating well with each other's coping mechanisms. Green (2007) and Maul and Singer (2007) also agreed that parents who had complementary coping mechanisms co-operated as a team in other countries, regardless of the presence of a child with difficulties in the family. Furthermore, Golish and Powell (2003) added that good spousal/partner communication resulted in effective teamwork and mutual understanding. Similar outcome were reported in the current study.

Nevertheless, some couples did not complement each other's coping styles at times, creating some marital conflict. This corresponded to Urbano et al.'s (2007) study with USA parents, Clarke and McKay's (2008) study amongst UK parents and Risdal and Singer's (2004) meta-analysis. These reported that conflict was more likely to occur during the early years of the disabled child's life. Agreeing with these authors, some parents in this study mentioned increased couple conflict during or prior the child's preschool years but not after 3;6 years of age. Indeed, one family separated around the postnatal period. Nonetheless, cultural influences in marital breakdown could be at play, similar to Fertig's (2004) findings upon comparing USA and UK parents of 'at risk' children. As expressed in attitude changes (section 6.3.2), since divorce was legalised in Malta later in 2011 and such cultural influences may differ in the future.

Gender roles in coping

All interviewed parents in the current study seemed to employ role sharing and division of responsibilities from a gender perspective, similar to prior literature with Maltese first-time parents of typical children (Borg Xuereb, 2008). Gender role divisions placed the mother as the child's main caregiver and with housework responsibilities (see section 5.5.3.2). Some mothers interpreted this decision positively, however, this seemed to be 'socially-allocated' rather than by personal choice. Feminist research argues that such role-allocation could be deeply grounded in social life and might in turn affect women's career commitments (Acker, 1989; Cook, 1993). Traditional roles might be highly influenced by the society's social expectations (Abela et al., 2005, Abela, 2009b). Indeed, most mothers, including those in paid employment, saw their spouse/partner as helping them with housework responsibilities rather than sharing.

Cultural characteristics may change over time (Goldbart and Mukherjee, 1999b), particularly given the financial burden Maltese families have reported earlier in this section. It is vital that professionals helping Maltese parents are aware of these features in order to deliver and design up-to-date culturally-appropriate and tailored family-friendly services and policies (see section 7.2.3).

6.4.4 Communication needs

Communication needs incorporated information and communication needs perceived by parents (see section 4.3). Although communication needs are typically classified as psychosocial needs, this study explored them separately.

Information needs

Information was perceived by parents to directly affect their emotions. This agreed with prior literature (Rosetti, 2001; Jackson et al., 2007; Guralnick, 2008a) across cultures (Verma and Kishore, 2001). The perceived lack of immediate information, combined with lack of immediate professional emotional support, was interpreted as a source of distress in the current study during news-giving episodes and hospitalisation periods. These times are critical for information-giving as part of the professional's role, so that parents could make informed decisions (Rosetti, 2001; Redmond and Richardson, 2003; Jackson et al., 2007; Guralnick, 2008a). Moreover, Golish and Powell's (2003) participants noticed that information about the immediate NPICU environment seemed

to have reduced their perceptions of shock. This for the majority of parents seemed to be an unmet need in the current study. This further highlights the need for readily-available and accessible information (cf. Jurkovich et al., 2000) to assist parents' emotional recovery.

Maltese parents in this study enlisted the time-frames outlined in section 6.3.3 as key points for information-giving by professionals. Indeed, both qualitative and quantitative studies identified that information needs of parents rearing children with disability were crucial (e.g. Golish and Powell, 2003; Graungaard and Skov, 2006; Hummelinck and Pollock, 2006; Nicolaou et al., 2009). This may reflect a universal parental need across cultures and may be related to fear of the unknown. Although information-giving was considered to be a fundamental part of the professional's role in this study, as has been previously reported, this may not take place as required (Erickson and Kruz-Reimer, 1999; Rosetti, 2001).

Maltese parents had an individually established need for information. The range of individual views was similar to those found by Hummelinck and Pollock (2006). The internet was viewed as a readily-available and a constantly-present source of information, where parents kept abreast with new and updated information. It placed the parent in an empowered position that compensated for the lack of perceived information given by professionals. This concurred with findings from Gundersen's (2011) study of Norwegian parents rearing a child with rare genetic disorders. Those who reported making use of the internet in this study perceived themselves as well-equipped with up-to-date information.

Nonetheless, some also reported using the internet to evaluate professionals' advice. This finding is similar to Graungaard and Skov's (2006) Danish study, where inconsistency of advice led to distrust towards professionals. Such behaviour may also concur with Sudia-Robinson and Freeman's (2000) claims, that their parents felt the need for time to build a trust relationship with professionals and used the information-seeking process as a means to validate their concerns.

Lack of and inconsistency of information received might have pushed the majority of interviewed parents towards constant information seeking. Such active information seeking behaviour seems to disagree with Hummelinck and Pollock's (2006) findings,

where although their participants claimed the need for information, few were actively seeking it. Perhaps more specialist professional advice is easily available outside of Malta, given that some Maltese parents felt the need to seek advice abroad. Furthermore, some participants in the current study may have adopted information seeking activities as a coping strategy. This has been reported in prior literature and was associated with a positive attitude towards the child's disability and reduced psychological distress (Frey et al., 1989; Shapiro and Tittle, 1990) as parents consciously or unconsciously channelled their energies towards finding ways to assist their child's development.

Seeking information independently was not always interpreted as helpful by some parents in the current study, who expected medical professionals to be their main source of information rather than having to provide the information to these professionals themselves. Padden and Glenn (1997) also claimed that parents prioritised information from doctors, over other sources, regarding concerns on their child's health. Yet, the current study's finding might originate from a high regard for medical professionals, who are seen as the elite in the professions' classification in Malta (Sultana, 1994). This study's findings seems more likely to point towards a cultural trend; that parents look at the specialist medical professional or paediatrician as the most knowledgeable professionals. Indeed, Malta is considered as having medium power-distance values (Hofstede et al., 2010). However, as outlined in section 2.4, it manifests cultural trends from both ends of the continuum; i.e. high power-distance regarding respect towards medical professionals and low power-distance involving close family relationships. Pragmatically, this finding of high regard for medical professionals may also arise from the fact that such a professional's role is crucial to obtain a referral to access other services in Malta.

Communication style

Maltese parents felt they experienced both sensitive and insensitive communication attitudes from the professionals with whom they interacted. Information giving and receiving have a 'double-edged' nature that could have consequences for the child: professionals' understanding of parents' lifeworlds and parental concerns about their child's illnesses (Hummelinck and Pollock, 2006). In this study there seems to be a breakdown in this communication process. Indeed, potential misinterpretations from either party may adversely affect the communication process (Sudia-Robinson and

Freeman, 2000). Patronising communication attitude included difficult medical terminology, a detached attitude, lack of rapport building, lack of active listening and treating the child in a routine-manner. This seemed to push parents away, reduce comprehension of the intended message and increase frustration. These findings are highly similar to Padden and Glen's (1997) participants' interpretations that also left a negative impact on their participants' emotions. Such a communication attitude could be avoided via adequate professional training. Although a few professionals were insensitive, these seem to have had the greatest impact on the parents' lives.

Some parents interpreted receiving supportive communication from the medical and allied health professionals as being helpful and critical to their emotional health. This further agreed with Levetown's (2008) study where effective communication was seen to be receptive to the family's needs and considered to be a building block towards family-centred care. Nurses and allied health professionals were reported to have more sensitive communication attitude than medical doctors, concurring with Padden and Glenn's (1997) findings; perhaps due to the caring nature of their profession or their pre-professional training in helping skills. Although Reid et al. (2007) reported that parent-staff communication for conversational purposes was considered as an option in professional care, it was interpreted as therapeutic by their participants. Such a finding was also identified in this study. Not all nursing staff took the initiative to talk to parents on a friendly basis; however those who did were interpreted, by the parents, to be of emotional support.

Participants saw the medical professionals as attempting to protect themselves by being too negative when sharing news or giving information; the parents' psychological well-being was not taken into consideration. Giving too much or false hopes could be interpreted as unhealthy, yet, without 'a ray of hope' (section 5.7.2.1) detrimental effects on a person's life-circumstances might occur; including potential suicidal thoughts or increased drug taking activity (section 5.7.1.1). Hope was reported in prior literature as a cognitive variable that was amendable to change (Lloyd and Hastings, 2009b) and was a commonly adopted parent coping strategy (Graungaard and Skov, 2006). Perhaps Maltese parents felt deprived of this coping mechanism.

Parents in this study expressed that they required some hope during professional-parent communications to help them maintain their motivation. This may be the case as parents

felt so disheartened, particularly during their child's hospitalisation or when seeing unachieved milestones, since hope could help them cope with their frustration. This concurs with prior literature that hope can act as a compensatory mechanism, one that assist psychological well-being and reduce psychological stress in other cultures, such as in the USA (Kashdan et al., 2002) and the UK (Lloyd and Hastings, 2009b). Thus it is recommended for professionals to give some hope as encouragement to parents' in order to assist their emotional coping and motivation to help their child's development.

Medical and diagnosis news-giving were interpreted as negative, hurtful and at times offensive by almost all parents in the current study. Rosetti (2001) warned of such negative reactions, especially soon after child-birth. Nevertheless, few parents felt aware that their psychological distress at the time could have contributed to the negative interpretation of professionals' communication attitude. Arguably, Baile et al. (1997) implied that medical professionals feel uncomfortable communicating negative information that is likely to upset parents. To reduce the discomfort of the news-bearer and the extent of the recipient's negative shock, it has been suggested that formal training to assist news-giving based on the individual parents' lifeworld attitudes may prove to be beneficial (Todres et al., 2007; Dahlberg et al., 2009). A need to improve these professionals' communication skills and the manner in which they give negative news was identified as these could influence parents' future coping mechanisms and long-term relationship with professionals (see section 7.2.1).

Participants reported they had limited time with medical professionals during outpatient hospital visits, resulting in increased frustration as their concerns could not be voiced and clarified. Similar experiences were interpreted as maintenance of power inequality by Runswick-Cole (2007). One might speculate that medical professionals may have limited available time to answer parents' queries and concerns about their child's development due to having untailed fixed appointment times for outpatients' services. Nevertheless, according to Fredheim et al. (2011) for parents, the medical professionals are consistent collaborating partners and thus vital to manage their turmoil.

Street (1992) argued that parent-physician encounters to share concerns might not necessitate longer appointments but greater perceived helpfulness. However, time-allocation for doctor-patient-carer communication was viewed as essential in the patient's intervention programme by this study's participants, since parents are the

environment on which the child (the patient) is dependent (Bronfenbrenner, 1994; Roush and McWilliam, 1994). It could imply that professionals in this study either might not dedicate sufficient time directly for parents' queries or they may not tailor their communication techniques to deal with both the patient (child) and parents simultaneously. If the latter was the case it could agree with Maguire and Pitceathly's (2002) claims of closed interviewing techniques by clinicians with parents; thus further suggesting the need for formal training in open communication skills. Towle and Godolphin (1999) and Liptak et al. (2006) also recommended increased appointment times. Such a recommendation would be helpful in assisting the Maltese participants in building a constructive info-emotional support cycle based on the individual's lifeworld, thus tailoring communication attitude and services to their individual needs (see section 7.2.1).

Team collaboration and decision making contributions

The few parents who reported experiencing opportunities for decision making interpreted such an event as positive and empowering. Similar positive perceptions were identified by parents who participated in family-centred care services (King et al., 1999). This bodes well for increased satisfaction with services and professionals, should Maltese public service embrace family-centred principles (see Dunst, 2007). A few parents in the current study moved towards using solely non-governmental services in order to have more control in their child's intervention decision making process. It is possible that these parents could have felt financially stable enough to take such a decision to seek more empowerment and create their own family-centred care at their own expense.

Parents noted that they were acting as their child's care-coordinators, collating information from different professionals and act as professionals' liaison since they felt there was a lack of team communication between different professionals and departments such as health versus education services. Similar dissatisfaction was observed among Thyen et al.'s (2003) and Stille et al.'s (2007) parents. The latter reported acting as the primary intermediary between professionals, very similar to the context of the participants in this study. Yet, Stille et al.'s (2007) investigation implied that paediatricians felt more comfortable when parents acted as the liaisons on their behalf. This also seemed evident even in family-centred care services, as was reported by parents raising children with varied disabilities (MacKean, Thurston and Scott,

2005). The lack of team work could be explained by the power distance and individualistic values embedded within the Maltese culture (Hostede et al., 2010). Nevertheless, lack of teamwork is unjustifiable for trained professionals claiming to work for the well-being of their patients. This calls for more applied teamwork approaches to be embedded within the professionals' training (see section 7.1.2).

Arguably, some parents in this study felt that acting as the communication link between services was a necessity given that the team-collaboration needs between parents and professionals were unmet. This may suggest that parents' voices were unheard in child-focused services. MacKean et al. (2005) criticised the lack of team-communication in their explored family-centred services, given that it is an integral aspect of family-centred care. This parental dissatisfaction further places Dunst's (2007) family-centred principles in the limelight as a tentative solution to lack of co-ordination. However, professionals themselves need to be prepared for effective collaboration as an 'expert-client' relationship is known to contribute to difficulties in professionals' relationships with parents (Bruder, 2000; Turnbull et al., 2000).

Paige-Smith and Rix (2006) argued that parents might not necessarily wish to participate as their child's educator. Contrarily, in this study parents did not avoid or complain about stimulating their child's development; only one mother reported feeling overwhelmed when her child was less than 2 years old. However, not all were aware of the importance of stimulation. This could be solved via time-based information giving depending on the child's age, as identified by parents themselves in section 6.3.3 (see recommendations 7.1.2). This paves the way for the implementation of family-centred principles using family-mediated child learning and enhancing parents' self-confidence and development-instigating learning opportunities (Dunst, 2007).

In summary, Maltese parents reported frustration when their needs were not taken into consideration. Although most of parents' needs are focused on striving for their child's developmental needs, some were overlooked and it is vital that these are addressed as much as possible, for the wellbeing of the whole family. Parents' dissatisfaction could reduce if their unmet needs are incorporated into services. This study highlighted parents' met and unmet needs and provides evidence for building future services that embrace family-centred principles.

6.5 Methodological discussion: Strengths and limitations

Strengths

This is the first study focusing on Maltese parents of children born with biological risks for ID during their first five years of life. One of the main strengths of the study is that the findings are of significant importance to the growing body of knowledge on parenting young ‘at risk’ children, cultural influences on parents’ lived experiences, parental needs to promote these children’s development and experiential differences during the first five years of the child’s life.

This study presented findings about the everyday experiences of these parents that would not have been obtained had a quantitative methodology been used. Following IPA methodological principles the uniqueness of experiences for each family were acknowledged and highlighted. The identified differences and similarities of these parents’ lived experiences indicated the adequacy of the inquiry method adopted to answer the research questions.

One of the main strengths of this study was the adoption of a cross-sectional design focusing on a step-wise child age-specific exploration. This study took a different stance from most other studies carried out about the subject. Previous studies included participants using a wide age-range (e.g. from birth to 18 years of age), while this study’s participants were interviewed at specific developmental points. This helped both long term recall of their past experiences from the birth of their child and the immediate lived experiences of each particular time-point. The latter could present a more vivid picture of how they were actually living the now experience. This also strengthened the credibility of the findings. Consequently, this research may be of significant assistance to paediatric and early intervention professionals, as well as social-policymakers, to learn and anticipate potential age-related needs in order to tailor services to the parents’ lifeworlds for each child’s and family’s benefit.

The interviews gave the parents the opportunity to voice their feelings and to reflect upon their lived experiences. This method also allowed parents to reflect on the future of their family and personal life, as it allowed time and space for them to go into detail about their changed realities. This was interpreted as a therapeutic exercise by the parents (see Appendix V).

Another strength of this study is its sensitivity to the family, in that both parents were interviewed together. The relationship and interconnectedness that exists between both parents as well as between the parents and their child/ren was apparent. This also highlights the need for more research which includes both parents together. To date, the majority of studies interviewed parents separately or opting to interview one parent. Having interviewed both parents together has shown the interconnectedness and inseparability of the family members as one person influences the other person during their daily lives and co-construction of their shared experiences. This context has highlighted the importance of both parents' embodied position in the world for their child/ren's development benefits.

Limitations

Differences in parents' experiences whilst rearing their child born with biological risk were explored via cross-sectional design, involving different people in each age group. Arguably, a longitudinal study could have offered greater opportunity to observe perceptual shifts over time by following the same sample. This was not possible due to the limited time-frame available for the research. Another alternative could have been to focus mainly on the hindsight interpretations of parents of 5 year old children, given that they had accumulated most experiences with smaller sample size. Following Sartre's (1948) philosophy, time could have changed their interpretations from when they lived their experiences: i.e. their hindsight interpretations of their child's first year could have been different if these were living it at the time of interview. This was observed when hindsight re-interpretations came to play. However, the experiences accumulated by those rearing a 5 year old child (group 4) have acted as a confirmation of the experiential differences observed in groups 1, 2 and 3.

In most interviews both parents seemed to see the interview itself as a therapeutic exercise (see Appendix V). This may also have biased the results of the study, as they could have given more importance to venting their frustrations. I also acknowledge that the interplay of insider-outsider perspective (see Appendix V) may have biased the participants' openness and their approach of expressing their interpretations during the interviews, giving greater emphasis to the negative aspects of their experiences and voicing their concerns, rather than elaborating on what was positive. Perhaps they thought I could make a change or be of assistance to other parents through participation in the present study.

Although this study offered a unique method where both parents were interviewed together based on their parenting influences on each other, it may have also acted as a barrier to divulging private disagreements in front of a third party. There were some occasions where parents talked about circumstances that the other spouse/partner was not aware of at the time (see section 4.11.2). Moreover, being a woman I may have given more importance to mothers' reflections rather than fathers. I might also have promoted a context where the mother felt more at ease to divulge her experiences more than the fathers, whilst also potentially influencing the explored topic as associated with women rather than men given the cultural traditional role influences (see section 2.4.1, 5.5.3.2). Nevertheless fathers did not seem intimidated from divulging new information about their experiences in front of their wives and the researcher. The interview could have also acted as an opportunity for fathers to make their voice heard. Although these situations added strength to the study, similar outcomes cannot be assumed for other research.

A few data collection challenges were unforeseen, such as the inaccessibility of hospital ward due to multi-bug resistant diseases and that parents of children aged 3;6 and 5 years of age could not be contacted due to changes in their personal details. Personal contact details of some parents were not kept updated due to lack of re-hospitalisations at the NPICU ward as the child grew older. This could have affected the selection of the participants made by the health professional.

The sample size was large for an IPA study. This could have acted as a limitation for the depth of the analysis (Smith, 2011) within a limited timeframe. However such a sample size was important due to the unpredictable nature of intellectual development and brain plasticity (see section 2.2) in order to address the homogeneity for each group.

Another limitation of the study is that results cannot be generalised to all other parents with similar circumstances, even though theoretical transferability is considered possible (Smith et al., 2009). The qualitative attributes of IPA, the unique culture of Malta and my double hermeneutic interpretations strengthen the findings and are considered valid for the population under study. Should this study have adopted a mixed-method approach, a quantitative perspective in combination with a qualitative element could have offered social-policymakers better opportunities for generalisability

of findings to the larger population. However, the Maltese context has a small population; hence generalisability would have also been limited. The interviews conveyed information about the parents' experiences that would have been unobtainable should surveys alone have been used.

6.6 Conclusion

This chapter discussed the findings of this study in the light of its research questions, previous literature and theoretical framework. Parents' physical, emotional, psychosocial and communication needs highlighted the extent of unmet parental needs throughout the biologically 'at risk' child's first five years of life. Culture was observed to play a significant role in parents' lived experiences. Professionals seem to be in a crucial position to assist and alleviate parents' stresses. Parents' experiential differences were noted at each time-frame and throughout the child's first five years. It is crucial that professionals assisting these parents are aware of such trajectories in order to adapt their service-delivery to the parents' evolving lifeworlds as the child grows. Such knowledge may also be useful to policymakers to assist these families' wide array of unmet needs. Methodological issues including strengths and limitations of the study were also discussed. Implications and recommendations from this study will be outlined in the following concluding chapter.

Chapter 7 Conclusion

In this chapter, I propose a number of implications and recommendations for practice, education and policy to support the needs of Maltese parents whose child is born with biological risks for ID. Suggestions for future research complete this thesis.

7.1 Implications for Malta

7.1.1 Maltese services

Parent-to-parent support seems to have been beneficial to parents in this study, both emotionally and for guidance purposes. The results suggest that the creation of a parent-to-parent support service may assist acceptance and child rearing. Emotional support seems to be particularly needed during neonatal hospitalisation and also throughout the child's first five years of life. Guidance from this type of support proved to be helpful for parents to access services and in anticipating the developmental needs of their child.

The study identified the need for more family friendly public services. Parents' hectic daily schedules and attempts to meet the needs of their child may impede access to all the required services available in the public sector. Although they could be facing financial difficulties, the added health needs of their child may prompt parents to choose staying at home to care for the child, over seeking paid employment outside the home, in the absence of appropriate child-care facilities. The creation of more child-care centres with special care facilities and personnel trained in special needs care may offer parents greater employment opportunities.

Findings also identified a number of unmet material needs in Malta, including preterm materials and clothes. Engaging the local commercial community regarding the unmet demand for preterm materials may reduce parents' stresses. There is also a need for child-minding services at the hospital premises for typically developing siblings while parents are visiting their hospitalised child, should they have reduced child-minding support from extended family. Such logistical support may assist parents with the most pressing early needs at a time of considerable stress: those of clothing and caring for a new baby while assuring the care of other siblings in the absence of parents.

7.1.2 Professionals working with Maltese parents

The communication styles of professionals were reported to influence the parents' emotional state and their perception of guidance. This suggests that all professionals assisting these parents should be aware of their responsibilities in the way they communicate news, information or situation briefings. Whilst many professionals were seen as supportive and helpful, others, especially those giving negative news, were sometimes found to be unsympathetic. The responsibility to communicate in an empathic style stems from the professionals' role to act for the benefit of the individual. This places the professionals in a crucial position where even if the situation is potentially upsetting, they could still alleviate the impact of news-receiving to support long-term emotional coping of parents.

Professionals were noted to be one of the parents' main information sources, alongside the use of the internet. This study highlighted the need for simplified, readily-available information to be given to parents at key stages whilst raising a child born with ID risks: namely at birth and during neonatal hospitalisation; at neonatal hospital discharge and before the main stages of the child's development. Information on what to expect when seeing their child at the NPICU ward could reduce the shock for parents. Parents suggested the use of DVDs especially during hospitalisation, and before entering the NPICU ward environment. DVDs may also be particularly useful for parents who have limited literacy. Also, information should include key developmental exercises that can assist the child's development at least throughout the first 5 years of life. At each stage an information pack could be provided both in Maltese and in English, containing key developmental exercises that parents can perform at home as well as key professionals' contact details. Such information-giving approaches may reduce feeling bombarded with too much information at one time, alleviate potential shock and address potential difficulties they may meet, in a step-wise manner.

Teamwork is an internationally known concept. This study further highlighted the importance of collaborating well in a team for the benefit of these families. Referral to other professionals was also identified as a tool to access services and financial assistance for parents. It also gives new hope to parents and is interpreted as a sign of professionalism. Teamwork assists in building bridges with other professionals within the health and education sectors, for the benefit of the affected child and the family as a whole. The need for continuity of services was deemed to be essential. This may also be

achieved by increasing the time-period of the professionals' transfers within the paediatric services, particularly in physiotherapy and occupational therapy.

Parents are a central part in the child's environment, thus they should be involved in all decision making processes in intervention programmes. This affected the way parents viewed themselves as having responsibility and active participation in their child's intervention programme. Such involvement also conveyed a greater sense of satisfaction among parents when developmental goals are met.

7.2 Recommendations

7.2.1 Education in Malta

There seems to be an urgent need to train professionals more on the use of an empathic communication style with parents of neonates born with ID risks. This may take place in pre-professional training or in continuing professional development. The individual's communication attitude seems to have a significant effect on the interlocutor's emotional state. Maltese parents identified an empathetic communication style as one that may involve a small message of hope no matter how negative the context, active listening skills, acknowledgment of parents' emotions, the willingness to collaborate with parents as well as adapting terminology and information to parents' educational background. Shared spiritual beliefs, between professionals and parents, were identified to be a source of emotional support. Participants also identified the need for a calm and patient communication attitude, together with readiness and available time to answer all parents' queries to ease their frustration and anxieties. As their child's carers it is important for the parents to be treated as team colleagues who can reflect on the situation and decide about the best option for their child after being given all the information needed to reach a decision. Consequently, parents also felt the need to be present during their child's hospital ward round and involved at all stages of their child's decision-making and intervention programme.

Professionals need to be well trained in negative news-breaking and on parents' possible emotional reactions including their lived experiences whilst rearing a young child with ID risks. This is essential for professionals to feel equipped to respond sensitively to parents. It is also vital that they become aware of parents' experiential

changes as their child grows. The educational programme should also highlight the need for a team approach, involving parents as important team members, the importance of early intervention and the impact of early referral to services. Such an awareness-building activity is vital to build insightful help-giving processes, based on parents' individual needs. Consequently, professionals could act as a source of support to the whole family and they would be shifting towards a family-centred service approach, using life-world led practice (see Todres et al., 2007, Dahlberg et al., 2009).

Community members also need to be aware of the stigma associated with the word '*misikin*' (Eng.: poor thing). The demand for and promotion of respect towards other persons' emotions, dignity and personal experiences may trigger a cultural change towards reducing stigma. Education of community members including parents of 'at risk' children should also include typical developmental milestones and stimulation advice as a preventive public intervention. Using public media for information-giving and sharing parents' personal experiences could be considered as a learning opportunity for the 'inexperienced' others. Although these actions may involve ethical repercussions, as the parents' identity may become known to others when parents themselves may wish to perform such an action for the benefit of other fellow parents.

7.2.2 Specialised services in Malta

This study indicated that parents felt concerned when their child manifested developmental delay. Consequently, they reported seeking services based on immediate and evident need: such as when their child fails to achieve physical independence. Thus, there is a critical need to create a link between the NPICU ward and early intervention services, as well as between health and education services, in order to follow up all parents whose child was born with ID risks. This direct multidisciplinary link and interchange of personnel may act as a preventive early intervention strategy. Professionals such as physiotherapists, speech and language therapists, child psychologists and professional counsellors, may provide regular services at the NPICU ward via parental training, prior to hospital discharge and during hospital-home transition. It is vital that these specialist services maintain regular contact with parents even after their neonate's hospital discharge, in order to perform regular developmental screening and to provide preventive developmental advice, accordingly. One may argue that these services may stimulate further concerns in parents that are unnecessary.

However, parents may feel reassured that their child may be developing well or that they are acting as early as possible to help their child achieve his/her maximum developmental potential. The first developmental screening could be carried out in parents' homes following discharge from hospital, as initially they are advised by paediatricians to avoid social contact and crowded places to protect their child's immune system. A strong collaboration between the various stakeholders is critical for the success and effectiveness of such a service.

In the absence of child-care from grandparents, the study suggested the need for more child-care centres, especially those that could accommodate children with special needs. The majority of child-care centres in Malta are privately run, and although, they are currently growing in numbers, they are still limited (Sollars et al., 2006). It is recommended that child-care centres offer flexible schedules to suit individual parents' daily lives to better assist family management. This also calls for more specialised early-education and disability-related-care trained personnel working in child-care centres to support children with particular health needs. The provision of individualised care settings may also widen their accessibility and reduce potential discrimination towards this population. Once the recommended changes are implemented in child-care centres, it is essential that these are well publicised to enhance public awareness and increase trust among parents who require this service.

Negative news-receiving was interpreted as a traumatic experience by the majority of participants. There is a critical need for a psychologist or counsellor to be present during news-giving meetings in order to offer immediate emotional support to parents; even when professionals have been trained how to deliver negative news as this can be a difficult for both the news-giver and, more so, for the news-receiver. The presence of a psychologist may also act as a reassurance, guidance and encouragement to professionals who feel insecure about how to divulge sensitive news to parents.

Parents need to be aware of available services and support, ideally, prior having an 'at risk' baby. This context may not be predictable thus parent-craft courses are recommended to begin before the 6th gestation month, as is currently the situation in Malta. The early sessions may focus on awareness of paediatric services, possible scenarios and available emotional support services.

There are a limited number of specialist services in the health and education fields such as orthotic services, paediatric ophthalmic services and professionals specialised in visual impairment. These service gaps need to be addressed by policymakers as service organisers. Although orthotic services are available in Malta, these do not reflect the young children's physical growth-spurts needs, as materials have to be ordered from outside the country with significant delay. The provision of full-time specialist professional services could result in greater patient satisfaction levels, with greater an efficient and effective service, that is more long-term cost-effective both for the affected families and for the country's economy.

7.2.3 Maltese family policy

The study highlighted the importance of the family institution, both for the benefit of the concerned child and the effects of various subsystems around parents. The study suggested the need for more services supportive of the family. Recommendations focus on parent-to-parent support, the adoption of more family friendly services and financial support that reflect the cultural commitment towards these parents' times of need.

Parent-to-parent support

Support to parents from others who share similar experiences was highly regarded. In Malta, parent-to-parent support is not organised at service level but based on one's informal contacts. Thus, it is recommended that a formal parent-to-parent support service be created. This service's headquarters may be based in hospital, given the intensive support needed for parents of hospitalised neonates. Such a service may also be extended to include other paediatric hospital wards, offering emotional support to carers or parents of hospitalised patients, including grandparents. These services may reach out to health centres, schools and local parish centres. These may also be delivered in the community family centres that were recommended by Abela et al. (2012) to support the needs of Maltese families with dependent children.

Parent-to-parent support services should be offered soon after news-breaking meetings, where 'experienced' parents of older children may be invited to hospital to share their experiences and answer questions posed by new parents of children born with similar conditions. These questions involve experiential knowledge that only parents with similar experiences can answer. Training in helping skills may be needed for those

parents offering support to others. Parents may thus not only feel emotionally supported but also reassured that they are not alone and that the experiences of other parents may guide them towards their next step with continued contact as the child grows, via the parent-to-parent support service network across the islands.

This service may also be linked to early intervention services, utilising a multidisciplinary approach and educational talks to parents, by various professionals, about stimulation or preventive early intervention. This may start from the neonatal period, based on voluntary attendance. A crucial part of the child's multidisciplinary team is the 'experienced' parents, who wish to share their story with others rearing younger children via group or individual sessions. Such a service may be empowering and provide support to parents who are passing through a similar emotional upheaval. For those parents who disclose their experience to others, they may fulfil their desire to be of support to others. Such a network of parents may be created through the signing of ethically approved consent forms during their hospitalisation period or prior neonatal hospital discharge. Parent-to-parent support services may also act as a source of practical support to parents during their hospital-home transition period. This period was marked with insecurities, feelings of abandonment by the health professionals and emotional anxiety. Parents may thus have a contact, to whom they can ask questions and guidance should they feel lost or insecure.

This study identified that single-mothers could be at a disadvantage due to feeling the need to fill both parents' roles and lacked emotional support. It would be advisable for single-mothers to be offered continuous follow-up via parent-to-parent support, in order to provide both emotional and management support.

Additionally, this study found that mothers felt emotional distress when they were hospitalised near other mothers who had typical births and quick discharges. Such distress may be avoided if these mothers are placed either in single bedrooms or at least allocated in joint bedrooms with other mothers who share similar birth experiences. This may also call for the need for more available single bedrooms for affected mothers at the national hospital. Sharing bedrooms with same-experienced mothers may not only reduce feelings of having an atypical experience, but also provide parent-to-parent support via informal sharing of experiences during the hospitalisation and recovery period of the mother.

Furthermore, it is highly recommended to allocate a small social area inside the NPICU at the national hospital that may be used by parents to relax, away from the child's incubator and to allow interaction with other parents. This may also act as a source of parent-to-parent support. Such an informal environment may also assist to reduce the self-shielding shock and perceived isolation during the initial stages of their emotional upheaval.

Maltese family friendly services

This study suggests the need for changes in financial, medical, educational and employment policies towards more family-friendly services. The application process for the disability pension was felt to be insensitive. Some parents recommended the sharing of hospital computer-based information and test results or postal verification, rather than personally visiting the administrative premises. It would be less emotionally distressing if they did not have to present themselves soon after diagnosis to claim such a pension. They also recommended a health professional or social worker interview at home soon after hospital-home transition. This procedure may also help parents to become informed of and access all the required services by a professional, on an individual basis. Some parents recommended 24 hour support service particularly during hospital-home transition, when queries or emergencies become evident and parents would require immediate assistance at least by telephone. Borg Xuereb (2008) recommended similar assistance for parents of typically born babies. However this has not yet been implemented and parents of 'at risk' children have greater immediate need for this support service.

Early intervention services should also adopt a family friendly style. This study's findings may be utilised as a foundation towards setting up such an evidence-based family-centred service. This service may be tailored to each family's needs via a meeting with the whole family prior implementing the intervention programme, where family members are encouraged to voice their opinions and needs since their participation is crucial for the team approach and programme success. This service may also focus on raising awareness amongst parents of 'at risk' children, about preventive aspects of early intervention to empower parents with adequate preventive skills to enhance their child's developmental potential as early as possible.

Hospital services need to adopt a more family friendly approach. This may include extended times for service provision of public health services: one that is not only offered during the morning or early afternoon but also after office working hours, so that working parents may access hospital services without suffering negative consequences on their employment. Appointment times, could thus be offered for an afternoon or evening session. This would support parents and could also increase employment opportunities for professionals seeking to work in the public sector and increase affected mothers' employability. This will also provide the potential to extend outpatient appointment times, allowing doctors more opportunity to build rapport and time to answer parents' questions as well as extended pharmacy opening times to increase access to children's controlled medicines. This may also present a possibility to reduce waiting-times at outpatients' services and increase the frequency of appointments for paediatric services, due to an increase in the number of available professionals. The reduction of waiting-times may also facilitate greater paternal involvement, as in this study fathers reported a desire to be more involved in their child's paediatric services, hence reducing dependency on their employer's generosity.

An LSA is allocated to children with disabilities in public and church schools in Malta during the school-year but not during summer schools. It is recommended that such an educational assistance should not be limited to the school-year due to limitations of parents' employment opportunities and continuity of educational routine among 'at risk' children. It is recommended that these parents may be given the opportunity to opt for a government-provided LSA if they wish to send their child to a summer school.

Few parents have reported the advantages of using teleworking to maintain their paid-employment and manage their family duties. Others reported financial difficulties due to their inability to seek paid employment due to child-care commitments. Available teleworking opportunities indicate that the Maltese policy is already shifting towards a more family-friendly perspective. Nevertheless, other parents may also benefit from such opportunities should this be advertised and made available more across occupations in the public and private sector, especially for parents of children with disabilities.

Services in Malta are currently child-focused. This study identified a number of unmet parents' needs due to having a child-focused approach. Children's development could

be affected by and directly affect parents' needs and experiences. It is thus vital for policymakers to incorporate parents' voiced needs into service delivery to move towards more family-centred principles using evidence-based approach. This study has clarified that a family's needs may not entirely be the same to another family's; the requirement of tailoring services is essential. Immediate investment in this service approach is essential in order to assist not only the child but the family as a whole.

Financial support for Maltese families

Some couples whose child was in need of urgent surgery in the UK had to buy the second-parent's flight ticket out of own pocket. This may discriminate against two-parent families and does not reflect the cultural Maltese family values. It is highly recommended that financial assistance during life-threatening surgery within the neonatal field be provided for both parents. The presence of both parents together during their neonate's or infant's surgery is vital and acts as a source of emotional support for each spouse/partner.

All mothers who wish to maintain their jobs after giving birth to a child with biological risks for ID should be given extended maternity leave rights due to the long neonatal hospitalisation period. Indeed, their maternity leave could initiate when the child is discharged from hospital as it would assist these mothers to fulfil the true purpose for maternity leave: settling at home with a new baby. Moreover, those fathers who wish to be involved with their child's intervention programme could be offered added family leave benefits besides their annual leave so as to reduce these affected fathers' limitations in paternal involvement. These added family leave benefits could be claimed-for by using a special form signed by the relevant professional clinician or medical professional on the date of session or consultation attendance.

Parents receive a weekly allowance for children with disability of 16.31Euros/week. It was reported that such a financial support does not reflect the actual expenses that parents face to meet their child's needs. They reported using a combination of public and private services to assist their child's development and due to their individual needs and schedules. At times they felt the need to go abroad because of a lack of specialist services whilst lack of professionals' referral may also pose a threat to access public services and financial assistance from Maltese charity organisations. An increase in the allowance to reflect the parents' actual expenses may be helpful. Parents also suggested

the provision of temporary permission for free parking for those parents whose child is hospitalised for more than three weeks. Moreover, these permissions may offer access to parking areas that are closer to the NPICU ward that may be less frequented during later afternoon and evening hours.

There may be initial costs to implement the suggested changes in services across Malta, due to demand for paediatric and early intervention services for children. However the long-term cost-benefit ratios are high; as older children may require less specialist services, maximising their educational achievement (Ramey and Ramey, 1999), leading to better jobs, the increased ability for parents to be in paid-jobs and consequently more tax for the state. Moreover, affected children may grow to become adults in society living independently with reduced need to depend on government-funded institutions and may be better skilled for employment. Indeed, early intervention services have been proved to have high cost-ratio benefits in USA and are considered to be a '*sound economic investment*' (Barnett, 2000, p.605).

7.3 Future research recommendations

It would be useful to perform a similar study exploring multiple perspectives, those of the parents' perceptions, the children's insights, together with a group of professionals and social policymakers. This triangulation of perspectives may shape a more realistic picture and may provide more practical changes that suit all the team involved in these situations.

This study was a cross-sectional exploration of parents of children from 0;6 to 5 years old. A longitudinal exploration of the same participants over a span of time may allow the researcher to observe perception changes of the same persons based on their daily lives, coping mechanisms and individual adjustments.

Performing a similar study using mixed methods approach may also offer the benefit of both qualitative and quantitative research worlds via pragmatic paradigms. The numerical aspect may be more appealing to social-policymakers who may wish to understand policy improvement impact from a wider perspective, such as the financial cost of services and their long-term benefit.

Exploring the experiences of the wider population parenting older children, incorporating siblings' perceptions could use a similar qualitative methodology to this study. However this may necessitate a holistic family interview or separate interviews of each individual in the family.

Exploration of the experiences of parents of children at risk for ID could take place internationally. This may necessitate collaboration across universities in different countries and communities, to extend the exploration of parents' experiences given the strong cultural influences. This is an opportunity for international collaboration as well as understanding similarities and differences of parents' experiences using similar inclusion criteria, so that the comparisons and application of recommendations may be of benefit to more populations. There are also EU funding opportunities for cross country research.

A follow-up investigation may prove interesting to understand the effects of policy changes or cultural attitude shifts in Malta. A repetition of the same study with the same participants may produce different interpretations. Nonetheless, a needs-analysis may be helpful in understanding the effects of implemented recommendations on parents' daily lives in the foreseeable future.

7.4 Conclusion

This thesis explored the perceptions and voices of Maltese parents of children born with ID risks, based on their daily child-rearing experiences. The results of the study identified the multiple challenges and needs that these parents face while assisting their child development during his/her first five years of life. I consider that the study has contributed to the general and local understanding of parenting young 'at risk' children from the perspectives of Maltese parents. The findings underline the need for further investigation to provide a wider representation of what it means to parent children with ID risks. In conclusion, this study highlighted the importance of taking into account the experiences that Maltese families face whilst raising their child with risks. It shed light on the responsibilities that professionals and policymakers have towards the wellbeing of the whole family, as the wellbeing of society depends on its families. This glimpse of the parents' lifeworlds could sensitise professionals and policymakers about how to communicate with parents and to plan services to meet the whole family's needs and to

promote their wellbeing. Changes in the provision of paediatric services are needed to reduce the level of parents' distress. The suggested recommendations have the potential to improve the quality of the Maltese families' lives under study. These may be costly, however lack of action may prove to be more expensive in the long run for parents themselves, for their child as a future adult and ultimately for society itself.

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Appendix I Literature search terms

Overall search strategy used for searches includes:

(experiences OR perceptions OR needs) AND (parents OR carers OR mothers OR fathers OR families) AND (children) AND ((intellectual disability OR cognitive impairment OR mental retardation OR disability) OR (birth complications OR congenital anomalies OR very low birth weight OR very premature OR low Apgar score OR biological risks for intellectual disability))

Search engines: Ovid, Web of knowledge, Ebsco, Scopus, Google scholar

Search data bases: PsychoInfo, CINHALL, Medline, Pubmed, Ovid Journals, Sage publications, University of Malta Melitensia library, British Library ETHoS

Searches initiated in September 2009 and was last updated on May 2013.

Since a large amount of general articles were identified these were filtered by relevance via abstract filtering. Subsequent searches were performed in relation to index referencing of identified articles. This created an expanded method of searching for literature. Other phrases related to methodology and theoretical framework were also used in a similar manner. Authors of inaccessible full articles were contacted and few replied whilst others did not.

Biological risks for intellectual disability: This search initiated from text books and expanded via indexing referencing links.

Malta, Maltese culture and experiences of Maltese parents of children with risks and/or disabilities: This search initiated from Maltese publications and unpublished dissertations available in University of Malta. This helped expansion to further secondary searches in databases.

Appendix II Intellectual disability definition

Intellectual disability definition

Various definitions of intellectual disability are used by clinicians for diagnosis and research purposes (Carr and O'Reilly, 2007); such as those provided by International Classification of Diseases (ICD-10) (World Health Organisation, WHO, 2010), American Association for Mental Retardation (AAMR-10) (Luckasson, Borthwick-Duffy, Buntinx, Coulter, Craig, Reeve, Schalock, Snell, Spitalnik, Spreat and Tass, 2002) and Diagnostic and Statistical Manual of the Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000). WHO (2007) acknowledges the presence of different labels for the same condition worldwide based on the country's most commonly used terms: such as mental retardation, mental handicap, intellectual disabilities and learning disability. All these labels have three common criteria: limited intellectual functioning, limited adaptive behaviour and manifestations of these criteria prior adulthood. International literature may thus use different terms for the same condition, unless this is specifically defined to have different criteria in a given study.

The Royal College of Speech and Language Therapists (RCSLT) and Department of Health in UK use the term learning disability instead of intellectual disability. RCSLT currently adopts the WHO (2010) criteria to define learning disability. WHO (2007, p.19) stated that 'both ICD and DSM-IV classifications systems use the term 'mental retardation' to refer to 'intellectual disabilities.' The Department of Health of UK, DoH (2001) also include functional descriptors and levels of support required by the individual. The definition of DoH, UK states that a person with intellectual disability has a reduced ability to understand new or complex information, to learn new skills with a reduced ability to cope independently; which starts before adulthood and has a lasting effect on development. Since Malta uses the definition adopted by the RCSLT, WHO (2010) and DoH, UK (2001), it is adopted in this thesis.

Both the ICD-10 and DSM-IV-TR classify ID in mild, moderate, severe and profound sub-categories, while AAMR-10 offers four different classification systems. These include classifications based on: intellectual level, similar to ICD-10 and DSM-IV-TR; with the addition of adaptive behaviour; aetiology; and supports, as separate classification criteria. ICD-10 provided an aetiological framework for classification, by diagnosis while ICF classify functioning and disability associated with health conditions. AAMR-10 adds a classification criterion of aetiology that is based on biomedical, social, educational and psychological features caused during pre-, peri- or

postnatal period (Luckasson et al., 2002). Carr and O'Reilly (2007) indicate that for research purposes it may be appropriate to classify cases by aetiology. Since the nature of the present study involves very young children, pre- and peri-natal biomedical factors are better suited for identification of the potential participant. Moreover, Carr and O'Reilly (2007) added that ID is also related to specific syndromes, distress at birth or those who have been exposed to significant prenatal risk factors or low birth weight. These conditions are typically detected during the early weeks of the postnatal period.

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Appendix III Ethical permissions

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19 May 2010

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Application for Ethical Approval from Elayne Azzopardi

Title of the Project:

The experiences of Maltese parents of children born with a biological risk for intellectual disability: The Early Years

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Dear Elayne

I am happy to confirm that you have ethical approval for your study.

Yours sincerely

Deirdre Connor

pp. Prof Carol Haigh PhD RN
Chair, Faculty Academic Ethics Committee

Pro-Vice-Chancellor and
Dean of Faculty
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UNIVERSITY RESEARCH ETHICS COMMITTEE

Check list to be included with UREC proposal form

Please make sure to tick ALL the items. Incomplete forms will not be accepted.

| | | YES | NOT APP. |
|-----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|----------|
| 1a. | Recruitment letter / Information sheet for subjects, in English | ✓ | |
| 1b. | Recruitment letter / Information sheet for subjects, in Maltese | ✓ | |
| 2a. | Consent form, in English, signed by supervisor, and including your contact details | ✓ | |
| 2b. | Consent form, in Maltese, signed by supervisor, and including your contact details | ✓ | |
| 3a. | In the case of children or other vulnerable groups, consent forms for parents/ guardians, in English | | |
| 3b. | In the case of children or other vulnerable groups, consent forms for parents/ guardians, in Maltese | | |
| 4a. | Tests, questionnaires, interview or focus group questions, etc, in English | ✓ | |
| 4b. | Tests, questionnaires, interview or focus group questions, etc, in Maltese | ✓ | |
| 5a. | Other institutional approval for access to subjects: Health Division, Directorate for Quality and Standards in Education, Department of Public Health, Curia... | ✓ | |
| 5b. | Other institutional approval for access to data: Registrar, Data Protection Officer Health Division/Hospital, Directorate for Quality and Standards in Education, Department of Public Health... | | |
| 5c. | Approval from person directly responsible for subjects: Medical Consultants, Nursing Officers, Head of School... | | |

| | |
|------------------------------------------------------|----------|
| Received by Faculty office on | |
| Discussed by Faculty Research Ethics Committee on | |
| Discussed by university Research Ethics Committee on | 9/7/2010 |

Monica Metropolitan
University 001/2010

UNIVERSITY OF MALTA

Request for Approval of Human Subjects Research

Please type. Handwritten forms will not be accepted

You may follow this format on separate sheets or use additional pages if necessary.

| | |
|--------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|
| FROM: (name, address for correspondence) Elayne Azzopardi | PROJECT TITLE: 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years' |
| TELEPHONE: | |
| E-MAIL: | |
| COURSE AND YEAR: PhD in Speech Pathology, 1st Year | FACULTY SUPERVISOR'S NAME: Professor Jois Stansfield |
| DURATION OF ENTIRE PROJECT: from 2009 to 2013 | |

ANTICIPATED FUNDING SOURCE: This course is funded by Strategic Educational Pathways, (include grant or contract number if known)

1. Please give a brief summary of the purpose of the research, in non-technical language.
Aim
• To explore the experiences and needs of Maltese parents of children aged 0-5yrs who were born with a biological risk of intellectual disability.

Objectives

- To explore the experiences of Maltese parents in raising a child who has a biological risk of intellectual disability when the child is 0;6, 2;0, 3;6 and 5;0yrs of age.
- To investigate the perceptions of Maltese parents of children aged 0;6, 2;0, 3;6 and 5;0yrs of age who have a biological risk of intellectual disability concerning the parents' physical, psychosocial and communication needs to nurture their child.

Please find attached an executive summary of my proposal.

2. Give details of procedures that relate to subjects' participation
(a) How are subjects recruited? What inducement is offered? (Append copy of letter or advertisement or poster, if any.)

The participants' recruitment depend of the age of their child and the presence of birth complications. The participants will be invited via posted information letter and consent form. They may sign the consent form and return it to the researcher in the pre-paid envelope if they wish to participate. No inducement will be offered, participation is based on a voluntary basis.

(b) Salient characteristics of subjects—number who will participate, age range, sex, institutional affiliation, other special criteria:

Selection of participants will be based on the child's age and the presence of birth complications. A total of 4 groups will be interviewed involving a maximum of 40 parents of children aged 0;6, 2;0, 3;6 and 5;0 years. Birth complications that the child may have experienced such as very low birth weight, very premature, born with syndromes, congenital heart diseases, syndromes, low Apgar score, Down's syndrome.

(c) Describe how permission has been obtained from cooperating institution(s)—school, hospital, organization, prison, or other relevant organization. (*Append letters.*) Is the approval of another Research Ethics Committee required?

Ethical permissions was sought and obtained from: Manchester Metropolitan University Research Ethics Committee; Director of Paediatrics in Malta; Head Consultant Paediatrician of NPICU; Consultant Paediatrician; Manager Midwifery Services; Midwifery Officer NPICU. Mater Dei Hospital data protection clearance to proceed with study was also granted.

Permission is being sought from the University of Malta Research Ethics Committee

(d) What do subjects do, or what is done to them, or what information is gathered? (Append copies of instructions or tests or questionnaires.) How many times will observations, tests, etc., be conducted? How long will their participation take?

The participants are parents of children who were born with risks for delays and for developing an intellectual disability during later childhood. They will be invited for a one-time interview which will last for a maximum of 1 hour -1.5hours depending on the participants' wish to communicate their experiences to the researcher. The interview will focus on the experiences, feelings and needs of these parents since the birth of their child.

(c) Which of the following data categories are collected?

| | |
|-------------------------------------------|---------------------|
| Data that reveals – race or ethnic origin | YES / NO |
| political opinions | YES / NO |
| religious or philosophical beliefs | YES / NO |
| trade union memberships | YES / NO |
| health | YES / NO |
| sex life | YES / NO |
| genetic information | YES / NO |

3. How do you explain the research to subjects and obtain their informed consent to participate? (If in writing, append a copy of consent form.) If subjects are minors, mentally infirm, or otherwise not legally competent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? How is it made clear to subjects that they can quit the study at any time?

The research participants will be informed of the research aims, rationale and potential uses of the results. They will be sent an information letter and consent form in Maltese and English (attached). If they wish to participate in the study they are invited to sign and send the consent form in the provided pre-paid postal envelope to the researcher. If they do not wish to participate they are encouraged to send the forms back to the research unsigned. The information letter informs them about the study as well as their rights to accept, refuse and/or withdraw at any time of the research process.

4. Do subjects risk *any* harm—physical, psychological, legal, social—by participating in the research? Are the risks necessary? What safeguards do you take to minimize the risks?

Participants may feel distressed during the interview as they may recall distressing experiences. The researcher has 7 years experience in clinical work with similar client groups and she is qualified to act in a professional and supportive manner during interviews. A debriefing session will take place after each interview. Should the researcher see the participant becoming distressed during the interview process, she will offer to stop the interview at the participant's discretion. Moreover, professional support will be available from the existing agencies (e.g. GP, nursing, social workers and psychological support) if required.

5. Are subjects deliberately deceived in *any* way? If so, what is the nature of the deception? Is it likely to be significant to subjects? Is there any other way to conduct the research that would not involve deception, and, if so, why have you not chosen that alternative? What explanation for the deception do you give to subjects following their participation?

No deception is involved. The participants are informed of the overall aim and process of the study. They are also informed that they are free to withdraw at anytime during the research process.

6. How will participation in this research benefit subjects? If subjects will be “debriefed” or receive information about the research project following its conclusion, how do you ensure the educational value of the process? *(Include copies of any debriefing or educational materials)*

The participants will be given all the information that came out of the study if they ask for it. The participants themselves may not directly benefit from it. However results will be beneficial in supporting and helping other parents who in the future will pass through similar experiences and the results will be beneficial for the setting up of early intervention services in Malta and for health professionals who come in contact with similar situations.

TERMS AND CONDITIONS FOR APPROVAL IN TERMS OF THE DATA PROTECTION ACT

- Personal data shall only be collected and processed for the specific research purpose.
- The data shall be adequate, relevant and not excessive in relation to the processing purpose.
- All reasonable measures shall be taken to ensure the correctness of personal data.
- Personal data shall not be disclosed to third parties and may only be required by the University or the supervisor for verification purposes. All necessary measures shall be implemented to ensure confidentiality and, where possible, data shall be anonymised.
- Unless otherwise authorised by the University Research Ethics Committee, the researcher shall obtain the consent from the data subject (respondent) and provide him with the following information: The researcher's identity and habitual residence, the purpose of processing and the recipients to whom personal data may be disclosed. The data subject shall also be informed about his rights to access, rectify, and where applicable erase the data concerning him.

I, the undersigned hereby undertake to abide by the terms and conditions for approval as attached to this application.

I, the undersigned, also give my consent to the University of Malta's Research Ethics Committee to process my personal data for the purpose of evaluating my request and other matters related to this application. I also understand that, I can request in writing a copy of my personal information. I shall also request rectification, blocking or erasure of such personal data that has not been processed in accordance with the Act.

Signature: S. Azzopardi

APPLICANT'S SIGNATURE:
I hereby declare that I will not start my research on human subjects before UREC approval

S. Azzopardi

DATE 17.5.2010

FACULTY SUPERVISOR'S SIGNATURE
I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the measures proposed for the protection of human subjects.

[Signature]

DATE 17.5.10

Return the completed application to your faculty Research Ethics Committee

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance **Refusal** **Conditional acceptance**

✓

For the following reason/s:

Please see email attached.

Signature _____ Date _____


To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance **Refusal** **Conditional acceptance**

○

For the following reason/s:

Signature  Date 7/7/2000

Subject: Study: 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: the early years'

From: Data Protection at MDH (datapro.mdh@gov.mt)

To:

Date: Tuesday, 25 May 2010, 6:57



25th May 2010

Ms Elayne Azzopardi

Dear Ms Azzopardi,

With reference to the above-named study, this is to confirm that, on the basis of all the documentation you submitted, from the MDH data protection point of view you have been cleared to proceed with your study.

Good luck with your study.

Regards,

Hugo Agius Muscat

Dr H Agius Muscat MD MSc

Consultant (Public Health Medicine)

Data Protection Officer, Mater Dei Hospital

Tel: (00356) 2545 5334

Director of Obstetrics and Gynaecology
Department of Obstetrics and Gynaecology
Mater Dei Hospital
Tal-Qroqq, Msida
MSD 2090
Malta

15th May 2010

Dear (Director),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'. This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and withdraw at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. Potential participants include parents of babies who's ages are between 6months and 5 years and are born with a low Apgar score or born with a congenital anomaly in Malta. I would like to request your permission to initiate my study data collection procedure as outlined in this letter.

The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Thank you in anticipation.

Yours sincerely,

Elayne Azzopardi
PhD Speech Pathology 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLP Special Education Services, Malta

cc. Professor Jois Stansfield,
Director of Studies
Professor of Speech Pathology, MMU

Chairman
Department of Paediatrics
Mater Dei Hospital
Tal-Qroqq, Msida, MSD 2090

15th May 2010

Dear (Chairman),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'. This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and withdraw at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. All parents whose children were born with complications, such as very low birth weight (<1500 g), very premature (<31 weeks), low Apgar score and/or presence of congenital anomaly from the register of the Neonatal and Paediatric Intensive Care Unit (NPICU) are eligible to participate in the study. The ages of the children range between 6months to 5 years of age. I would like to request your permission to initiate my study data collection procedure as outlined in this letter.

The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Thank you in anticipation.

Yours sincerely,

Mrs Elayne Azzopardi
PhD Speech Pathology, 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLT Special School Services, Malta

cc. Professor Jois Stansfield,
Director of Studies,
Professor of Speech Pathology, MMU

Consultant
Head of NPICU
Mater Dei Hospital
Tal-Qroqq, Msida, MSD 2090

15th May 2010

Dear (Consultant),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'. This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and withdraw at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. All parents whose children were born with complications, such as very low birth weight (<1500 g), very premature (<31 weeks), low Apgar score and/or presence of congenital anomaly from the register of the Neonatal and Paediatric Intensive Care Unit (NPICU) are eligible to participate in the study. The ages of the children range between 6months to 5 years of age. I would like to request your permission so that the health professional may choose some parents from among your patients for my study data collection procedure as outlined in this letter.

The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Thank you in anticipation.

Yours sincerely,

Mrs Elayne Azzopardi
PhD Speech Pathology, 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLT Special School Services, Malta

cc. Professor Jois Stansfield,
Director of Studies,
Professor of Speech Pathology, MMU

(Consultant)
Consultant Paediatrician
Mater Dei Hospital
Tal-Qroqq, Msida, MSD 2090

15th May 2010

Dear (Consultant),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'. This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and withdraw at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. All parents whose children were born with complications, such as very low birth weight (<1500 g), very premature (<31 weeks), low Apgar score and/or presence of congenital anomaly from the register of the Neonatal and Paediatric Intensive Care Unit (NPICU) are eligible to participate in the study. The ages of the children range between 6months to 5 years of age. I would like to request your permission so that the health professional may choose some parents from among your patients for my study data collection procedure as outlined in this letter.

The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Thank you in anticipation.

Yours sincerely,

Mrs Elayne Azzopardi
PhD Speech Pathology, 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLT Special School Services, Malta

cc. Professor Jois Stansfield,
Director of Studies,
Professor of Speech Pathology, MMU

Manager Midwifery Services
Mater Dei Hospital
Tal-Qroqq, Msida, MSD 2090

17th May 2010

Dear (Manager),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'. This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and withdraw at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. All parents whose children were born with complications, such as very low birth weight (<1500 g), very premature (<31 weeks), low Apgar score and/or presence of congenital anomaly from the register of the Neonatal and Paediatric Intensive Care Unit (NPICU) are eligible to participate in the study. The ages of the children range between 6months to 5 years of age. I would like to request your permission so that a health professional may choose some parents from the Neonatal and Paediatric Intensive Care Unit for my study data collection procedure as outlined in this letter.

The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Thank you in anticipation.

Yours sincerely,

Mrs Elayne Azzopardi
PhD Speech Pathology, 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLT Special School Services, Malta

cc. Professor Jois Stansfield,
Director of Studies,
Professor of Speech Pathology, MMU

(NPICU Midwifery Officer)
Midwifery Officer
NPICU
Mater Dei Hospital
Tal-Qroqq, Msida, MSD 2090

17th May 2010

Dear (NPICU Midwifery Officer),

I am reading for a PhD in Speech Pathology with Manchester Metropolitan University (MMU), Manchester, on a full-time basis. My proposed research study is entitled 'The experiences of Maltese parents of children born with a biological risk for intellectual disability: The early years'.

This project aims to explore the experiences of parents of children born with a biological risk to develop intellectual disability. For data protection purposes a health professional will be invited to identify and contact the participants. Details of the study will be provided both in written and verbal form. If participants accept to participate in the study they will be invited to sign the consent form. All ethical considerations are prioritised. The participants' safety, anonymity and confidentiality will also be respected at all times. The parents will also be informed on their rights to accept or refuse and stop at any time during the study. Data is collected by means of a one-time semi-structured interview, which will be tape-recorded and transcribed verbatim. All parents whose children were born with complications, such as very low birth weight (<1500 g), very premature (<31 weeks), low Apgar score and/or presence of congenital anomaly from the register of the Neonatal and Paediatric Intensive Care Unit (NPICU) are eligible to participate in the study. The ages of the children range between 6 months to 5 years of age. The project was approved by the Research Ethics Board Committee of MMU (please find attached letter of approval) and I am currently applying with the University of Malta Research Ethics Committee. The results will provide insights on the experiences of these parents to professional services and how these parents wish to be supported throughout the first five years of their child's life. Could you be so kind and accept to be the health professional who will identify and contact the participants for my study please? Thank you in anticipation.

Yours sincerely,

Mrs Elayne Azzopardi
PhD Speech Pathology, 1st Yr Student, MMU
Senior Speech-Language Pathologist
Co-ordinator of SLT Special School Services, Malta

cc. Professor Jois Stansfield,
Director of Studies,
Professor of Speech Pathology, MMU

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Speech Language Department
Ingiered Road
Luqa

Date

Dear Sir/Madame,

I am a Senior Speech and Language Therapist currently employed by the Speech and Language Department, Luqa, I am reading for a PhD in Speech Pathology with the Manchester Metropolitan University, Manchester. The aim of the study is to explore the experiences and needs of Maltese parents whose children experienced complications during birth. The results from this study will help the researcher assist other parents who undergo similar experiences. This study will also propose guidelines for professionals to tailor their services to families with similar experiences.

I am inviting you to participate in my study as your child experienced birth complications and s/he falls within the age groups that I would like to explore. I will need to interview you, either at your home or where you feel most comfortable, to understand better your everyday experiences and needs especially with regards to your concerns about your child and the services that are available for your needs. The interview may last for about one hour. The interview will be audio-recorded and the recordings will be stored securely. Personal details will be kept in a separate file under lock and key and will be available only to me. These will be destroyed once the research is completed. Pseudo names will be used throughout the research process and only the researcher and her supervisors will have access to the audio-tapes. Information from the interview will be analysed by me, and by another researcher to audit my data analysis. You will be provided with a transcription of the interview. You are free to accept, refuse and refrain from continuing the interview or your participation at any stage during the study; should you wish to do so kindly contact me using the contact details provided below.

If you wish to accept my invitation to participate in this study, kindly send the signed consent form in the attached pre-paid envelope. I greatly appreciate your participation. Findings from the study will assist other Maltese parents who may be going through

similar experiences in order to alleviate their everyday concerns and to enhance their child's development through tailored early intervention services in the Maltese Islands. If you do not wish to participate in this study, kindly send me the empty consent form in the attached prepaid envelope as a sign of refusing to participate. Thank you in anticipation for your kind help.

Kind regards,

Elayne Azzopardi
PhD Speech Pathology Student
MSc. Cl. Comm (MMU), BSc (Hons) Comm Ther.
Manchester Metropolitan University, Manchester
Senior Speech and Language Therapist
Co-ordinator of SLP Special School Services, Malta
Address: Speech and Language Department, Ingiered Road, Luqa
Tel:
Email:

Manchester Metropolitan University header paper

Speech Language Department
Ingiered Road,
Luqa

Date

Għeżież Sinjuri,

Jiena Senior Speech Language Therapist u attwalment impjegata mill-Speech Language Department, Luqa. Qegħda nagħmel PhD fl-Speech Pathology ma' l-Metropolitan Manchester University, Manchester. L-għan ta' l-istudju huwa li jesplora l-esperjenzi u l-ħtiġijiet tal-ġenituri Maltin li t-fal tagħhom kellhom kumplikazzjonijiet waqt it-twelid. Ir-rizultati minn dan l-istudju ser jgħini nassisti lill-ġenituri l-oħra li jgħaddu minn esperjenzi simili. Dan l-istudju ser jipproponi wkoll linji ta' gwida għall-professionisti biex ifasslu s-servizzi tagħhom lill-familji b' esperjenzi simili.

Nixtieq nistiedinkom biex tipparteċipaw fl-istudju tiegħi ghax it-tifel/tifla tagħkom twieled/twieldet b'kumplikazzjoni u għandha/u l-eta li nixtieq nesplora f'dan l-istudju. Ser jkollkom intervista miegħi, jew fid-dar tagħkom jew fejn tħossokom l-aktar komdi, biex nifhem aħjar l-esperjenzi ta' kuljum u l-bżonnijiet tagħkom speċjalment fir-rigward tal-tħassib tagħkom dwar it-tifel/tifla u s-servizzi li huma disponibbli għall-bżonnijiet tagħkom.

L-intervista` tista' ddum għal madwar siegħa. Din se tkun rrekordjata bl-awdjo *tapes* u dawn ser jiġu maħzuna f'post sigur. Id-dettalji personali se jinżammu go fajl separat u msakkar. Dawn ser ikunu disponibbli biss għalija. Dawn il-fajls ser jinqerdu ladarba r-riċerka tkun tlestiet. Ismijiet pseudo se jintużaw matul il-proċess ta' riċerka u jien u s-supervizuri tiegħi biss se jkollhom aċċess għall-*tapes* tal-awdjo. Informazzjoni mill-intervista` ser tiġi analizzati minni, u minn riċerkatur ieħor (wahda mis-supervizuri tiegħi) sabiex jivverifikaw l-analiżi tiegħi.

Intom ser tkunu ipprovduti bit-traskrizzjoni ta' l-intervista. Intom hielsa li taċċettaw, tirrifjutaw jew żzommu lura milli tkomplu l-intervista jew il-parteeċipazzjoni tagħkom fi kwalunkwe stadju waqt l-istudju. Fil-każ li tixtieq tagħmel hekk ġentilment ikkuntattjani permezz tal-email jew telefon imniżżlin hawn taht.

Jekk intom tixtiequ taçcettaw l-istedina tiegħi biex tipparteçipaw f'dan l-istudju, jekk jogħgobkom ibghatu il-formola tal-kunsens iffirmit fil-envelop *pre-paid* meħmuż. Napprezza ħafna il-parteciżazzjoni tagħkom. Sejbiet minn dan l-istudju ser jgħinu lill-ġenituri Maltin oħra li jistgħu jgħaddu minn esperjenzi simili sabiex jgħin lil ġenituri stess u biex jissahħaħ l-iżvilupp tat-tfal tagħhom permezz ta' servizzi ta' intervent speçjalizzati bikri fil-Gzejjer Maltin. Jekk intom ma tixtiequx li tipparteçipaw f'dan l-istudju, jekk jogħgobkom ibagħtuli l-formola tal-kunsens vojta fl'envelop meħmuż bħala sinjal ta' ma tixtiequx tipparteçipaw. Grazzi bil-quddiem tal-ghajnuna tagħkom.

Dejjem tagħkom,

Elayne Azzopardi
PhD Speech Pathology Student
MSc. Cl. Comm (MMU), BSc (Hons) Comm Ther.
Manchester Metropolitan University, Manchester
Senior Speech and Language Pathologist
Co-ordinator of SLP Special School Services, Malta
Address: Speech and Language Department, Ingiered Road, Luqa
Tel:
Email:

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CONSENT FORM (English)

Parent/s name/s: _____

Date: _____

Please mark your response to each question: Yes / No

I have read and understood the information sheet about the research project on the experiences of Maltese parents of children with birth complications.

I consent to be interviewed and audio-recorded for this study only.

I understand that personal details will be kept in a separate file under lock and key and will be available only to the researcher. These will be destroyed once the research is completed.

I consent that the researcher may reproduce findings in the form of anonymous direct quotes.

I understand that pseudo names will be used throughout the research process and only the researcher and her supervisors will have access to the audio-tapes. My participation or non-participation will have no negative effects on the health provision to any member of my family or myself. Confidentiality will be respected at all times during the research process. Information will be used by the researcher and her supervisors for this research only.

I understand that I have the right to withdraw my consent at any time, either before, during or after the information is collected and until the study is completed.

I understand that I will be provided with a summary of the results if I ask for it. I can contact the researcher if I have any questions about the study or about my rights as a participant.

Participant's signature

Contact information

Researcher's signature

Telephone
Speech-Language Department,
Ingiered Road, Luqa

Thank you

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FORMULA TAL-KUNSENS (Maltese)

Isem il-ġenitur/i: _____

Data _____

Jekk jogħġbok immarka ir-risposta tiegħek għal kull sentenza Iva / Le
Jiena qrajt u fhimt il-karta ta' l-informazzjoni dwar il proġett fuq l-
esperjenzi tal-ġenituri Maltin li kellhom tfal li twieldu b'xi
kumplikazzjonijiet.

Jien nagħti l-kunsens biex niġi intervistat/a u rrekordjat/a bl-'audio-
recorder għal dan l-istudju biss.

Nifhem li d-dettalji personali ser jinzammu go fajl separat u
msakkar Dawn ser ikunu disponibbli biss għal-riċerkatriċi u ser
jinqerdu ladarba ir-riċerka tkun tlestiet.

Nagħti l-kunsens li l-riċerkatriċi tista' tirriproduċi s-sejbiet fil-
forma ta' kwotazzjonijiet diretti anonimi.

Nifhem li ismijiet psewdo se jintużaw matul il-proċess ta 'riċerka u
r-riċerkatriċi biss u superviżuri tagħha ser jkollhom aċċess għall-
audio-tapes. Il-parteċipazzjoni jew nuqqas ta' parteċipazzjoni tiegħi
mhux ser jkollhom l-ebda effetti negattivi fuq il-provvista tas-
servizzi tas-saħħa għal membri tal-familja tiegħi jew għalija.
Kunfidenzjalità ser ikunu rispettata fil-ħinijiet kollha matul il-
proċess tar-riċerka. L-informazzjoni ser tiġi użata mill-riċerkatriċi u
s-superviżuri tagħha għal din ir-riċerka biss.

Jiena nifhem li għandi d-dritt li nirtira l-kunsens tiegħi fi
kwalunkwe hin, qabel, matul jew wara li l-informazzjoni tkun
miġbura u sakemm l-istudju jitlesta.

Nifhem li se niġu pprovduti b'rapport tar-riżultati jekk nitolbu lir-riċerkatriċi. Jien nista'
nikkuntattja l-riċerkatriċi jekk ikolli xi mistoqsijiet dwar l-istudju jew dwar id-drittijiet
tiegħi bħala parteċipant.

Firma tal-parteċipant/i

Contact information

Firma tar-riċerkatriċi

Telephone

Speech-Language Department,
Ingiered Road, Luqa

Grazzi

Interview Schedule (English)

- How is (name of child) doing and how is your everyday experience in caring for your child at present?
- What was your experience / reaction when you were told that your child may have a complication?
- Do you think about your future and that of your child? What are your feelings about the future?
- What do you know of the present support services that are available? How can these help you in your everyday life?
- If new supportive professional services are created/ or existing ones are changed / adapted to become more supportive for parents' everyday life what would you recommend as a parent?
- Do you wish to add something that we did not discuss? / Do you have any questions?

Skeda tal-Intervista (Maltese)

- Kin inhu/i (isem tat-tifel/tifla) u kif inhi l-esperjenza ta' kuljum tagħkom waqt li qedin tiegħu hsieb it-tifel/tifla tagħkom bħalissa/fil-present?
- X'kienet l-esperjenza tagħkom / reazzjoni meta qalukom li it-tarbija jista' jkollha/u xi kumplikazzjoni?
- Taħsbu dwar il-futur u dak tat-tifel/tifla? X'inhuma l-emozzjonijiet/ ħsibijiet tagħkom dwar il-futur?
- Xi tgħidu / x'tafu dwar servizzi ta' għajnuma li huma disponibbli? Kif dawn jistgħu jgħinukom fil-ħajja ta' kuljum?
- Jekk xi servizzi professjonali godda jiġu maħluqa /jew dawk li hemm ikollhom tibdil / jiġu adattati biex isiru iktar ta' għajnuma lil ġenituri fil-ħajja ta kuljum, kieku x'tirrakkomanda bħala ġenitur?
- Tixtieq iżżid xi haġa li ma ddiskutejniex/. Għandkom xi mistoqsijiet?

Debrief

Thank you for taking part in this study. The purpose of the study was to explore your everyday experiences and needs especially your child's concerns and feelings. The data collected from the interview will be transcribed and analysed. If you wish to withdraw your data from the study or have any queries or concerns regarding this study, do not hesitate to contact me, Elayne Azzopardi on [EMAIL](#) or telephone number NUMBER.

Your willingness to participate in this study is greatly appreciated.

If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings please contact myself on the above email or

Mr./Ms. NURSING SUPPORT contact number (nearest Health centre)

Mr./Ms. SOCIAL WORKER contact number (nearest Health centre)

Dr. GENERAL PRACTITIONER contact number (nearest Health centre)

Thank you very much for your participation.

Elayne Azzopardi

Tel:

Appendix IV Examples of analysed text

Examples of the analysis process steps for section 4.9.2

Step 1: Integration with the transcript

This step involved reading and re-reading of the transcribed interview. I consulted the field notes and while I listened to the same interview on tape contemporaneously to re-familiarise myself of non-verbal communication aspects.

Step 2: Initial note-taking

The transcribed interview was inserted on NVIVO8 and first level of 'nodes' represented note-taking (see Snapshot 1). Left column represent some of the list of free nodes of all the transcription: these include descriptive and interpretative notes. The centre column is the transcript of the interview. The right column represents how the notes are attached to the text.

Step 3: Developing emergent themes

All the free nodes were transferred to tree nodes; these represented the lowest level (notes from step 2) of the individual's hierarchy analysis. From these, emergent themes were identified to form the second tree node level (see Snapshot 2). Should the quote needed direct re-reading the free node was double clicked (on NVIVO8) as these were directly linked at all times.

Step 4: Searching for connections across themes

This step is represented in the above picture where connections among emergent themes are represented in the third tree node level.

Step 5: Moving to the next participant's transcript

Each participant within a single group was analysed one at a time. For each participant steps 1-4 were repeated, respectively.

Step 6: Looking for patterns across cases of one group

Connections were noted based on a hierarchical layer system of themes on NVIO tree node style. The following example represents the super-ordinate theme of family orientation in group 3 (the highest tree-node level). 'Parenting' theme (second tree-node level) has a child-centred approach as a sub-theme, hence third level lower in tree-node style on NVIVO8. The sub-theme of 'Child-centred approach' has various sub-sub-

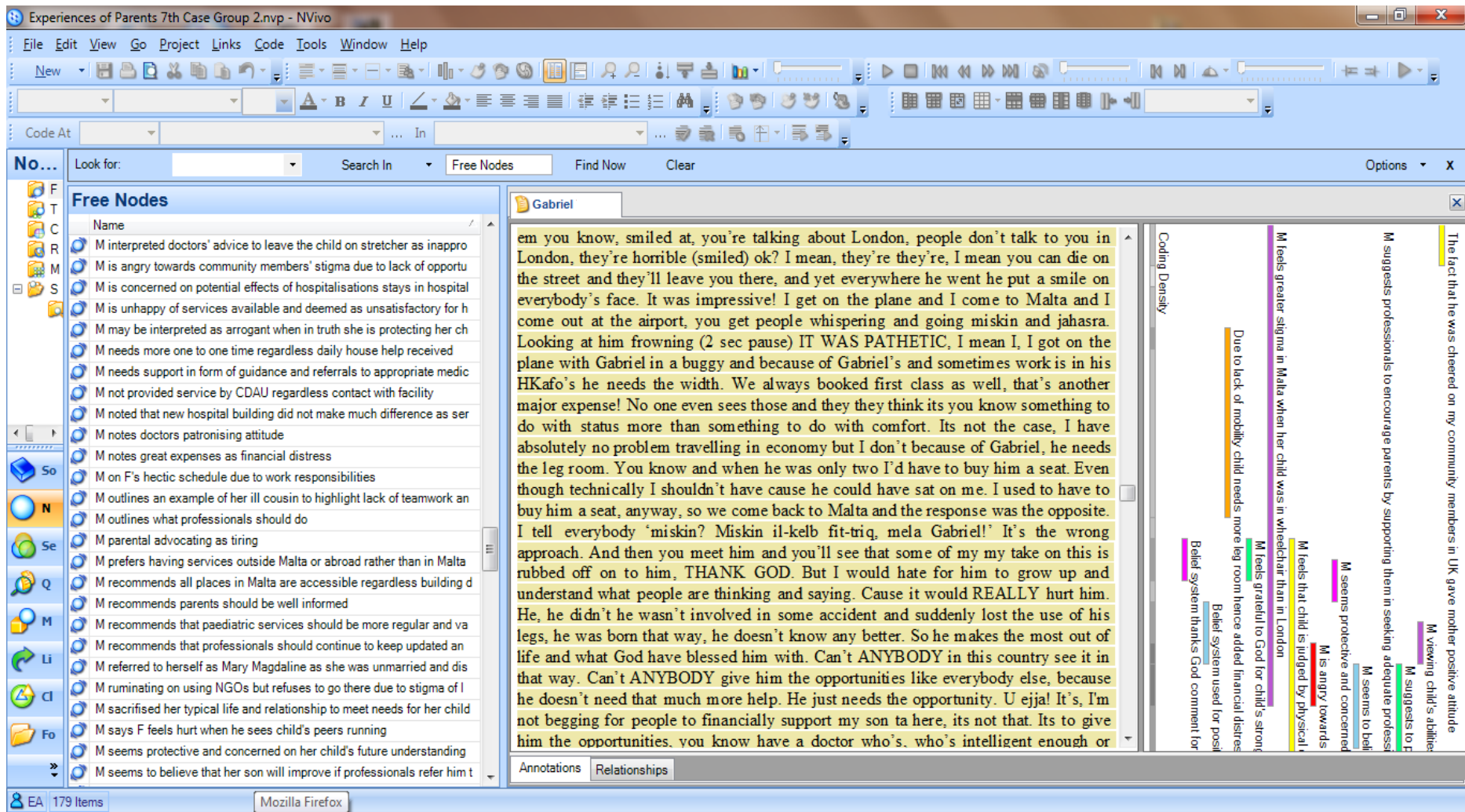
themes such as ‘child centred perspectives in family schedule’ and ‘financial re-balancing’ (see Snapshot 3). The sub-sub-themes, in this step, contain the themes of the individual participants within which the initial note-taking nodes are incorporated (containing direct links to the quotes as mentioned in step 3). For a theme to qualify as a ‘theme’ in a group it had to be present in at least 4 from 9 participants or 5 from 10 participants’ analysis.

Step 7: Repeating steps 1-6 for the other three groups

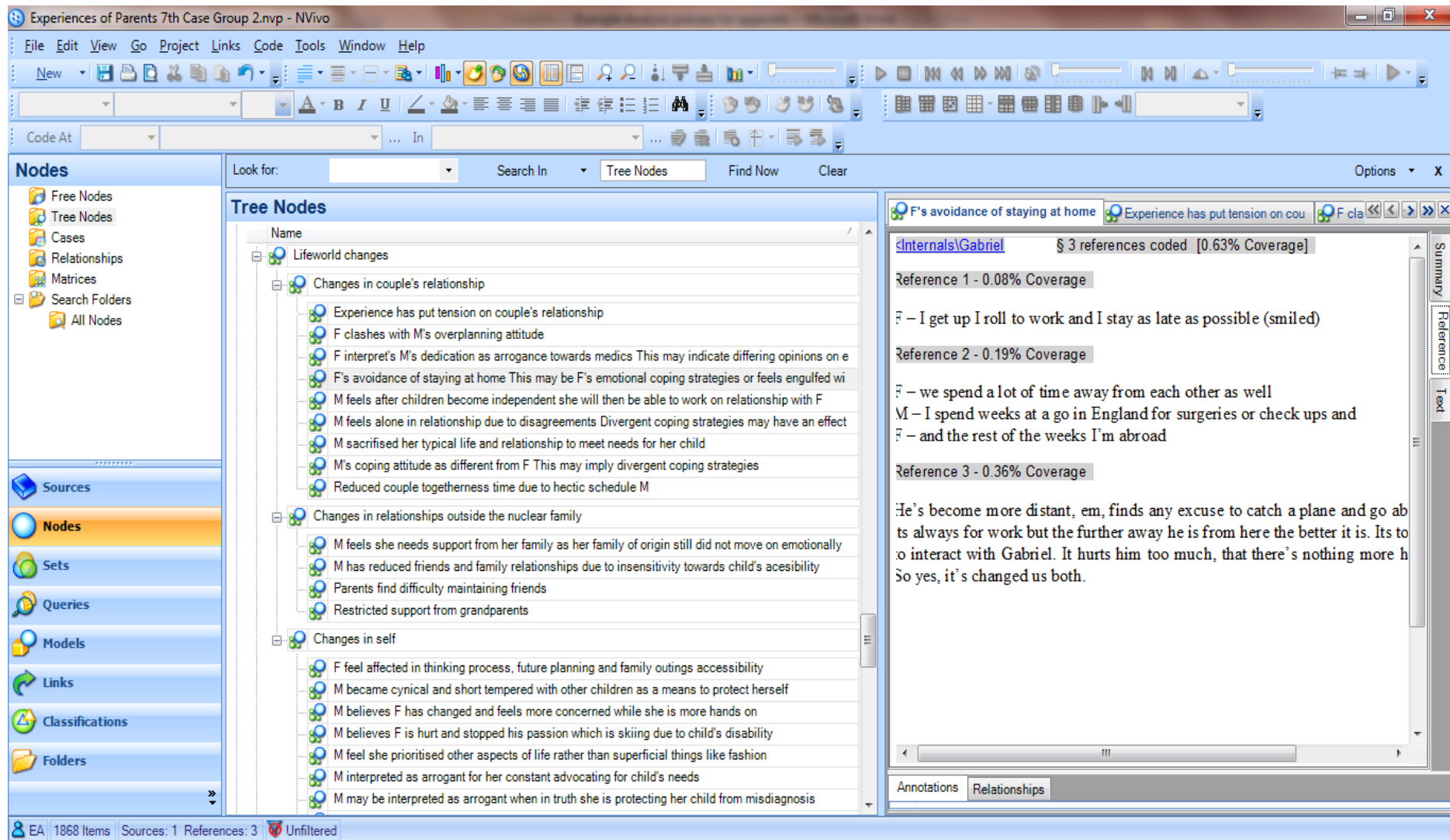
Steps 1-6 were repeated for all the other three groups.

Step 8: Searching for commonalities and divergences across groups

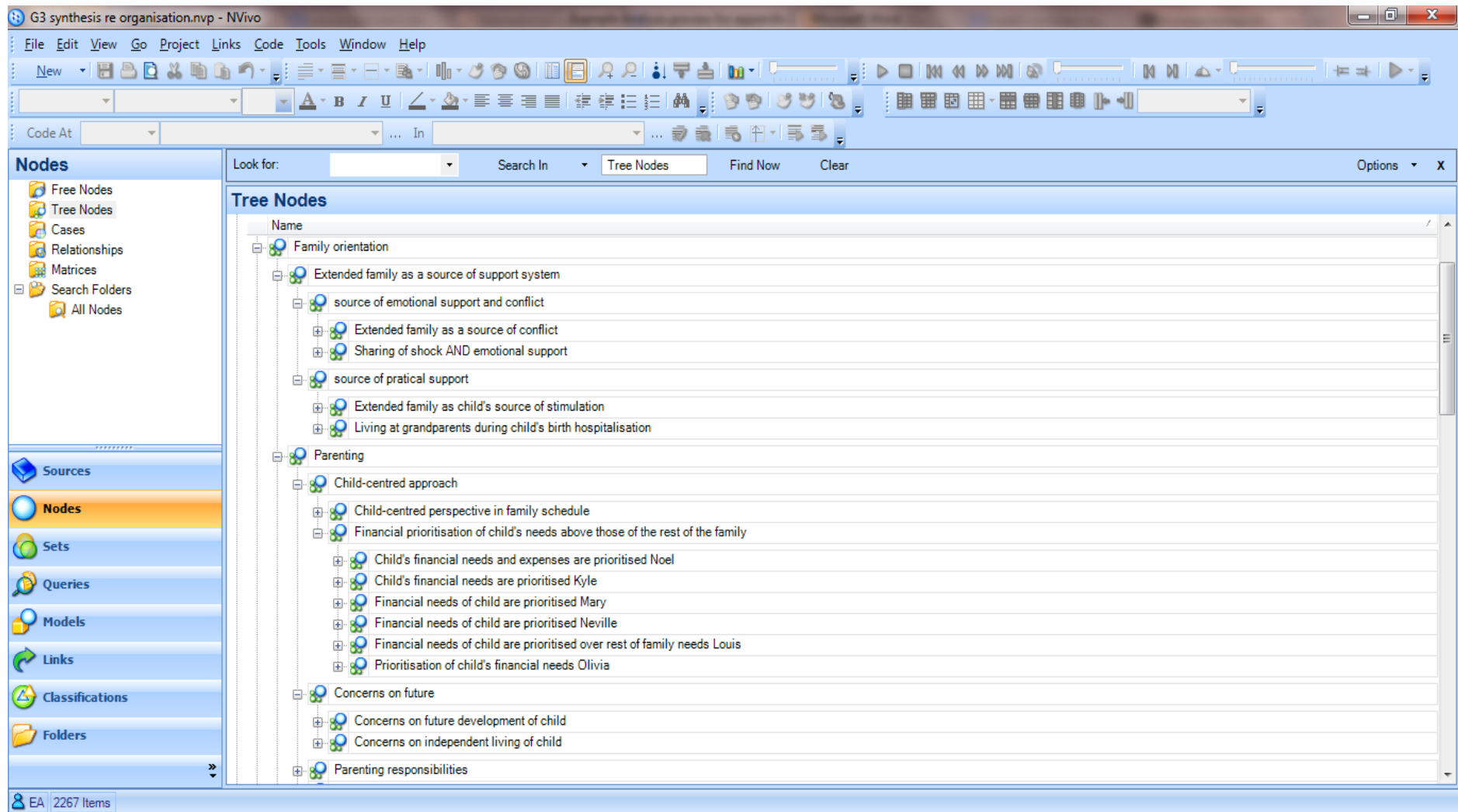
The analysed hierarchies of all four groups were imported in one NVIVO8 file. Similarities and differences across groups were incorporated into one hierarchy, following a similar procedure of step 7. The sub-sub-themes, as manifested in picture X, were amalgamated within the sub-theme as ‘topics’, due to not qualifying to stand as distinguishable themes.



Snapshot 1: NVIVO8 set up of a case initial note-taking



Snapshot 2: Tree-node format with direct links to quotes



Snapshot 3: Hierarchy example of 'Family Orientation' Super ordinate theme in a group

Appendix V Reflections

Reflections examples during data collection

| Personal reflections (general) | Reflections based on professional background |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>I knew that there will be parents that may feel distressed and me being a very emotional person when talking to people who are emotional about their experience I managed to remain composed during all interviews and feel that I have transmitted encouragement to these parents to look forward. There were no occasions when they have asked to stop the recordings and even though they have just been discharged from hospital – the participants themselves were sending advice to other parents through me. This has further motivated me towards completing this project.</p> | <p>The majority of parents (all parents who did not have a child with Down Syndrome), tend to report a lack of awareness of services. Those who did report a small amount of services seemed to be insecure about their knowledge (still parents who did not have a child with Down Syndrome).</p> <p>Parents of children with Down syndrome seemed to be very well informed about all services from group 2 – 4 be it governmental services or NGO’s (Non-Governmental Organisations). These also tended to have better access for services as well as reflected a more mature emotional state of mind. They seemed to have accepted the situation quicker than other parents. Upon comparison, other parents (especially in Group 1) seem to report that the experience is in the past and now they reflect a happy and settled feeling.</p> <p>Furthermore, it may be the case that parents of children born with Down Syndrome have obtained a diagnoses at birth or shortly after (1 month after birth) unlike the children who were not diagnosed at birth and are still awaiting diagnoses. Hence, they may have had more time to accept the situation unlike other parents.</p> |
| <p>As a recently married person I too, similar to these parents, wish to expand my family. My mother is a midwife and in my country of origin pregnancy time is considered to be the happiest period of a woman’s life, as she is preparing and bearing life within her. After completion of each interview I felt rather anxious of future pregnancies that I am planning in my near future. Almost all interviewed parents felt traumatised that their experience was unexpected.</p> | <p>From a speech-language background with an interest in early intervention, I have noted that most of the parents (not who did not have a diagnosis at birth) seem to be unaware that they may not just ‘sit and wait’ (Group 1 Camille, Carla, Brooke, Abigail; Group 2 Francesca, Gaia) but they can search for help and advice. Because when they enter school at 3 years of age they may realise that there is something wrong with their child that is not comparable to their peers, or wait till the teacher realises and approaches the mother (Group 3 Krista).</p> |

| | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | <p>This may reflect unexplained cultural aspects or lack of general awareness of developmental risks and difficulties.</p> <p>On the other hand, parents may show concern on children's developmental risks however they do not know whether they should verify their concerns with other professionals. In some occasions paediatricians tended to refer the child to speech and language therapist upon an evident language delay after the child is 3 years of age, unless this child was diagnosed at birth with a syndrome or unless this child did not need speech and language therapy for feeding difficulties from a tender age. In the case of parents of 1 child who was referred to speech and language therapy services from birth, for feeding difficulties, after the feeding difficulties have been resolved these parents were monitored once every 3 months for delays instead of providing a preventive and simulation services.</p> |
| <p>Meeting with all these parents I have noted that most of them were married. During all but 1 interviews I felt a strong bond between the couple. Each one influence the other in everyday life, they also help and assist each other in terms of practicalities, child-minding plans, as well as emotional support. At the time of interviewing I was living for weeks at a time away from my husband. This has helped me strengthen my relationship with my husband, my emotional bond with my husband and prioritise what are the real aspects in life to worry about.</p> | |
| <p>All parents after the interview have thanked me after I thank them for their time and stories. I always said why thank me I did nothing. They all answered in different manners. Some told me because they had the opportunity to talk to someone about their experience and I listened to them. Others told me they felt better after talking to someone about how they felt and how they feel today. A few also thanked me on behalf of other parents, <i>"because to our knowledge you are the first who showed interest in voicing our concerns and feelings"</i> (Angelo,</p> | |

G1; Tom, G4). The interview, although it was perceived initially that it may make the parents feel upset because they remember their past experiences as a sensitive subject, it was in fact beneficial to them as reported by themselves. They made me feel that I have the responsibility to inform policymakers about their experiences and everyday needs. It also boosted my confidence that the project will actually not only help future parents of children who are born at risk for ID but also parents of children who are born with complications in general, to a certain extent. If the proposed suggestions are implemented, changes may not only effect parents of children born with biological risks for intellectual disability but also potentially other parents whose child is hospitalised after birth.

Insider-outsider epistemological stance

Reflexivity is one of the pillars of critical qualitative research (Fontana, 2004). Jootun et al. (2009) noted that it is an invaluable tool to promote understanding of the phenomenon under study, the researcher's role and the degree of influence that the researcher exerts intentionally or unintentionally on the findings. During this research process I had both insider and outsider roles, each carried advantages and disadvantages. Clarification of my position was essential and an ever-present aspect of the investigation as it assisted good understanding and influences research data and analysis (Merriam, Johnson-Bailey, Lee, Kee, Ntseane and Muhamad, 2001). It provides epistemological privileges in constructing knowledge from the researcher's stance whilst conducting research (Griffith, 1998).

Being an insider

The hermeneutic underpinning understands social reality by interpreting the meanings held by the social actors of the social group: such as entering into the culture, understanding shared values and speaking the culture's language (Brannick and Coghlan, 2007). As a Maltese citizen I speak both Maltese and English, the national languages of the participants, so they could feel more at ease to choose either language to converse in. I interpreted the participants' lived experiences from the parents' same broad cultural perspective. Having lived in the same culture as the participants most of my life to date inferred cultural social values absorbed through socialisation (Baerveldt and Voestermans, 2005). This adhered to IPA's insider perspective from knowledge created through dialogue (van Manen, 1990; Smith et al., 2009; Smith, 2011), as much as possible. Although it may not necessarily imply the necessity to be cultural 'insiders', I felt advantaged as parents could relate to me, their interviewer, as a co-patriot, one who is aware of their ways and social processes.

As a woman, mothers appeared to feel more at ease taking the lead to talk to me, given that gender roles as the main carer of the child were evident (see section 5.5.3.2). Some fathers might have felt uneasy at first sharing their emotions with an unknown woman. Merriam et al. (2001) indicates this as a potential influence from the interviewer's gender. Yet, a number of fathers by the end of the interviews seemed to have opened up, perhaps because they saw the comfortableness of their spouse/partner

Being an outsider

Being a speech and language therapist who worked in the health system could have acted both as an advantage and as a disadvantage. Participants were aware of this aspect of my background from the information letter. Being a health professional could have acted as a 'trust warrant' for parents that I am used to maintaining confidentiality and invited them to be more open regarding their inner feelings. Furthermore, being introduced by a familiar hospital ward clinician enhanced a positive relationship with the participants and boosted my credibility as a researcher. This, however, presented a challenge for me as at times the participants inferred shared-knowledge assumptions in passing such as 'you know what it means', due to their misconception that I work at hospital. During these moments, I used prompts 'can you tell me more about it?' for clarification.

Besides Merleau-Ponty's (1958) embodiment concept, I was an outsider since I have a different embodied-position in the world, I was also a total stranger and did not belong to their social circle. Corbin-Dwyer and Buckle (2009) indicate disadvantages when one does not share similar life events, such as reduced immediate trust and openness levels, where the interviewer has to 'earn' it in the participants' eyes as the interview process advances. This might indicate a potential reason why my interviews were at times longer than planned. Yet, it assisted me to maintain an open-minded attitude towards their stories/narratives, in order to accept them as presented. If I had had a similar past experience or had been a mother at the time of data collection and analysis, it might have influenced my interpretation of the findings.

Thus being an outsider was an advantage to the analysis process allowing a more balanced (not too personal, not too distant) perspective, whilst not undermining the acknowledged insider's stance. As a professional it could have presented an opportunity for parents to vent their frustrations. I acknowledge that being seen as an outsider might act as a limitation, due to being seen as 'the potential enemy' (i.e. a professional not a parent). This outsider attitude was also, however, beneficial as parents made extra efforts to explain their emotions as there was no assumed shared experiential knowledge.

The intermediate space

The insider-outsider perspectives are considered as two ends of a continuum in this study. Although as the researcher, my knowledge is always based on my positionality (Mullings, 1999), being an insider or outsider does not make a better or worse researcher or research outcome but it depicts a different type of research perspective (Corbin-Dwyer and Buckle, 2009). Acker (2000) has suggested trying to find a way to be both for a balanced position, others labelled it as ‘the space between’ (Corbin-Dwyer and Buckle, 2009) or ‘hybrid position’ (Jootun and McGhee, 2006). Noting the ways in which we are different from others requires that we also note the ways in which we are similar; allowing both insider and outsider positions simultaneously. Hellowell (2006) reflected that one may be both inclined towards ‘insiderism’ and ‘outsiderism’ of different dimensional continua in qualitative research, such as age, gender, professional background, beliefs and ‘community’ belongingness.

To a certain extent, the interview itself may have benefited parents as they had a listener to their lived-experience, they felt “*lighter*” (Carla, G1; Rose, G4). For some, the interview served as a memory reminder: “*we enjoyed it that you came and we talked about it because it’s a side of life I had forgotten, not that you can forget it. But I do not want to forget it as when she was born we were very happy*” (Sarah, G4). Whilst some interpreted the interview itself as a self-evaluation: “*we enjoyed it...it was the first time that we talked about it in great detail...we never had the opportunity. It was helpful for us...it felt like we did an in depth evaluation*” (Joanne, G2). Angelo (G1) thanked me “*on behalf of other parents for what you are doing and what you will do with their stories*” after completion of the interview.

The majority of the interviewees behaved in such a way that by the end of the interview, I was becoming a ‘newly qualified insider’ or approaching the insider’s perspective in their eyes, as I became aware of all the various experiences of parents through this research. In some cases, I felt that they held the power to teach me, when they constantly used the second person singular to explain their emotions; for example: “*you would feel XXX*”, “*you’ll feel it too*”, “*you’ll need XXX*”. Some seemed comfortable as by mid-interview some regional dialect, swearing or slang words were evident in their speech. It felt as if listening to their experiences gave me the tools to be able to assist other parents who in the future may have similar experiences. For example some

parents, such as Timothy (G4) said that I was acquiring “*skills*” through listening to his experiences in order to provide a change in future services to assist other parents. I believe that a balance of insider-outsider stance was created in this study.

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Appendix VI Published Abstracts from this study

Published abstracts from this study

Azzopardi, E., Stansfield, J. and Marshall, J. (2010) Looking at the bright side of life: A systematic review of positive perceptions of parents of children with disabilities. In: *Child, Family and Disability Conference*, Manchester Metropolitan University, John Dalton Building, 28th April. Manchester: Manchester Metropolitan University.

Azzopardi, E. (2010) Experiences of parents of children born with risks for intellectual disability. In: *Research Institute for Health and Social Change: 2010 Annual Conference*, John Dalton Building, Manchester, 1-2 July 2012. Manchester: Manchester Metropolitan University.

Azzopardi, E. (2012) 'You have to live it to know what it really means': Maltese parents' perceptions while raising young children with intellectual disability risks. In: *Research Institute for Health and Social Change: 2012 Annual Conference*, Elizabeth Gaskell Campus, Manchester, 2-3 July 2012, Manchester: Manchester Metropolitan University.

Azzopardi, E., Stansfield, J. and Marshall, J. (2012a) The voices of Maltese parents raising young children born with intellectual disability risks. In: *Conference Abstracts Society for Reproductive and Infant Psychology (SRIP) 32nd Annual Conference: Society for Reproductive and Infant Psychology*, St. Anne's College, University of Oxford, 12-13 September 2012. *Journal of Reproductive and Infant Psychology*, 30 (3), e1-e21.

Azzopardi, E., Stansfield, J. and Marshall, J. (2012b) Lived Experiences of Maltese Parents of Children Born with Biological Risks for Intellectual Disability. In: *From Birth to Three Years of Age: Possibilities in the Field of Early Childhood Intervention*, Stefania Palace, Budapest, 29-31 October 2012. <http://eciconf-2012.hu/en/program.html>.

Azzopardi, E. (2013) Needs of Maltese parents while rearing young 'at risk' children. In: *The 9th Annual Research Institute for Health and Social Change Conference*, Manchester Metropolitan University, Business School, 4-5 July 2013. Manchester: Manchester Metropolitan University.