“Every mother wants to bring her child home”: An Interpretative Phenomenological Analysis of Romanian mothers experiences of caring for a child with disabilities at home.

Thesis submitted for the Degree of Masters of Arts

Tríona Collins
BSc (Psychology)

Department of Education & Professional Studies, University of Limerick
Supervisor of Research: Dr. Barry Coughlan, Department of Education & Professional Studies, University of Limerick

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Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other University. I declare that this thesis is entirely my own work.

Signed:_____________________________

Tríona Collins
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Abstract

Background: To ensure the right of the child with an intellectual disability to grow up in the family home is maintained, this study explores mothers ability to overcome the many challenges to the provision of care so as to guarantee a good quality of life for their child.

Aims: This study will explore mothers experiences of the disclosure process of a disability and the impact it had on their ability to cope with providing care for their child. It asked mothers to describe their relationships in the family and community since the disclosure of their child’s disability. It explores how mothers made decisions regarding care, and what impact, if any, disability policies had on their lives.

Method: In this exploratory qualitative study, eleven interviews were carried out with the assistance of a bilingual interpreter with mothers of children with disabilities who live at home, in the South of Romania. Of these, eight mothers’ interviews fulfilled the criteria of the study resulting in the transcription and analysis of these interviews using Interpretative Phenomenological Analysis.

Results: The analysis uncovered four master themes of uncertainty, disempowering bureaucracy, a lack of understanding and the desire of mothers in going forward. Due to various socio-cultural barriers and ambivalent attitudes, mothers struggled to navigate the bureaucratic processes of meeting specialists. These encounters contributed to a lack of understanding by themselves and others, of their child. However, all mothers spoke of the desire in going forward with their child and thus continuing to provide care for them at home.

Conclusions: This unique study reveals the strength of these mothers through their ability to cope with caring for their children in the face of a dearth of formal supports. The research has the potential to form the basis for change in the areas of clinical practice, policy, future education and research and continued professional development.
Glossary of Terms

**World Health Organisation (WHO):** is a specialised agency of the United Nations (UN) that is concerned with international public health.

**Intellectual Disability (ID):** disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills and emerges before the age of 18 years.

**European Union (EU):** is an economic and political union of 27 member states which are located primarily in Europe.

**Non Governmental Organisation (NGO):** is any non-profit, voluntary citizens' group which is organized on a local, national or international level.

**Interpretative Phenomenological Analysis (IPA):** is an experiential qualitative approach to research in psychology and the human, health and social sciences.

**Institutionalisation:** is the committal of an individual into a long stay residential institution setting which usually is largely isolated from society.

**United Nations International Children's Emergency Fund (UNICEF):** is a United Nations Programme, that provides long-term humanitarian and developmental assistance to children and mothers in developing countries.

**Normalisation:** is the process of providing people with a disadvantage or disability the opportunity to experience the same normal patterns of life and normal experiences as others in society.

**Mental Disability:** in this study, mental disability refers to individuals with an intellectual disability.

**Family-Centred Practice:** occurs when service providers and professionals uphold the belief that parents have the right to determine what is most important for their child and recognise them as the experts in relation to their own families.
Chapter One: Overview of the Thesis

1.1 Introduction and Context

This thesis will guide the reader through the life experiences of mothers who care for their children with multiple disabilities at home, in Romania. According to the 2011 World Health Organisation (WHO) and World Bank report on disability, over one billion people are thought to have a disability worldwide. The report highlighted the widespread unequal treatment of people with disabilities. Within this group, lies children with intellectual disabilities (ID) and multiple disabilities. These children are wholly reliant on the loving care given to them by their primary caregivers - usually their mothers, in order to survive their early years.

It is recognised that all families experience joys and challenges throughout their life cycle (Broberg, 2010). However, families of children with disabilities may be more vulnerable to additional challenges because of the presence of various socio-structural barriers (Kelso, French, & Fernandez, 2005). With the increasing recognition that people with disabilities are marginalised in society and an awareness of the gap between disability policies and the unequal delivery of these policies in practice, research is now evolving to reflect this. There has been a call for research to focus on the role families have in supporting their loved ones with disabilities. To date, little research has focused on how caregivers of children with ID overcome daily challenges thus enabling care for their child.

Since the accession of Romania to the European Union (EU) in 2007 and given the complex history of institutionalisation in Romania, it is unknown how effectively supported families are in the provision of care to their children with disabilities, given the lack of the implementation of formal supports. This research intends to explore mothers’ life experiences.
of coping with caring for their child at home. This research is the first of its kind to be conducted in Romania and in Eastern Europe. To understand why this topic was chosen, an overview of the researchers background and interests will be given to position the research.

1.2 Personal Background and Interest in the Topic

I am 26 year old Irish female who holds an undergraduate degree in Psychology and an advanced diploma in Inclusive Education. My interest in Romania began in 2010 while I was working as an Applied Behavioural Analysis tutor in a school for children with autism. At the time I was also volunteering with a support group for adults with ID and their parents. In the Summer of 2010 I was accepted on a professional volunteer programme with the Irish non Governmental Organisation (NGO) The Comber Foundation, to volunteer with adults with ID who had recently moved from long term inhumane institutional care into homes providing supported living in the community in South East Romania. I spent six weeks volunteering with these adults and a parents support group who cared for their children with disabilities at home.

This experience changed the course of my life. In April 2011 I left my job after being invited by the NGO to return to Romania to participate in an evaluation of the NGO’s activities. I was curious to carry out a research masters in the field and I was eager to use this opportunity to explore the idea further. During this time, I met many people who shared their story with me and this confirmed my desire to facilitate them to have their story heard by a wider audience. In tandem with the NGO’s objective to end institutionalisation for adults with disabilities, I was compelled to discover how parents who mind their children at home coped with the minimal support available, thus preventing the institutionalisation of their loved ones.
This research has been a life changing process. I hope that revealing the stories of these mothers will empower others in similar situations regardless of where they live. Their life experiences speak for themselves, and I am indebted to those involved. I am forever grateful to have been given the opportunity to share their experiences with others:

“I didn’t send him to a centre because I cannot stay without him. He represents too much for me. He is a special kid. He’s a special kid, not a kid with special needs, he is special by himself”

-Mother of a son with multiple disabilities, Romania, June 2012.

1.3 Outline of Thesis

Family centred approaches to assessment and early intervention for children with ID is becoming a topical issue for research. Driven by human rights and advocacy movements, it is now recognised that children with disabilities belong in the family, and not segregated from family and society in institutional care. This study will explore mothers experiences of the disability disclosure process and the impact it had on their ability to cope with providing care for their child. It asked mothers how they made decisions regarding care, and what impact, if any, disability policies had on their lives.

1.3.1 Literature Review

To inform the development of this study, a vast literature search was carried out to critique national and international research pertinent to the topics of study in this research. In particular, the researcher was keen to explore Romanian literature related to care giving for a
child with a disability, coping, decision making, and the impact of others upon these experiences.

1.3.2 Methodology
This chapter clearly describes the processes involved in the preparation of this study, participant demographics, data collection, inclusion of an interpreter in this research and the procedure undertaken during interviewing. A clear rationale is provided for the methods employed in this study to ensure the production of valid, credible and reliable results.

1.3.3 Results
The results section provides an overview of the four master themes and their associated superordinate themes as analysed using Interpretative Phenomenological Analysis (IPA). Using an illustrative figure, the connections between these themes will be demonstrated to show the reader how themes impact on one another. The section explores these themes in depth, with supporting quotes being selected to illuminate each theme.

1.3.4 Discussion
The discussion chapter frames the findings of the results within current disability literature. It reflects upon the interview process, reflexivity and methodological considerations. Finally, the chapter uses the findings to recommend changes in the areas of clinical practice, policy, future education and continued professional development and research.
1.3.5 Conclusion

This thesis closes with some concluding insights into the research findings. Finally, the researcher considers the impact of the research for those involved. The chapter finishes with the desire for this study to act as a catalyst for future research to be carried out to support the progression of disability supports for families in similar positions in future years.
Chapter Two: Review of the Literature

2.1 Chapter Introduction
This chapter will inform the reader about the topics surrounding caring for a child with an ID at home in Romania. It will begin by exploring the national and international literature before focusing specifically on Romanian literature. It will explain the term ID in line with the current models of disability and explore the impact of the parent – professional relationship on the family. It will explore how caring for a child with an ID can influence relationships in the family and the wider community. Finally, it will provide a historical background to disability in Romania by critically reviewing the research emerging from Romania around disability issues and discuss the impact of these issues on the development of this study.

2.2 Aims of the Chapter
This chapter aims to provide a comprehensive insight into the issues surrounding caring for a child with a disability at home. By presenting the literature, it aims to identify why research into these issues is important and uncover gaps in our knowledge from the Romanian perspective. Dima and Skehill (2008) previously acknowledged a lack of evidenced based knowledge emerging from Romania and this acknowledgment. This challenge was also experienced within this research. Therefore, in line with their study, the literature used to inform the current study will be guided by international literature from EU and non EU countries.

The review was guided by searches of the literature using the search engines: PsycINFO, PsycArticles, Academic Search Complete, AMED, Biomedical Reference Collection, EBSCO, Wilson Omnifile and Google Scholar. Searches of these databases
yielded sparse results when focusing on literature emerging from the Romanian context. In light of this, the researcher contacted staff in Romanian universities who recommended a small number of articles in this area. In addition, research pertaining to disability in Romania was sought from volunteers and staff employed by NGOs who work in Romania.

The chapter will critique empirical research papers which explore parents experiences of the disclosure process and how they describe their social relationships and coping since the disclosure of the disability. Also, the chapter will present information from the grey literature base to contextualise the experiences from the Romanian perspective. By analysing this information, a gap in the literature will be identified thus providing a rationale for the current study while also highlighting the gap in research that this study intends to inform.

2.2.1 Positioning the Current Study


In the past, people with disabilities experienced inhumane infringements on their basic human rights through their segregation from society as they were placed in large scale institutions which isolated them from the outside world. This practice of institutionalisation is
gradually changing through the application of the United Nations Convention on the Rights of Persons with Disabilities which was influenced by the principles of community integration and normalisation (Wolfensberger, 1972). To achieve successful deinstitutionalisation and to prevent institutionalisation requires access to available community based services to support people with disabilities and their families to experience inclusion in everyday life (European Commission, 2009).

In 2011 the WHO and the World Bank jointly produced the world report on disability to facilitate the implementation of the 2006 United Nations Convention of the Rights of Persons with Disabilities. The report revealed a bleak picture of unequal access to health care services for people with disabilities and their exclusion from society through a lack of opportunities to engage in community activities (WHO & World Bank, 2011). The onset of the global economic crisis in 2008 has caused many people to experience severe financial strain and families of people with disabilities are particularly vulnerable to this strain, specifically the succession of reductions in support. The full impact of this crisis on the care of people with disabilities has yet to be realised (United Nations International Children’s Emergency Fund, 2010).

The current study supports the principles of normalisation and community inclusion for people with disabilities and their families. In line with international guidelines, this research supports an end to institutional practices for people with ID and supports the prevention of institutionalisation through the provision of community based supports to families of people with ID (European Commission, 2009). This study also supports the inclusion of families in research to ensure the development and provision of evidence based services for people with disabilities.
2.3 Intellectual Disability

2.3.1 Defining Intellectual Disability

This study focuses on the experiences of caregivers of children with ID in Romania. An understanding of the term ID is useful to contextualise the research. The most prominent definitions for ID come from the International Classification of Diseases (ICD-10), the Diagnostic and Statistical Manual from the American Psychiatrist Association (DSM-IV) and the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD definition allows the explanation of ID in terms of a multidimensional classification system and the definition is in line with best practice guidelines from the International Association for the Scientific Study of Intellectual Disabilities (IASSID). ID is defined as being “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18” (p12, AAIDD, 2010).

This definition emphasises the inclusion of people with ID into society based on their abilities. The definition detracts from focusing on deficits, with a preference for evaluating the support needed by an individual with an ID in order to experience inclusion in all aspects of life (AAIDD, 2010). Today, the focus is on a multidimensional classification system looking at the five dimensions of intellectual abilities, adaptive behaviour, health, participation and context. The tests used to measure both intellectual functioning and adaptive behaviour are well developed and standardised. The definition must be understood according to this multidimensional perspective in order for society to be able to respond with the implementation of interventions that recognise the strengths of the individual and the importance of supports to enhance functioning (Wehymer et al., 2008).
2.3.2 Diagnosing Intellectual Disability

The AAIDD proposes the diagnosis of ID through an assessment of intellectual functioning and adaptive behaviour along with a consideration of the environment in which an individual lives while acknowledging linguistic diversity, health and cultural differences (AAIDD, 2010). Adaptive functioning refers to the conceptual, practical and social skills required to function in the community. Using this diagnostic framework, a measure of intelligence quotient (IQ) along with measures to assess adaptive behaviour such as social, conceptual and practical skills are carried out. The disability must manifest itself before the individual is 18 years old. This ensures a multidimensional approach by considering intelligence functioning, adaptive behaviour, health, participation and context (AAIDD, 2010). Using the aforementioned definition, ID can be arranged into 4 degrees mild, moderate, severe and profound.

Table 2.1: Impact of level of disability on IQ and adaptive functioning

<table>
<thead>
<tr>
<th>Level of disability</th>
<th>Intelligence Quotient (IQ)</th>
<th>Adaptive functioning</th>
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<tbody>
<tr>
<td>Mild</td>
<td>50/55- 70</td>
<td>Generally good level of adaptive behaviours e.g good communication skills.</td>
</tr>
<tr>
<td>Moderate</td>
<td>30/ 35- 50/55</td>
<td>Comparable level of deficits in adaptive behaviours e.g decision making can be impaired.</td>
</tr>
<tr>
<td>Severe</td>
<td>20- 35</td>
<td>Significant deficits in adaptive behaviours e.g social and interaction skills are less developed.</td>
</tr>
<tr>
<td>Profound</td>
<td>&gt;25</td>
<td>Significant deficits in adaptive behaviours e.g limited communication skills.</td>
</tr>
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</table>
2.3.3 Prevalence of Intellectual Disability

A recent meta analysis (Maulick, Mascarenhas, Mathers, Dua & Saxena, 2011) sets the prevalence rate for ID at 1% globally. Among this group, 85% of individuals are classified as having a mild ID, 10% with a moderate ID, 4% with a severe ID and the remaining 2% with profound ID (King, Toth, Hodapp & Dykens, 2009). From an Irish perspective, in 2010 there were 26,484 people registered on the National Intellectual Disability Database (Kelly, Craig & Kelly, 2010).

In 2005 the United Nations International Children's Emergency Fund (UNICEF) noted the lack of prevalence rates for children ID in Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS) countries because of the variation in defining and diagnosing children with ID in these countries. In 2011, in Romania the General Directorate of Protection of the Persons with Disabilities of the Ministry of Labour, Family and Social Protection recorded a combined total of 196,303 children and adults with a mental disability (Appendix A). According to figures received from the County Director of Social Services in June 2012, the number of children registered with a “mental disability” in the county within which this study was conducted is 193. Of these, 25 children are in state care. There are a further 231 children registered with an “associated handicap”, 57 of whom are in state care. This group may include children with ID (Appendix B).

2.3.4 Intellectual Disability Terminology

Historically, there have been many changes towards the manner in which people with ID have been treated by society. By the end of the 18th century words such as mania, imbecility and moral insanity were commonly used to describe individuals with ID. By the 19th century the concept of ID was seen as an individual deficit of intelligence and therefore tests of
intelligence were developed to measure this deficit (Brown, & Radford, 2007). This approach to categorisation gave rise to the use of the label “mental retardation”, literally meaning an inferior state of mental capacity cumulating in a mental slowness (Wehmeyer et al., 2008). Prior to the use of the term mental retardation all attempts to define the concept resulted in the production of terms such as mental debility, hydrocephalous, cretin or mentally deficient—all terms which assumed the deficit resided within the individual and within the mind (Wehmeyer et al., 2008). The term mental retardation has since evolved and has more recently been replaced with the term intellectual disability to reflect the changing ideologies in models of disability and to support best practice research emerging from the IASSID. The use of different terminology varies between countries and is indicative of the competing underlying models that guide their implementation.

Table 2.2: Examples from the literature of the differing use of intellectual disability terminology across countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Terms currently recognised by legislation</th>
<th>Terms used in the past</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Intellectual Disability</td>
<td>Mental retardation, developmental disability</td>
</tr>
<tr>
<td>United States of America (USA)</td>
<td>Intellectual Disability</td>
<td>Mental retardation</td>
</tr>
<tr>
<td>United Kingdom (UK)</td>
<td>Learning Disability</td>
<td>Mental handicap, mental deficiency</td>
</tr>
<tr>
<td>Ireland</td>
<td>Intellectual Disability</td>
<td>Mental handicap, mental deficiency</td>
</tr>
<tr>
<td>Romania</td>
<td>Mental deficiency</td>
<td>Mental retardation, mental handicap</td>
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2.3.5 Historical Background in the Provision of Care for People with Intellectual Disabilities

Since the 19th century large scale institutions were built to accommodate people with ID as it was thought that these individuals needed specialised training facilities to ‘correct’ their impairments. In the absence of correction, institutions were seen as residences where the “incurable” could be placed so that they could be kept separate from society (Brown & Radford, 2007). This model of care has changed through the process of normalisation which has taken place since the Second World War (Wolfensberger, 1972). Normalisation was influenced by the Anti-Psychiatry Movement which aligned itself with the social model of disability.

The second influential movement impacting upon care was the Independent Living Movement. This gained popularity due to the lobbying by individuals with physical disabilities for a change from institutional practices to community inclusion through the adaption of the environment and the provision of personal assistance (Brown & Radford, 2007). The push for deinstitutionalisation and community living has encouraged the inclusion of people with ID into the community with a focus on normalisation and a rejection of the segregation of people with ID from the rest of society (UNICEF, 2007). Research on the impact of deinstitutionalisation for people with ID in many countries is now in its second generation. No longer focusing solely on outcomes for individuals as a result of the transition, it is now recognised that families play a leading role in the provision of care for people with ID. Families are key resources for planning and developing supports to ensure people with ID remain included in the family and society (Bradley, 1996).
2.3.6 Models of Disability

Variations in how professionals work with families of people with ID reflects a change in the implementation of models of understanding disability across countries. The medical model and social model of disability have contributed towards the shaping of the term ID and the provision of care for people with ID.

In the eighteenth and nineteenth century the medical model of disability was the dominant model utilised by health care professionals. This model viewed disability pathologically, as a problem that was inherent in the individual. Therefore it was seen as necessary that these individuals required a cure and rehabilitation, with the aim of these strategies being that the individual adapted to societal norms (Brown & Radford, 2007). The model is based in part on the premise that there are norms against which a person with a disability can be measured and that this norm is based on a person without a disability (Whyte, 2006). The model is viewed as disempowering, at times infringing upon the basic human rights for these individuals and reinforcing the marginalisation of this group. In addition, the model is one which is seen to bolster the traditional power base of professionals (Moore, Beazley & Maelzer, 1998).

The social model challenged this deficit orientated model and posited that disability is a social construct. A defining characteristic of this model is its’ focus on the disabling structures that exist in society rather than on an individual’s disability (Oliver, 1996). This model has been expanded using a rights- based approach to include an all- encompassing view of the individual’s life experiences within cultural, biological, psychological, societal and political perspectives (Oliver, 1996). In the United States of America (USA) this model is often known as the “minority group model” of disability (Landsman, 2005). The model rejects an assumed norm as proposed by the medical model and recognises the interaction
between the medical and social model to represent a common human experience (Oliver, 1996). Today, the IASSID supports the application of the biopsychosocial model of disability.

2.3.6.1 Impact of Culture on Models of Disability

How individuals make sense of disability is invariably impacted upon by the socio-cultural context in which they live. It is acknowledged that there is a dearth of cross cultural research on the impact of culture on ID (Littlewood, 2006). In many cultures, family care giving is viewed as a duty. Cultural norms play an important role in the identification of disability and how the family respond to disability within society (Landsman, 2005). Only in the recent past is this re-emerging in individualistic western cultures, as formerly, parents of children with ID were encouraged to relinquish care giving duties to the state (Allison & Strydom, 2009).

Understanding these cultural norms can help us to understand how services for people with disabilities have developed in different cultural groups. In the USA, atypical child development is viewed in terms of differences to the typical pattern of child development which would highlight the early emergence of behaviours such as social engagement and verbalisations. The aim of identifying early deviations from typical development is to provide early intervention to improve child development and family adaption (Weisner, Matheson & Bernheimer, 1996). In contrast, in South Africa, traditional healers believed that those with ID were affected by acts of witchcraft. Through this externalised explanatory framework, the person with an ID was viewed as being an innocent victim of their difficulties thus increasing the likelihood that they would be cared for within the family (Kromberg, Zwane, Manga, Venter, Rosen & Christianson, 2008).
The impact of cultural differences is more recently emerging in the literature surrounding the identification of Autism Spectrum Disorder (ASD) in children. In India it was found that signs of atypical development such as not engaging in social interactions was viewed by some parents of children with ASD as a sign of maturity thus delaying the diagnosis (Daley, 2004). Kim (2012) examined the implications of having a child with ASD in Korea. An implicit tenant in this culture is a concern with how you are perceived and judged by others. In this patriarchal society, it is believed that disability is a sign of shame and guilt, with parents and specifically mothers often being blamed for their child’s disability. Mothers are primarily responsible for child rearing. In this culture, the diagnosis of Reactive Attachment Disorder (RAD) is equitable with autism. However, RAD is a more culturally accepted diagnosis than autism. Mothers are frequently blamed for their child’s autism and therefore are often forced to accept a diagnosis of RAD instead (Kim, 2012). By analysing cross cultural studies one can begin to identify differences in how professionals recognise disabilities which invariably will impact upon the interventions delivered and the child’s development and family well being.

2.4 Historical Background of Family Research

An overview of the changing focus of research concerning the family of a child with a disability is useful to position the current study. Historically, parents were blamed for having children with disabilities (Ferguson, 2002; Watson, Hayes & Radford-Paz, 2011). Between 1920 and 1980 in the USA, health care professionals felt that to keep a child with a disability at home would damage the family (Ferguson, 2002). The rationale for this advice was multiple fold stemming from the idea that the associated emotional strain would be too great for caregivers, that home care for the child with the disability would impact negatively on
other siblings and that parents were incapable of providing the technical nursing and physical care required to care for a child with a disability (Lash & Kahn, 1998).

This professional opinion led to a trend in the research of documenting the experiences of grief and sadness experienced by parents upon receiving the news that their child was diagnosed with an ID, with the diagnosis being viewed as a tragedy (Broberg, 2010; Ferguson, 2002; Olshansky, 1962). Institutionalisation of people with ID was common during this time in the USA and UK. Research began to look at the factors influencing parental ‘abandonment’ of people with disabilities into institutional care (Downey, 1965; Olshansky & Schonfield, 1964). In many cases, a contributory factor towards this ‘abandonment’ was the encouragement by professionals for parents to relinquish care (Ferguson, 2002; Sherman & Cocozza, 1984). This advice reflected the prevailing ideology of the professional as “expert”, as someone who provided uncontested expert opinion based on the medical model of disability (Landsman, 2005).

The paradigm of professional as ‘expert’ has increasingly been called into question (Carpenter, 2000). Dissatisfaction or passiveness of parents with contact with professionals was traditionally viewed as displaced anger or denial in reaction to the receipt of a diagnosis (Landsman, 2005) rather than as an interpretation of justifiable anger towards inadequate practice by professionals and a lack of services (Ferguson, 2002). The challenging of this ‘professional as expert’ stance began in the USA as a result of an advocacy movement which was led by parents of children with disabilities. This movement also occurred in the UK when advocacy groups called for increased parental involvement in their children’s care (MacKean, Thurston & Scott, 2005).

Trends in research regarding families living with a child with a disability was typically divided into two themes, that of stress and coping and of the development of the
family over the life course (Ferguson, 2002). No longer focusing only on issues pertaining to stress and coping by mothers, research is expanding towards looking at adaption and resilience from multiple family perspectives as it is known that most parents adapt well to caring for a child with ID (Broberg, 2010). This is gradually resulting in the prevailing theme in such research to reflect the shift from stress and coping towards adaption and resilience (Blacher, Neece, & Paczkowski, 2005).

These emerging research trends are constantly challenging the ‘disability as tragedy’ discourse which was previously prevalent in the UK and USA. Using discourse analysis, a recent Swedish study which analysed semi structured interviews carried out with 17 parents of children with ID showed that parents often felt victimised when professionals judged that having a child with a disability in the family was a tragedy. It was found that such judgements encouraged parents to disprove professional opinion, and resulting from this challenge came mixed feelings of stress, guilt, pride and determination for families across their life course (Broberg, 2010). Some research highly criticises viewing families of children with disabilities as ‘problem families’ is and it is now widely accepted that these families are like every other family. In a summary of interviews and focus groups carried out with 26 primary caregivers of children with a disability, these families were found to equitable to the typical family, as they too were balancing the daily needs of their children with factors posed by society and the environment (Kelso, French, & Fernandez, 2005).

2.4.1 Family Research to Support the Parent/ Professional Partnership

Family centred practice calls on professionals to view families as collaborators, with the view that this partnership has a long term impact on the development of the child (Espe-Sherwindt, 2008). It asks the professional to enable the family to make informed decisions
regarding the support they require according to the wishes of their child (Jansen, van der Putten & Vlaskamp, 2012). Research calls for professionals to recognise the expertise and unique perspective of the family (Watson, & Radford- Paz, 2011; Rodger, O’ Keefe, Cook & Jones, 2012). In doing so, it is important that professionals can recognise key strengths in families and aim to strengthen them, which should in itself should lead to positive outcomes for the child (Ylvén, Björck - Akesson & Granlund, 2006).

On the other end of the scale in the USA, following the family centred approach of early intervention for children with disabilities, professionals sometimes assume that parents will learn the therapeutic skills shown to them and continue to provide these interventions in the home environment (Leither, 2004). Leither (2004) sought to uncover any dilemmas with the family centred approach, with the view that this may inhibit its implementation within the family. Employing a qualitative methodology, analysis of interviews with 31 families and 19 health care professionals demonstrated that families willingness to engage in the family centred approach process was regarded by professionals as a reflection of their compliance and acceptance of the disability. Professionals overlooked the possibility that non-compliance may result from the families feelings of being overwhelmed by this expectation (Leither, 2004). The increased responsibility being placed upon parents for the design and implementation of interventions can lead to the delivery of family centred care with minimal professional support (Shields, Pratt, & Hunter, 2006). This study is useful as it informs us about the parent- professional practice when the family is actively engaged within this practice. However, it does not inform us about those parents who are not engaged or those who may have exited such practices. However, these studies bring to our attention that there is still a requirement for professionals to remain cognisant of the need to work in partnership with parents. In doing so, they are ensuring collaborative communication that allows the
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sharing of information and to problem solve any issues which may impede the provision of care within these families.

Efforts have been made in the USA to increase professionals’ competence in the area of family centred practice, such as training programmes run by the Westchester Institute for Human Development, which offer comprehensive training for professionals in the area (Levitz, Allard, & Edwards, 2010). The extent to which parent and professionals collaborate is still an under researched area (Watson, Hayes & Radford-Paz, 2011) especially from a non-Western perspective with minimal research being carried out with families of children with disabilities (Watson, Hayes & Radford-Paz, 2011; Ferguson, 2002).

2.4.2 The Changing Pattern of Disability and the Increased Need for the Parent/Professional Partnership

With the advancement of modern society in terms of medical developments, coupled with issues of intergenerational poverty, a changing pattern of disability is now being recognised in children in Ireland and the UK. Children with this pattern of disability are presenting with Complex Learning Difficulties and Disabilities (CLDD) (Carpenter, Egerton, Brooks, Cockbill, Fotheringham & Rawson, 2011). These children have multiple levels of need in the areas of relationships, mental health, behavioural, sensory, physical, cognition, medical and communication. Some of these complex needs have resulted from premature birth or these children may have acquired disabilities through parental abuse of substances during pregnancy and/or have rare chromosomal disorders. In 2011 a host of recommendations were made by The Complex Learning Difficulties and Disabilities Research Project in the UK about how to best provide for children with CLDD. Of notable importance, is the recognition that families of these children are instrumental in developing new practices for the care,
education and provision of therapeutic support to their children. The project expressed a renewed call for professionals to work with families in the ‘spirit of equal partnership’ (p10, Carpenter et al., 2011) thus highlighting once more the urgency of these partnerships to ensure a good quality of life for the child and family.

In the UK, considerable efforts have been made to ensure the rights of the child with a disability to grow up in the family setting. The 2004 Children’s Act legislated this right while recognising that families need individualised support in order to achieve this. This act requested the appointment of a Children’s Commissioner who would promote the recognition and awareness of the rights of the child. Two papers - the white paper *Valuing people* (Department of Health, 2001) and the *Valuing people now* (Department of Health, 2009) were produced to increase support for families of children with ID and outlined a cross-governmental strategy for people with ID in the UK. Several other strides have been made to improve the provision of family centred care in the UK such as the initiative in 2007 *Aiming high for disabled children* (HM Treasury and the Department for Education and Skills) which aimed to avert the use of negative imagery of children with disabilities and promote inclusion. It also promoted respite for parents and caregivers and the active inclusion of caregivers in the development of services (WHO, 2010a).

### 2.5 Impact of Disability on the Family

The disclosure of a disability to parents will impact upon the child, the parents adjustment and that of other family members. Thus the manner in which a child’s disability is communicated to the family becomes a turning point for this cycle of change. There are a number of challenges that these families may commonly experience which are presented below.
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2.5.1 The Disclosure of Disability and its Impact on the Child

The most likely first point of contact to occur between parents and professionals is during the disclosure process, which is the point when a health care professional tells the parent that their child has a disability. The impact of the disclosure process on coping for parents remains an under researched area (Bingham, Correa, & Huber, 2012). Inevitably, culture will impact on the relationship between parents and professionals (Ravindran & Myers, 2012). Culture will dictate what role the professional assumes, be it a paternalistic stance of ‘expert’ or a more collaborative approach. It is acknowledged that from a Western perspective, the ideal is to have a collaborative relationship but this viewpoint is not mirrored in other cultures where often the parent is left uniformed (Ravindran & Myers, 2012).

The impact of the disclosure of a disability on the family is varied and is strongly influenced by the socio-cultural context where the individual resides (O’ Hara & Bouras, 2007). From a UK perspective it has been established as a critical time for parents (Sloper & Turner, 1993). Similar findings have been found from the Irish literature (Doyle, 2004; Harnett, 2007). The manner in which a parent is told about their child’s disability is shown to have long term effects on their understanding and acceptance of their child (Watson, Hayes & Radford-Paz, 2011; Todd & Jones, 2003). In the past, the impact of disclosure on the parent had an obvious immediate effect on the child with the child being removed from the family environment and institutionalised (Lash & Kahn, 1998). This practice is changing at different rates across countries to reflect the changing ideologies around how disability is understood and the provision of care for children with disabilities.

In 2007 National best practice guidelines for informing families of their child’s disability was developed by the National Federation of Voluntary Bodies and launched in Ireland. The guidelines were the product of a research process which consisted of a review of
national and international literature, a series of focus groups with parents and professionals and the dissemination of a nationwide questionnaire. The national survey revealed a large gap between parental satisfaction with the disclosure process and professional awareness of recommendations surrounding best practice (Harnett, 2007). In 2010, after positive results of the evaluation of the pilot scheme of the programme, a ‘Roadmap for Implementation’ was delivered nationwide. The guidelines formed the impetus for a host of good practice events, with a series of training programmes for health professionals, students and parents being held in the intervening years. Programme’s such as these are offered as a good example about how the disclosure process can be carried out sensitively while meeting the needs of the family and thus fostering a parent-professional partnership.

2.5.2 Parental Satisfaction with Disclosure

Prior to the disclosure of disability parents are faced with many potential sources of stress through their interactions with health care professionals during the processes of assessment and diagnosis (Ylvén, Björck-Akesson & Granlund, 2006). In order to improve outcomes for the child and family, research has been conducted to establish parents satisfaction with the process of disclosure. One such study carried out in the UK interviewed 22 parents of children with disabilities. Many of these parents were dissatisfied with the process because of the manner in which they receive the news of a diagnosis, specifically because of the non-empathic approach of the professional delivering the news (Davies, Davis & Sibert, 2003). It must be noted that this study does not provide details of the methods employed. In similar research carried out in Ireland, 42.9% of parents surveyed reported being satisfied or very satisfied with the disclosure of their child’s disability (Harnett, 2007).
Goodley and Tregaskis (2006) acknowledged the need for professionals to demonstrate sensitivity when talking about disability with parents and an awareness of how they as professionals understand and react to disability in practice. Applying narrative analysis to the data collected in a focus group with health care professionals revealed a desire to learn how to break ‘bad news’ to parents. It was thought that the very nature of the notion that the news was framed as ‘bad’ reflected professional attitudes viewing disability as a ‘tragedy’. The research challenged professionals to reflect critically on their understanding of impairment or disability (Goodley & Tregaskis, 2006). Applying narrative strategies to 25 interviews of parents of children with disabilities revealed that the disclosure process is viewed by some parents as a time during which they must ask the right questions in order to avoid being ‘fobbed off’ by professionals. These professionals were seen by parents as individuals who possessed expert knowledge, but also who had a reluctance to share this knowledge with families (Fisher & Goodley, 2007).

Most research with parents of children with disabilities has been carried out in Anglo Saxon countries, resulting in a lack of data on parental experiences from other cultural contexts (Broberg, 2010). A mixed methods study which examined the disclosure process from the perspective of 162 parents of South Asian origin living in the UK found that these parents had similar mixed satisfaction levels with the process as demonstrated in previous UK studies (Hatton, Akram, Robertson, Shah & Emerson, 2003). The researchers suggested a universalist approach towards the disclosure process and tentatively suggested the basic manner in which parents adapt to disclosure is similar across cultures (Hatton, Akram, Robertson, Shah & Emerson, 2003). Caution is exercised in generalising these findings given the complexities involved in cross-cultural research. The study highlighted the importance of being open to viewing parental satisfaction with disclosure as a means of long term...
adaption to the child regardless of the country of origin of the parent (Hatton, Akram, Robertson, Shah & Emerson, 2003).

Parental dissatisfaction with the disclosure process is not evitable. Best practice guidelines have been implemented in health care services in many countries, to positively influence the parent-professional relationship. There is a need to dispel the idea that parental dissatisfaction with disclosure is due to the diagnosis itself, in an attempt to move towards implementing these best practice guidelines (Harnett, 2007).

### 2.5.3 Impact of Disclosure on Collaborative Relationships

In a qualitative study of 30 mothers of adolescents with ID, it was found through the application of grounded theory analysis that difficult relationships with professionals could be traced back to initial encounters with professionals and a dissatisfaction with how the news of the disability was delivered (Todd & Jones, 2003). These initial encounters continued to hold relevance throughout the family life course. Some mothers viewed professionals as barriers rather than facilitators of support for their child and found they often had to fight to let their voice be heard by professionals (Todd & Jones, 2003; Fisher & Goodley, 2007).

A strong desire from caregivers was for a stronger commitment from professionals to support them to provide home care (McDonald, Couchonnal & Early, 1996). A considerable body of evidence shows that children’s developmental needs are best met in the home, but there are inequalities or a lack of services to support the claim that “all children should grow up in families” especially when addressing the issues of permanency for children with disabilities (Rosenau, 2000).
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2.5.4 Impact of Disclosure on Attachment

For parents, discovering that their child has a disability can result in an amalgamation of emotions ranging from grief, confusion or anger (Einfield & Emerson, 2008). For some these feelings are displaced with the feeling that their child is a huge gain to them and their family (Dúra- Vilá, Dein, & Hodes, 2010). Upon disclosure, professionals have the opportunity to provide parents with clear, easily understood information regarding the nature of their child’s disability which can facilitate understanding and acceptance of their child (Harnett, 2007). Some view the formation of attachment with a child with a disability as potentially challenging due to less sustained interactions between caregiver and child and the slower development of self care skills of the child (Dobson, Middleton, & Beardworth, 2001).

Marvin and Pianta used the Reaction to Diagnosis interview to decipher if 70 parents reactions to the disclosure of disability was related to their attachment to their child. Results found that parents who had not ‘resolved’ their grief over having a child with a disability were three times more likely to form an insecure attachment to their child, than mothers who were seen to have ‘resolved’ their grief (Marvin & Pianta, 1996). Caution is advised in interpreting these results given the small sample size limiting the generalisability of findings.

Professionals have been criticised for their tendency to relay only negative messages to parents about the disability upon disclosure (Bećirević & Dowling, 2012; Harnett, 2007). The disclosure process has the potential to kick start a parent- professional relationship that is either fraught with difficulty and stress, or if the disclosure is handled sensitively, it can mark the beginning of a partnership that fosters shared understanding and open communication. A series of focus groups were carried out across Bosnia and Herzegovina to explore the views of 89 parents of children with disabilities around their experiences of supports. Through this, one father from Bosnia and Herzegovina reflected on his negative experience of the
information provided to him at the point of disclosure stating that if he was told at that point about how his child currently functioned that ‘I would never have cried to start with’ (p7, Bećirević & Dowling, 2012). Although this research lacks a clear overview of the method of analysis applied, such research is useful to bring our awareness to such practices in order to highlight this area as one which warrants further exploration.

2.5.5 The Financial Impact of Disability

Muir (2008) provides a review of the many impacts of childhood disability on the family. In 2001, a quantitative study was undertaken in which questionnaires and diaries were returned by 182 parents of children with disabilities, and 42 questionnaires were returned by children within these families. Results revealed that caring for a child with a disability can change a parents work- life balance, with some parents decreasing working hours or leaving the work force to facilitate the provision of care for their child (Dobson, Middleton & Beardsworth, 2001). This impacts on the family income, which may already be under pressure in order to meet the extra cost associated with caring for a child with a disability. Despite limited financial assistance available to families of children with disabilities, the upkeep of paid employment is often incongruent with the circumstances surrounding caring for a child with a disability at home (Breen, 2009). Parents may reduce their social activities to bridge the financial gap which can contribute to further social isolation of the family (Dobson, Middleton & Beardsworth, 2001). As suggested by Bećirević and Dowling (2012), the elevated cost associated with caring for a child with a disability highlights the need for financial assistance for these families. In the same vein, parents have recognised their reluctance to speak to professionals about their support needs in relation to employment or financial assistance. This reluctance exposes a complex relationship between mothers sense
of identity and sense of ‘motherhood’ with the oftentimes conflicting cultural notions of the roles of a mother of a child with a disability (Todd & Jones, 2003).

### 2.5.6 Impact on Siblings

The impact of disability on siblings is important to explore in order to inform the provision of support that can be provided to families. Siblings too will experience a process of adjustment and adaptation when they have a sibling diagnosed with an ID (Mulroy, Robertson, Aiberti, Leonard & Bower, 2008). Past research has shown that the impact of disability on siblings varies according to the disability of the sibling (Mulroy et al., 2008), family functioning (Dyke, Mulroy, & Leonard, 2009) and social support available to the parent (Gardner & Harmon, 2002). Research has traditionally focused on the negative outcomes experienced by siblings, sometimes referring to their grief at the loss of a ‘normal’ childhood (Strohm, 2002). However research is now changing to consider the idea that living with a brother or sister with a disability does not inevitably mean the sibling will experience a life trajectory of grief or struggle. Cuskelly and Gunn (2006) have added weight to this idea that siblings do not inevitably show poor adjustment, as was previously anticipated by professionals and parents alike.

### 2.6 Coping of Parents with a Child with a Disability

Research in the area of coping with the care of a child with a disability is changing. It is acknowledged that parenting is a process of coping even if the family doesn’t contain a child with a disability. Managing the daily family routine is a common challenge for all families but it may be more demanding for families of children with disabilities (Gallimore,
Bernheimer & Weisner, 1998). Research recognising the impact of culture on coping strategies employed by parents of children with ID has to this point focused predominantly on Western countries (McConkey, Truesdale-Kennedy, Chang, Jarrah & Shukri, 2008). It is thought that the greatest disparities would be seen in terms of the professional supports offered to parents. This information is vital to ensure health care services are meeting the needs of parents (McConkey et al, 2008). Given the lack of research pertaining to this topic from an Eastern European perspective, it is unknown what impact, if any, is felt by parents in these areas.

Without adequate support, parents of children with disabilities can find it difficult to cope with providing care. It is now widely accepted that supporting the emotional well being of caregivers inevitably impacts upon the quality of life of the recipient of that care (Rollisson & Wright, 2012). Coping is now seen as being a life-long process of adaption which involves changes at every level of family life (Poehlmann, Clements, Abbeduto & Farsad, 2005). Coping is defined as the thoughts and behaviours used to manage the internal and external demands that are linked to situations which are appraised as stressful (Lazarus & Folkman, 1984). Using grounded theory to analyse the data obtained from 8 parents of children with disabilities over a two-year period, Graungaard, Andersen and Skov (2011) challenged the notion that the existence of accompanying positive psychological states are a sign of parental maladjustment. Identification of coping strategies by these parents resulted in the appreciated view that parenting a child with a disability can result in associated positive affect (Graungaard, Andersen, & Skov, 2011). This positive affect is representative of internal states that can facilitate positive coping strategies (Folkman & Moskowitz, 2000).

Families use a combination of personal and socio-economic resources to cope. Personal resources refer to caregiver personality, physical health, beliefs, parenting skills and
previous coping strategies. Socio economic coping resources tend to feature more frequently in the literature due to their relative ease of measurement such as different types of support: social support from partners and community, and formal support accessed via employment or state services (Graungaard, Anderson & Skov, 2011). If these resources are unavailable or under additional strain it will impact negatively on the ability to cope.

Examples of good coping strategies utilised by parents are linked to having good information, acceptance of the diagnosis, good social support and family co-operation (Taanila, Syijälä, Kokkonen, & Järvelin, 2002). Coping is important when looking at parents decision to place their child in out of home placements. In Western cultures, premature out of home placements for a child with an ID occurs when the demands of the child’s disability along with any associated mental health difficulties, behaviours that challenge or problems with physical health exceed the limits of parental coping resources (Carr & O’ Reilly, 2007).

2.6.1 Impact of Disclosure on Coping

Qualitative research carried out in Denmark which looked at parents experience of the diagnostic process and its impact on parental coping found that parental coping was heavily influenced by both the receipt of a diagnosis and the diagnostic procedure (Graungaard & Skov, 2006; Graungaard, Anderson & Skov, 2011). This small scale study found that parents experience of passing through chaos differed according to the variations in the diagnoses and diagnostic procedures which significantly contributed towards a sense of regaining control and order in their lives. The study found that the experience of the diagnostic procedure shaped how parents perceived the child, their creation of future images, their communication with health professionals, hospitalisation and identification of possibilities for acting (Graungaard & Skov, 2006; Graungaard, Anderson & Skov, 2011).
Within this, the researchers outlined parents attempts to cope with these additional stressors and also their resource-creation strategies. Resource-creation was shown to be an adaptive coping strategy, where parents engaged in constant positive reappraisal of the situation, seeking out information and hope. In contrast to previous studies, they saw the utilisation of avoidance-coping strategies, for example ‘distrusting information’ as being a resource-maintaining strategy and not related to a lack of adjustment or denial (Graungaard, Anderson & Skov, 2011).

In an Australian study Gray (2006) tracked changes in the coping strategies utilised by families of 28 parents of children with autism over a ten year period using ethnographic methods. It was found that as the child aged, parents relied more heavily on religion and reframing the situation as examples of problem-solving coping strategies. Interestingly, with the advancement of time, parents utilisation of professional supports decreased. Tentatively suggested is the notion that this lack of utilisation may be indicative of a lack of appropriate services available for young adults with disabilities living at home (Gray, 2006).

2.7 Care Related Decision Making for Children with Intellectual Disability

Factors affecting parents decision making have been studied in the context of factors influencing caregivers decision to place their child with a disability in out of home placements. Specific child specific and situational factors were isolated that were seen to influence parents decision making. Examples of these are level of functioning of the child, family characteristics such as size of family, available community services and social supports (Sherman & Cocozza, 1984).
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Over a three year period, Mitchell, Maddison and Beresford (2011) gathered data from 27 children with disabilities and 44 parents of children with disabilities to examine their experiences of making choices about services. They illustrated various factors parents consider when making choices for and with their child with a disability. Factors such as parents perception of the choice, namely the risk it may carry towards their child’s health and parents own beliefs impacted upon their choice. In particular the value they placed on the level of independence they wanted for their child as they grew older influenced their decisions about care and services chosen (Mitchell, Maddison, & Beresford, 2011).

Research into factors affecting parents choice of care has shown that parents repeatedly have called for quality information to guide their decisions (Nieboer, Cramm, Meij & Huijsman, 2011). Little research has been conducted to ascertain how parents and children with ID make decisions, and how information and support impact on their decisions (Nieboer, Cramm, Meij & Huijsman, 2011). Using an experimental study design, 147 parents of children with ID participated in a study to determine the extent to which the offering of personal decision making support and information impacted upon parents choice of care. It found that these supports impacted on the decision made but not on satisfaction with the care chosen (Nieboer, Cramm, Meij & Huijsman, 2011).

Similar to emerging trends in family- centred practice, research is now looking at the extent children with disabilities are included in decision making regarding their care (Garth, Murphy & Reddihough, 2009). Parents have traditionally advocated for the child, perhaps because of their legal responsibility to do so (Garth, Murphy & Reddihough, 2009). The study by Garth, Murphy and Reddihough (2009) is novel in its decision to invite a mix of 14 parents of children with cerebral palsy, 9 paediatricians, and 10 children with cerebral palsy to demonstrate the efforts made during the consultation process and at home to actively
include the child in the decision making process. Using substantive and theoretical coding, the study showed that children, while not equal partners in the decision making process, can contribute to decisions ensuring the contribution is valued (Garth, Murphy & Reddihough, 2009). However, it is still unknown how parents make decisions in the absence of formal support. This study intends to inform that gap.

2.8 Disability Literature in Romania

This section will outline what is known of coping and care giving from the perspective of literature pertaining to Romania. At a time when the Romanian government is under increasing pressure from the EU to provide more services for people with disabilities, it is important to consider the voice of the family.

A search conducted using Journal Citation Reports 2010 revealed that of the 44 journals listed for Romania, no journal was related to health or psychology. A search carried out using PsycINFO in May 2012 revealed 362 results under the search terms “~Romania*” and “~Disabilit*”. Upon analysis, none of these articles were relevant specifically to intellectual disability, family care, disclosure or coping. The lack of evidenced-based knowledge to guide the researcher was perceived as a challenge in this study. However, this added to the rationale of conducting the study, giving the researcher the unique opportunity to contribute to a body of evidenced-based knowledge in this area.
2.9 Background into Institutionalisation in Romania

2.9.1 Reasons for High Rates of Institutionalisation in Romania

Romania has a legacy of state care for people with disabilities which is intertwined with a long history of communism in the country. Reasons for the high rates of institutionalisation of children and adults with ID in Romania are complex and explanations must be framed within a wider historical and political perspective (Morrison, 2004).

In 1965 the Communist dictator Nicolae Ceausescu took power and implemented draconian measures which were to last until he was executed in 1989 to increase the population of Romania. Walker (2011) outlines these measures which included the banning of contraception and abortion, an increase in tax for those who were childless- regardless of the mothers’ marital status. Women under 45 years of age were required to bear a minimum of four children and men who were unmarried were required to pay a celibacy tax (Cojocaru, 2008). Financial incentives were offered with each birth, but the money received was inadequate to support the upkeep of a child. To further encourage child birth despite the poverty of the nation, the state encouraged relinquishment of childcare to the state thus giving rise to the perception that state care was superior to home care (Hogue, Lickfelt, Mylet, Perris, Thomas & Young, 2004). A lack of finances for foster placements, an ignorant attitude of some towards children with disabilities and the general isolation of the population at large coupled with oppression perpetuated the situation (Walker, 2011).

A particularly vulnerable group for institutionalisation were children with disabilities. The stigma attached to having a disability contributed towards this group of children being hidden away in state orphanages (Walker, 2011). Family supports were limited with the establishment of organisations to support people with an ID illegal under the communist regime making access to support networks for parents impossible (Miles, 2002). Additional
familial strain arose as Romanian women had one of the highest participation rates in Europe at the time in the work force, with grandparents also being forced to work. These factors contributed towards a reduction in family care options for children (Morrison, 2004). Both the outside world and many Romanian people were unaware of the appalling standard of care for those in institutions or orphanages because of the tight control by the government of the media and the isolation of these institutions from society (Walker, 2011).

In addition to the tight control exercised by the regime in the areas of family care, during Ceausescu’s reign, the practice of psychology was severely restricted. In 1977, psychology was considered to be dangerous and therefore was subjected to “ideological purification”. Psychology departments were abolished and in 1982 psychology was banned outright (Stevens, 1998). As a result, psychology in Romania experienced a revival since the fall of Communism. However, the Communist dictator left Romanian practice and policy lagging behind and this has impacted on the development of services for the nation as a whole, but in particular in the areas of intellectual disability and mental health.

2.9.2 The Collapse of the Communist Regime

The end of the Communist regime in 1989 was the beginning of the process for the entry of Romania into the EU and has resulted in the closure of large scale children’s orphanages. Since Romania applied to enter the EU in 1995, many changes occurred in child care policies and practices resulting in Romania being approved for accession into the EU in 2007 (Anghel & Beckett, 2007).

These developments in disability policies have nurtured the start of deinstitutionalisation of services for people with disabilities, a movement that is primarily
being driven by international NGO’s. The deinstitutionalisation movement in the West began as a result of human rights movements and a concern about the quality of care afforded to people with disabilities. In contrast some researchers suggest the push for deinstitutionalisation in Romania has been ignited due to other pressures such as pressures from international organisations such as the EU and the WHO (Friedman, 2009). It is unknown to what extent these claims are supported and if correct, what impact this has on families who are caring for people with disabilities at home in Romania. Anecdotal evidence suggests that examples remain in Romania whereby parents are told that their children can receive optimal care in institutional settings rather than in the family home (Ahern & Rosenthal, 2006; Walker, 2011; Lansdown, 2003).

In Romania, once an institutionalised child is 18, their care is no longer handled by child care authorities and a problem arises about who takes over this role (UNICEF & Centre for Legal Resources, 2006). Many of the chronic patients in psychiatric hospitals in Romania are young adults with severe disabilities who have been placed there due to an absence of a service that would meet their needs. The conditions in these centres are inhumane and in violation of basic human rights standards (UNICEF & Centre for Legal Resources, 2006). Many of these centres are under investigation for breaches of these rights (Cojocariu, 2011; Nelson & Koval’ová, 2011). Outcomes for people in these institutions in Romania are comparable to what was found in the 1970s in institutions in the UK, USA and Sweden (Freyhoff, Parker, Coué, & Greig, 2004).

There is a growing awareness in Eastern Europe of the need to educate families in general about why children may not “fare better in the orphanage” (p35, Robila, 2012) to eradicate the misconception that still lingers since communist times in Eastern Europe. The Romanian National Strategy on the Protection, Integration and Inclusion of People with
Disabilities states it will promote the family environment as one which best meets the developmental needs of the person with a disability. For the first time there is a changing dynamic in legislation in Romania whereby families now have responsibility for providing care. A large gap in research remains regarding the experiences of families of children with disabilities in Romania. This exploratory study seeks to uncover the impact of these practices on the family.

2.10 Categorising Intellectual Disability in Romania

By law, disabilities in Romania are categorised into ten different types: physical, visual, auditory, somatic, mental, psychological, HIV/AIDS, associated, rare diseases and deaf blind. The term “mental disability” is used to refer to people with ID (Österblom, 2008). Mental disability is classified on a four level classification system (mild, moderate, severe, profound) in line with the ICD-10 (Vann, 2007). The law sets out situations where the level of disability can be increased. An example would be in the situation where an individual is determined to have a mild “mental disability”. If the disability is associated with another deficiency “sensory, somatic, psychological (for language and communication, hyperactivity, emotional, behaviour)” then the level of disability is changed to increase the degree of disability (Order 725/2002). The term ‘associated disability’ is used to refer to individuals with two or more disabilities and therefore people with intellectual disabilities may also be included in this category. This adds to the difficulties in recording prevalence rates of people with intellectual disabilities (Österblom, 2008).
Chapter Two: Review of the Literature

2.11 Varying use of Disability Terms in Romanian Legislation

The use of multiple terms for ID in Romanian legislation and research is recognised as an ongoing problem within Romania (Gliga & Popa, 2010). These inconsistencies make it difficult to compare Romanian studies with international research. The Romanian National Strategy issued by the Romanian Government states “the terms invalidity and handicap have often been used confusedly, expressing rather the interest in the medical and diagnosis issues than in the relationship with the environment, which hinders the development of unitary and coherent social policies at the national level” (p9, 2006).

As the term ID is not recognised in Romanian legislation, the most frequently used terms to categorise this group of individuals is “mental disability” (Ahern & Rosenthal, 2006). In an attempt to discourage the use of different terms, The National Strategy on the Social Protection, Integration and Inclusion for People with Disabilities 2006- 2013 requests that the use of the terms “handicapped, irrecoverable, incapable of being educated, incapable of work” (p7, 2006) are avoided in any administrative, legal or official acts.

2.12 Diagnosis and Certification of Intellectual Disability in Romania

Concern has been expressed by UNICEF on the diagnostic process of disability in the CEE/CIS of which Romania is a member. It has uncovered several issues of malpractice, such as the issuing of medical certificates for the child without an actual examination of the child and the issuing of medical certificates as a means of accessing cash benefits, services, or access to adoption for families. It raises concern over the practice of separating a child with a disability from their family on the basis that their inclusion in the family would negatively impact upon the development of others in the family (UNICEF, 2005).
In Romania, in order for a child with an ID to benefit from state services, they must be registered with their local County Council Disability Commission and undergo assessment by an team of professionals known as ‘The Expert Service for Complex Evaluation Expert Committee’\(^1\) in order to receive a Certificate of Disability (Ahern & Rosenthal, 2006; Vann, 2007). This registration is reported to involve a new assessment made by the local expert committee to determine the disability and degree of disability (Radu, 2009). After this, a ‘certificate of disability’ is issued and a program for therapy and rehabilitation is distributed. For adults, at this point it is also decided whether the adult has the capacity to be employed (Radu, 2009). This process must be repeated annually for both children and adults in order to retain access to state benefits or services (Radu, 2009).

Similar to the AAIDD definition, the International Classification of Functioning, Disability and Health (known more commonly as ICF) definition of disability takes social aspects into account to avoid focusing on disability purely in terms of a physical or medical dysfunction (Ravindran & Myers, 2012). It is suggested that the assessment and evaluation process undertaken by the Expert Committee relies 95% on the medical records in order to determine the disability and degree of disability (Mostavi, 2011) which allows little consideration of social aspects. This assessment process is similar in many South Eastern European countries, such as Bosnia and Herzegovina and Croatia (Bećirević & Dowling, 2012). In Romania, diagnosis and classification of ID for children is made by the Child Protection Commission at local county level via local county councils. Variation in the reference works which are used during assessment has led to confusion and a lack of standardisation of a diagnosis of ID (Ahern & Rosenthal, 2006). Psychologists lack standardised assessment tools which means that there is no specific training required to carry

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\(^1\) This team is required to contain a paediatrician, psychologist, social assistant, psycho-pedagogue and a neuro-psychiatrist.
out these assessments. In some instances, it is reported that psychologists have devised their own assessments (Ahern & Rosenthal, 2006).

In an article reviewing 50 years of the education of individuals with ID, Radu (2009) criticised the process of evaluation, stating that experts on these commissions do not know the “particularities of knowledge acquisition and skills formation in children with intellectual disabilities” (p133, 2009). During these evaluations, decisions are made about what type of schooling the child with an ID should access. He argues that integration of children with disabilities into ‘mass schooling’ is not the best solution. In Romania, there are special schools of arts and craftsmanship. Here, pupils learn how to work in various professions such as waiter, barber, cook, or other practically orientated professions.

Radu states that to work in these fields requires “knowledge in mathematics, motor skills and spontaneity in solving some situations, pleasant figure, and communication capability with the interlocutors” (p134, 2009). He feels that none of these skills can be appropriately attained for those with “real intellectual disabilities”. He asserts that the inclusion of people with disabilities in employment is scarce, with employers who chose to do so being the exception and are doing so “as charity” (p134, 2009). It is difficult from such articles to decipher how comprehensively the social model of disability is applied in the writings of those in academia.

2.13 Rates of Children with Disabilities in Non Family Based Care

UNICEF (2010) shows that the rate of children in formal care (non family-based care) has increased between 2005 and 2007 to approximately 1.7% of the child population. This
includes care for children with disabilities. Residential care for children with disabilities in general is most common in the Western Commonwealth of Independent States (Belarus, Russia and the Ukraine). In Croatia and Moldova the numbers are increasing, whereas in Armenia and Belarus although rates are high they are reducing (UNICEF, 2010). Due to conflicting means of assessing individuals with ID, it is unknown how many individuals with ID reside in out of home placements in Romania. However, in 2010, UNICEF reported that the number of children with disabilities in formal care in Romania has risen from 7,100 in 2005 to 10,108 in 2007 (UNICEF, 2010).

2.14 Research on the Family in Romania

A 2009 report carried out by the United States Economic and Humanitarian Assistance (USAID) shows that in the European transition countries and Eurasia, families of children with disabilities are still encouraged by professionals to relinquish care of their child to state institutions, although many of these countries have adopted the social model of disability. In Eastern European countries like Romania, it is unknown to what extent professionals encourage relinquishment of care although it has been known to still occur (UNICEF, 2005). This has profound effects on the development of the child, knowing that the effects of institutionalisation can lead to severe developmental delays, poor physical health, and potentially irreversible psychological damage (European Commission, 2009; Tottenham et al., 2010).

In 2010 at a conference held in Romania, the World Health Organisation issued a number of papers focusing on children with ID and their families. They recognised the importance of the environment in which a child with an ID grows up in upon their quality of life. It is shown that children with ID are at a greater risk of abuse in out of home placements.
than their typically developing peers, highlighting the importance of preventing children with ID from being admitted to institutional care (WHO, 2010a; WHO, 2010b; Sobsey & Doe, 1991).

A recent study of parents experiences of disclosure in Bosnia and Herzegovina and Croatia found that there was no emphasis on collaboration between parents and health care professionals (Bećirević & Dowling, 2012). This study also showed the fragile and often disempowering relationship between parent and professional, with the parent viewing the diagnosis as essential for accessing social care while surrendering to the unwillingness of professionals to accept any of the parents suggestions (Bećirević & Dowling, 2012).

2.14.1 The Disclosure Process and Coping in Parents of Children with ID in Romania

From an Eastern European perspective, it is unknown how the disclosure process impacts upon parents understanding of their child or what factors influence parents decision to accept or reject professional advice (Bećirević & Dowling, 2012). This study will explore parents experience of the disclosure process and how parents describe their care related decisions and understanding of and adaption to their child since the disclosure process.

One study carried out in Romania measured the coping strategies of parents with and without disabilities according to parental gender differences (Moldovan, 2009). The researcher applied the COPE Inventory by Carver, Scheier and Weitraub to 185 parents, in person or via email. It concluded that there was a significant difference in the coping strategies employed by the two gender groups. The researcher found that mothers of children with disabilities used ‘acceptance’ more frequently as a coping strategy. It also compared coping strategies according to gender, finding that mothers showed higher scores in areas of
positive reinterpretation’ and ‘growth’ than fathers. This research had many limitations such as limited generalisability of the study due to the broad inclusion criteria for participants, an incomplete report on the methodology used and no reference of ethical procedures adopted. Due to its quantitative nature, it is still unknown what are parents qualitative experiences of caring for a child with an ID in Romania.

2.15 The Current Study

2.15.1 Shaping the Methodology

Following a critical reading of the literature surrounding parents experience of the disclosure process and the manner in which parents describe their daily experiences such as coping after this event, it was learnt that parents experiences while unique, had common themes. It was felt that there may be a lingering long term effect of the disclosure process upon how parents cope with providing care for their child. It was realised that there is no known empirical Romanian research into these areas. These points shaped the formulation of the methods employed for this study.

2.15.2 Establishing the Feasibility of the Current Study

A series of communications between the researcher and university staff and colleagues working in Romania, in conjunction with a review of the literature alerted the researcher to the consideration that there was a degree of scepticism towards foreigners when conducting research in Romania (Dickens & Groza, 2004). In light of this finding, the researcher was keen to determine the feasibility of carrying out research in Romania as an outsider.
Chapter Two: Review of the Literature

As the researcher was due to travel to Romania in July 2011, it was decided to use this opportunity to extend an open invitation to members of a local parents group of children with disabilities in the South of Romania to attend a focus group with the researcher (Appendix C). The purpose of this invitation was to establish the openness of members of the group to participate in a research study conducted by a non national. Attendee’s provided some important advice which helped shape the aims and methodology of the study. It was found that parents were open to share their unique and personal experiences. There was a unified desire to learn as much as possible from each other.

Parents stated that individual interviews were preferred to focus group settings. People were uncomfortable with the focus group format as they were not accustomed to speaking about their personal experiences in a group setting.

From the researchers experience of carrying out volunteer work in Romania, it was observed that the completion of forms or assessments were often viewed in a negative light. During the process of carrying out research in Romania, Dima and Skehill (2008) noted participants dislike of self-administered questionnaires and a preference for individual discussions. In this way, it was felt that a suitable approach to the research would be qualitative.

Based on a critique of the literature and conclusions drawn from the meeting with parents in July 2011, it was felt that a data-driven approach was needed. As a result, the study was conceived as qualitative and would be based on the subjective experiences of parents of children with disabilities.
Chapter Two: Review of the Literature

2.15.3 Identifying a Gap in the Literature and Rationale for the Current Research

The current study was developed to inform the gap in research emerging from Romania about parental experiences of the disclosure process and how parents describe caring for a child with an ID following this experience. The research wanted to ensure the voice of the parent was heard in order to support a good quality of life for the child within the family home. It is important to note that there are no empirical studies into these topics in Romania and the current study attempts to inform this gap in the literature. Due to the absence of published literature on this topic, national and international literature was consulted to gain insight into the issues to be addressed in this study. The six main areas for exploration and the gaps in knowledge pertaining to these areas are now presented.

- **Parents experience of receiving a diagnosis of ID**
  
  There is a scarcity of qualitative research in this area, most of which has come from Western countries. This study will be the first to explore this in the context of Eastern Europe and specifically Romania.

- **How do families describe making care related decisions after the disclosure of a disability**
  
  The preferred model of care in the UK and Ireland is family based care. The manner in which parents describe their care related decisions following the disclosure of disability is unexplored in Romania. This study will be the first to explore how Romanian parents interactions with professionals affected their decision to accept or reject professional advice around the provision of care for their child.
Chapter Two: Review of the Literature

- *How to parents describe how they cope with the care of their child following the disclosure process*

In line with current research trends, this will be the first study to address the impact of the disclosure process on parents in Romania.

- *Factors affecting care related decision making*

In the last decade, there has been a shift towards home care provision for children with ID. As there still remain high numbers of children in out-of-home care in Romania, a gap in the literature emerges for the application of in-depth qualitative analysis to determine factors impacting upon care related decision making for parents.

- *What are parents experiences of their relationships and their families relationships following the disclosure of their child’s disability*

International research has been conducted to determine how parents experience their relationships within the family and the wider community following the disclosure of their child’s disability. This study will be the first to explore this from a Romanian perspective.

- *What is parents knowledge of legislation that relates to the care of their child with a disability*

Parents awareness of disability legislation and how this affects their daily care giving for their child has begun to be more widely researched. This trend is in line with current best practice guidelines which encourages the involvement of families in service development. This study will be the first to address parental knowledge of disability legislation in Romania and to what extent parents are aware of this legislation when they are carrying out daily care giving duties and decisions for their child.
2.15.4 Research Questions

Given the gaps in the literature, the present research aims to contribute to the literature by exploring the following issues for parents of children with an intellectual disability in Romania.

- What is the experience of the disclosure process for parents of children with intellectual disability in Romania?
- How do parents describe making care related decisions in light of the disclosure process?
- How do parents describe coping with the care of their child after the disclosure process?
- What factors impact on parents care related decisions for their child in Romania?
- What are parents experiences of relationships with their family and community in light of the disclosure process?
- To what extent are parents aware of disability legislation and how do parents describe the impact of this on how they care for their child?
Chapter Three: Methodology

3.1 Chapter Introduction
This chapter will provide a rationale for the methods employed in the current study. It will present the study design, participant information, limitations of the methods employed and describe the procedure undertaken.

3.2 Rationale for Qualitative Methods
This study is concerned with how human participants make sense of something that has occurred and how this meaning making influences their actions, rather than deciphering what actions actually occurred (Maxwell, 2005). The aim of this study was to capture the experiences of caregivers without being restricted by the answering of pre-decided questions (Graungaard, 2007). Qualitative methods are apt for the studying of coping processes, as they provide a systematic way of investigating complex issues which otherwise cannot be separated from the specific context within which they occur (Kelso, French & Fernandez, 2005).

3.3 Interpretative Phenomenological Analysis (IPA)
IPA is a qualitative approach to research which aims to explore the meaning participants attach to their personal and social worlds, with an emphasis on the meaning of particular experiences in participants lives (Smith & Osborn, 2008). The main commitments in this approach are to give a voice to participants via the phenomenological requirement and the interpretative commitment of making sense of these experiences by contextualising them
from a psychological viewpoint (Larkin, Watts & Clifton, 2006). Getting close to the participants life world is reliant on and complicated by the researchers own conceptions (Smith & Osborn, 2008). This results in a double heuristic process, whereby the researcher attempts to make sense of the participant, who in turn, is making sense of their lived experience (Smith & Osborn, 2008).

IPA offers the researcher an opportunity to engage on an idiographic level with the research questions. The researcher is allowed to become an active agent in the ‘lived experience’ of participants lives through the reflective and subjective processes involved in interpretation (Reid, Flowers & Larkin, 2005).

3.4 Recognising Limitations

The assistance of a bilingual interpreter was required to enable this research to take place. This was necessary as the researchers first language is English, with a beginners level of proficiency in the Romanian language and the participants were exclusively Romanian language speakers. The use of an interpreter in qualitative research raises methodological considerations, ranging from how the ethnicity of researcher, selection of interpreter and degree of involvement of the interpreter affect the quality of data and translation (Adamson & Donovan, 2002). Despite the considerations, employing the assistance of an interpreter allows this unique research to be undertaken and to access participants who would otherwise not have been included (Ingvarsdotter, Johnsdotter & Östman, 2008). To manage the inclusion of the interpreter and the production of accurate interpretations, best practice guidelines (BPS, 2008; Nurse, 2012) and rigorous preparation of the interpreter (Appendix D) were adhered to.
Chapter Three: Methodology

The role of language in IPA has been critiqued. Some question the participants’ ability to communicate the richness of their experience through their engagement with language and the manner in which some struggle to convey the intricacies’ of their experience (Willig, 2001). The use of an interpreter in this study adds another layer to that challenge. To manage this, it is argued that the researcher also interpreted the emotional state of the participants during the interviews (Smith & Osborn, 2008). The researcher asked systematic and critical questions in the analysis stages to interpret what is both said and unsaid (Smith & Osborn, 2008). The use of these strategies ensured ample opportunity for the collection of rich participant accounts.

In line with best practice guidelines, the interpreter played an important role throughout the process by acting as a cultural broker thus providing the researcher with further information about the cultural world of the participants (BPS, 2008). The researcher had a basic understanding of the language and was able to monitor the interpreters’ rate of translation during the interviews. Any inconsistencies in the transcripts was clarified before analysis.

3.5 Rationale for Choosing IPA

IPA was chosen as the method of analysis as the aim of this study is to explore the subjective experiences of parents who care for their child at home in Romania. In choosing a specific method of analysis, many approaches were considered. Grounded theory was considered but deemed unsuitable as it focuses on theory construction that may be formed to account for experiences. In contrast, interpretative phenomenological analysis (IPA) adopts a psychological focus to gain a deeper understanding of the intricacies of the individuals experience (Willig, 2001).
Chapter Three: Methodology

Discourse analysis was also considered but discounted given the importance it places on the role of language in the creation of social realities (Willig, 2001). In contrast, IPA gives more credence to understanding the lived experience then the manner in which language is used (Smith & Osborn, 2008). Also, given the use of a bilingual interpreter in this study, discourse analysis was deemed inappropriate.

IPA allows experience to be explored within a cultural context, allowing for the identification of contextual factors in the participants life which may impact on meaning making (Shaw, 2001). The idiographic nature of IPA meets the objective of this research as it aims to explore in depth the lived experience of a small group of participants as opposed to making generalising claims for larger populations (Smith & Osborn, 2008). Given the unique nature of this study, IPA was considered apt as it is “useful when one is concerned with complexity, process or novelty” (p55, Smith & Osborn, 2008). A benefit for the use of IPA was the clear guidelines regarding the application of IPA provided by Smith and Osborn (2008) which were used to guide the researcher through the process of analysis.

3.6 Design

This study was conceived as an exploratory qualitative study. Ethical approval was granted by the University of Limerick Research Ethics Committee (Appendix E). The researcher underwent Garda Vetting to enable access to vulnerable participants (Appendix F). Data was gathered through the application of semi-structured interviews and subsequently analysed using IPA.
3.7 Participants

Participants were recruited through a local parents group supporting families of people with disabilities in one county in the South of Romania. Contact was made with the leader of the group who acted as gatekeeper for the recruitment of participants. The group supports families with members who have physical, mental or associated disabilities\(^3\).

Inclusion criteria stated that participants must be over 18 years of age and be the main caregiver for their child who is under 18 years. The child must hold a disability of “mental deficiency”\(^4\) or its equivalent as registered with the Local County Council Disability Commission. In line with previous research (Llewellyn, Dunn, Fante, Turnbull & Grace, 1999) this functional approach to the categorising of disability is accepted with scepticism, but was utilised as it is in line with current Romanian disability policy.

The rationale for choosing parents of children with a mental deficiency or its equivalent was made as this term is the equivalent of “intellectual disability”. From the literature, it is known that there is no Romanian research looking at how parents of children with intellectual disabilities cope with the care of their child. Other inclusion criteria stated the child must live within the family home, as this study is concerned with how participants cope with providing daily ongoing care for their child in the family home.

Participants identified by the gatekeeper were those who met the inclusion criteria, and in that respect represented a homogenous and purposive sample (Smith, Flowers & Larkin, 2009). Eleven participants were identified at this stage. One participant opted out of the research by failing to respond to multiple attempts by the gate keeper to arrange an interview time. A further participant was removed from the sample as their child did not

\(^3\) Individuals with associated disabilities are individuals with more than one disability.

\(^4\) Otherwise referred to as intellectual disability.
reside in the family home on a full time basis. A final participant was removed from the sample as repeated attempts to receive her validated transcript were unsuccessful in the time period allocated for this study.

The final group consisted of eight participants. This sample size fulfilled the requirements for IPA research to ensure rich analysis (Smith, Flowers & Larkin, 2009). All participants were the mothers of the children who had a disability. A breakdown of the demographics of the participants according to child characteristics is provided in Table 3.1.

3.8 Timing of the Data Collection

Data collection occurred in Romania in June 2012. Participants interviews offer a snapshot of their life experiences at a particular point in time, and are invariably shaped by the social and cultural context within which they occur. The interviews coincided with a time of political change as local elections were concurrently being held.

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5 All participants have been assigned pseudonyms to ensure anonymity.
Table 3.1: Participant information according to child’s diagnosis

<table>
<thead>
<tr>
<th>Participant pseudonym</th>
<th>Gender of child</th>
<th>Age range of child</th>
<th>Child’s Registered Disability that equates to that of ‘Intellectual Disability’ as recorded by the local County Council Disability Commission&lt;sup&gt;6&lt;/sup&gt;</th>
<th>Child lives with</th>
<th>Marital status of mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anca</td>
<td>Male</td>
<td>13-15 years</td>
<td>Severe psychomotor retardation plus multiple disabilities</td>
<td>Parent</td>
<td>Divorced</td>
</tr>
<tr>
<td>Viorica</td>
<td>Male</td>
<td>13-15 years</td>
<td>Severe mental retardation plus multiple disabilities</td>
<td>Parents, sibling.</td>
<td>Married</td>
</tr>
<tr>
<td>Madalina</td>
<td>Female</td>
<td>13-15 years</td>
<td>Profound mental delay plus multiple disabilities</td>
<td>Parent</td>
<td>Divorced</td>
</tr>
<tr>
<td>Stela</td>
<td>Male</td>
<td>16-18 years</td>
<td>Profound mental retardation plus multiple disabilities</td>
<td>Parents</td>
<td>Married</td>
</tr>
<tr>
<td>Tatiana</td>
<td>Male</td>
<td>a. 10-12 years b. 16-18 years</td>
<td>a. Profound psycho psychic delay plus multiple disabilities b. Moderate psychic delay plus multiple disabilities</td>
<td>Parents and four members of the extended family</td>
<td>Married</td>
</tr>
<tr>
<td>Iulia</td>
<td>Male</td>
<td>10-12 years</td>
<td>Important mental retardation</td>
<td>Parents</td>
<td>Married</td>
</tr>
<tr>
<td>Mihaela</td>
<td>Male</td>
<td>10-12 years</td>
<td>Mental delay plus a behavioural difficulty</td>
<td>Parents, sibling</td>
<td>Married</td>
</tr>
<tr>
<td>Georgeta</td>
<td>Male</td>
<td>10-12 years</td>
<td>Mild psychic delay, plus a learning disability</td>
<td>Parents, sibling and three members of the extended family</td>
<td>Married</td>
</tr>
</tbody>
</table>

<sup>6</sup> Exact disabilities apart from that which is equitable to intellectual disability have been removed to protect the identity of the child and family
3.9 Data Collection Process

3.9.1 Devising the Interview Schedule

A semi-structured interview schedule was developed by the researcher to address the main research questions (Appendix G) according to IPA guidelines (Smith, Flowers & Larkin, 2009). The suitability of the questions was discussed and verified by the research supervisor. The questions were sent to the interpreter to ensure cross cultural transferability. A pilot interview was conducted and the schedule was changed slightly to reflect additional areas of questioning. The schedule was used as a guiding tool as opposed to being systematically and rigidly adhered too, to reflect a sensitivity to context (Yardley, 2000).

3.10 Procedure

In preparation for the recruitment process, the researcher met with the Director of an Irish NGO who are working in Romania to ask if they would facilitate initial contact with participants. A local parents support group in Romania who were known to the NGO and the researcher were chosen as a group who could provide participants. In July 2011 the leader of the group was approached to determine the level of interest. The leader confirmed their interest in supporting the research and agreed to act as gatekeeper during the recruitment process.

The group of parents formed in 2003 and has approximately 70 members, 10-15 of which are active members. The gatekeeper requires all members to submit their official disability certificates to confirm membership. From this information, the gatekeeper identified 11 families who met the inclusion criteria of the study and contacted them on the researchers behalf. Participants were directly recruited over a three week period in June 2012.
The gatekeeper disseminated the details of the study to include the information sheets while emphasising the voluntary nature of participation to potential participants. Once participants indicated their desire to participate, an interview time was arranged at the participants convenience.

### 3.10.1 Interview Procedure

Before the interview began, participants were encouraged to ask questions as most participants indicated their newness to the process and were uncertain about the value of their contribution. This informal question and answer phase was invaluable for building rapport with the participants. Before signing the consent form and interpreter agreement, the perimeters of confidentiality was explained to participants.

All interviews took place in the building where the group of parents met on a weekly basis. The researcher asked all questions and probes and the interpreter provided a direct translation of the researcher and participants’ responses.

Interviews were audio-recorded to enable word for word transcription. Interviews lasted between 27 minutes and 89 minutes. The average interview lasted 75 minutes. At the end of the interview, participants were asked if they wanted to validate their transcript. This required clarification as many participants initially thought this was a compulsory requirement. When the optional nature of the transcript validation process was clarified, only one participant signaled her desire to do so. The other participants claimed they ‘trusted’ the researcher not to alter the content. One participant stated that she felt re reading her interview would not help her.
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The English version spoken by the interpreter during the interviews was transcribed, and any language related queries were checked before analysis. Previous research has used a similar procedure, with the marked difference that the interpreter provided a third person summary of responses (Williamson, Choi, Charachuk, Rempel, Pitre, Breitkreuz & Kushner, 2011). Williamson et al., (2011) found that there was notable consistency between the English interpretation provided at the point of interview. It was hoped that the decision to request the interpreter in this study to interpret in the tense spoken by the participant and/or researcher would strengthen the consistency of the interpretations provided.

3.11 Ethical Issues

3.11.1 Ethical Approval

Ethical consent was sought by the researcher through the University of Limerick where the researcher is enrolled. In the absence of ethical procedures in the location where the study was undertaken, supporting documentation was required by the University of Limerick before approval was granted. This included a letter of support from the Irish NGO working in Romania who acted as gatekeepers for the access to participants (Appendix H). The researcher liaised with colleagues in the University of Bucharest, Romania to determine the existence of any local guidelines for undertaking research (Appendix I). As there was no procedure identified locally for undertaking research, as a precaution the researcher applied for approval to process personal data through the Romanian National Authority of Monitoring of the Processing of Personal Data. In the absence of an ethical process in the county, this procedure was undertaken to ensure that best practice standards for the processing of personal information were obtained. This Authority grants permission to retain
personal information. Permission was granted from the National Authority in May 2012 (Appendix J).

3.11.2 Informed Consent

Prior to the interview participants were given information sheet’s (Appendix K) detailing the purpose of the research and consent forms (Appendix L). Most participants had already received the information from the gate keeper. They were given ample time to read the information and consider their participation. The researcher encouraged participants to ask questions about the study to encourage full comprehension. The majority of the participants stated that they were wholly unfamiliar with research and were thankful to be given an opportunity to have their story heard.

Before each interview, participants were reminded that they were free to terminate the interview in confidence at any time and that their participation would not be discussed with anyone outside of the research team. Participants signed an individual consent form and three way interpreter- participant- researcher consent form (Appendix M). Both forms were co-signed by the researcher and the interpreter so that each participant could retain a true copy.

3.11.3 Confidentiality

Confidentially and its meaning for the study was clearly explained to each participant while also being detailed on the information sheets. Participants were informed that any personally identifiable information would be removed from transcripts and any quotes used would be made anonymous.
Most participants reiterated their eagerness to participate and their desire to waive their anonymity. Participants were advised this would not be possible as it may breach the confidentiality of other participants and that all participants would be assigned pseudonyms in the write up. All information was stored securely in a locked drawer at the University of Limerick and all electronic data was password protected.

### 3.11.4 Potential Distress

The management of potential participant distress during the interview was considered. Every measure was used to minimize distress such as the use of processual consent (Rosenblatt, 1995) throughout the interview process. In the event that further support was required, participants would be redirected to the parents support group through which they were recruited. Given the lack of psychological services in the county, the support group was considered to be in the best position to provide advice regarding further support needs.

### 3.12 Considerations within Cross- Cultural Research

#### 3.12.1 Ethnicity of the Researcher

Qualitative research can be impacted upon according to ethnicity of the researcher (Appendix D). A researcher from the same ethnic group as the participants can help establish rapport and provide an ‘insider’ view. A potential pitfall is that the researcher may be seen as an expert and the participants may not consider it important to explain information that the researcher is presumed to already know (Adamson & Donovan, 2002). Having a researcher who is an outsider has afforded some participants more openness to speak freely due to their opinion of the researcher as being more broad minded (Ingvarsdotter, Johnsdoeter & Östman, 2008).
This study provided a balance between the two positions as the interpreter was from the same ethnic group as the participants (Romanian) but the researcher was from a different ethnic group (Irish).

3.12.2 Guidelines for Hiring Interpreters

In line with guidelines from previous research (Adamson & Donovan, 2002) the interpreter hired held a professional qualification as a Romanian-English bilingual interpreter and translator. The interpreter was from the same ethnic group as participants as it was hoped that they would add depth to the interviews by being able to explain cultural issues to the researcher (Adamson & Donovan, 2002).

3.12.3 Reflexivity of the Interpreter

In conducting qualitative research, the researcher must be aware of reflexivity and acknowledge the contribution of their background and presence on the research data. The researcher must also consider the impact of the interpreter upon the data. One such way to do this is by interviewing interpreters about their experiences, perceptions and beliefs about the research topic (Temple & Edwards, 2002). This process was applied for this study to allow the researcher to be sensitive to the potential influence the interpreter may have on the data. Before the commencement of the interviews, the interpreter was interviewed about their experiences and expectations of the research project (Appendix D, section 1.2.1). The researcher noted the interpreters responses for consideration during analysis.
3.12.4 The Interpreter Preparation Phase

Given the intricacies of cross-cultural research a preparation phase with the interpreter was added before the pilot interview (Appendix D). This was an opportunity to reiterate the importance of the balance between cultural knowledge and language proficiency (Larkin, de Casterlé & Schotsmans, 2007). It was an opportunity to build rapport, to become accustomed to each other’s pace of speaking and to answer any outstanding questions.

The interpreter was reminded to inform the researcher of any cultural issues or topics that may be common between the interpreter and participant but novel to the researcher, in order to open these up for exploration and clarification (Adamson & Donovan, 2002). The interpreter underwent a full briefing before the interviews and a full debriefing after each session to allow further observations to be added to enhance the richness of the data collected.

During the preparation phase the interpreter identified their concern about their unfamiliarity with disability terminology. It was decided that any terms would be translated after the interview. This did not impact the quality of the interview as the researcher was somewhat familiar with the differing and interchanging use of Romanian disability terms e.g “încapacitate”, “deficiență”, “problemă”, “boală” (meaning illness) or “oligofrenie” (coming from the term oligophrenia).

The second concern centered around the interpreters uncertainty towards participants willingness to speak freely. The interpreter felt that the researchers position as a non-national would have a positive influence upon participants responses. However the interpreter questioned if participants would be open to disclosing information due to the interpreters position as a local member of the community. This concern was noted by the researcher and
it was decided to proceed with the pilot interview and revisit this concern with the interpreter once the pilot was carried out.

3.13 Conclusions from the Pilot Interview

A pilot interview was conducted to test the interview procedure and suitability of interview questions. Upon completion of the pilot interview, a concern was raised by the participant about the willingness of fellow participants to engage in the process due to the position of the interpreter as a local community member. This concern was previously mentioned by the interpreter and noted by the researcher prior to the commencement of the pilot interview. The researcher was also concerned about the speed of translation of the interpreter.

Based on these two concerns, it was decided to appoint a different interpreter. The new interpreter, although Romanian, was not from the local community and had worked in the area of disability for more than twenty years. In addition, the researcher had worked closely with the interpreter both as a fellow colleague and interpreter for the past two years and was confident that the level and speed of translation was sufficient.

As the pilot interview was deemed to be rich in data, the transcript was sent to the new interpreter to correct any inconsistencies. The corrected script was added to the sample for analysis. After the pilot interview, the schedule was expanded to include an additional area of questioning around the impact of the Disability Commission on participants lives.

3.14 Analysis

As a novice in IPA analysis, the researcher consulted several sources of information to become familiar with this method and to ensure good quality research. The researcher
adhered to the procedures as outlined by Smith, Flowers and Larkin (pp. 79-108, 2009). An online interactive discussion group for IPA researchers worldwide (http://groups.yahoo.com/group/ipanalysis/) and a video and blog developed by Michael Larkin were also used to guide the analysis (http://ipacomminterpretation.tumblr.com/). Regular supervisions were maintained with the research supervisor who was skilled in IPA analysis. An overview of the stages involved in analysis is presented below.
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Figure 3.1: Stages of Analysis

Step One:
Placing the participant at the core of the analysis by total immersion in the interview by listening to the audio recordings. Reading of transcript multiple times. Re-reading of reflections noted at the time of interview. Record any new memo’s arising from repeated reading.

Step Two:
Maintaining an open mind, engage in line by line noting of the script in the left hand margin. Researcher made descriptive comments- focusing on describing the content; linguistic comments – to note the language used; conceptual comments - to interrogatively generate conceptualisations of the data (Appendix N).

Step Three:
Developing emergent themes by looking at comments in discrete chunks.

Step Four:
Listing themes and allowing them to magnetise to one another. Check validity of superordinates by cross referencing with primary material. Use of mind mapping tool ‘the brain’ (Appendix O) to organise material.

Step Five:
Repeat process and maintain openness to facilitate emergence of new themes. Active use of memo’s.

Step Six:
Searching for patterns or potent themes among cases. Generate master themes with their associated sub themes to support goodness of fit.
3.15 Reflexivity

IPA acknowledges the impact of the researcher upon the analysis, with the researchers experience facilitating or hindering the quality of analysis (Smith & Osborn, 2008). In achieving reflexivity, the researcher kept a reflective journal throughout the research process to memo any assumptions, thoughts or feelings arising throughout the process. An insight into the researchers own thoughts and feelings throughout the research process are useful to demonstrate the relationship between the researcher and participant (Shaw, 2010). Throughout the results, the researcher will endeavour to give the reader an insight into the thoughts and feelings arising from the interviews which demonstrated the researcher-participant relationship. These will appear in the form of memo boxes. To contextualise the analysis, the position of the researcher will now be demonstrated.

3.15.1 The Position of the Researcher

I am a 26 year old white middle class Irish female. I have worked in the area of disability for 5 years in Ireland and Romania. I am currently undertaking a one year research masters in Psychology in the University of Limerick. From a young age I was involved with people with disabilities, as my mother managed local services for adults with ID. After my undergraduate Psychology degree, I volunteered in a social group for adults with ID. This broadened my understanding of disability and complimented my then day employment of teaching children with autism.

Through these experiences, I developed an understanding of the importance of a continuum of support for families across their life cycle. In 2010 I travelled to Romania to volunteer with people with disabilities with the Irish NGO The Comber Foundation. This experience heightened my awareness of the challenges experienced by families in Romania.
when compared to my experience of working in Ireland. I was struck by parents resiliency to continually adjust to daily life in Romania and the similarities and differences between their approach and that of the families I met in Ireland. I was compelled to discover how parents made sense of their lives therefore ensuring the best care they could provide and guaranteeing the child remained within the family unit.

3.15.2 Bracketing Assumptions

As a result of my personal experiences and in conjunction with my educational and employment history, I was aware that I had developed certain assumptions and biases before entering into this study. Following criteria laid out by Yardley (2000) it was important to acknowledge these to ensure an objective stance was reached during the research. Through my personal experiences in Romania and from reading the literature, I developed the assumption that it may be more culturally acceptable for families to consider placing their children in out-of-home care given the history of state care in Romania.

From personal experiences I suspected that parents might feel anger towards the State for the lack of attention given to them. In line with IPA, I endeavoured to enter each step of the process with an open mind. I actively logged memo’s and personal notes in my reflective journal to ensure reflexivity and facilitate my position as a “learner” who was curiously making sense of the participants life world.
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3.16 Validity and Quality in IPA Research

Issues of validity and quality are central to conducting good IPA research. To maintain good practice in IPA methods, a number of guidelines were followed in accordance with IPA criteria (Smith, Flowers & Larkin, 2009). In addition, Yardley’s (2000) criteria for assessing quality in qualitative research were applied.

3.17 Yardley’s Criteria for Establishing Quality

Yardley’s (2008) four principles for conducting quality research in qualitative studies were applied to ensure research of good value. These principles are sensitivity to context, commitment and rigour, transparency and coherence and the principle of impact and importance. Yardley states that sensitivity to context can be shown via the consideration of relevant empirical literature to the study (Yardley, 2008). Sensitivity to context can also be demonstrated by a sensitivity towards the participants perspective and socio-economic context (Yardley, 2008). As previously mentioned, a sensitivity to context was demonstrated during the data collection phase and by developing a rapport with the gatekeeper. This sensitivity was further evidenced by the inclusion of verbatim extracts to support claims made in the study.

Yardley (2008) identifies four areas for consideration where the principle of commitment and rigour can be evidenced. These are, through the data collection, the quality of analysis, in-depth engagement with the topic and level of methodological skill (Yardley, 2008). Rigour relates to the thoroughness of the research, specifically in relation to the research questions and the completeness of the analysis employed (Smith, 2003). The research strived to ensure the principle of commitment and rigour to the participant during the interview phase and the stages of analysis. Rigour was evidenced through data collection by
choosing a purposive homogenous sample and by including a selection of themes from each participant to ensure appropriate illustrations of the themes.

The third principle of transparency and coherence was demonstrated by the clear explanation of the research process. Coherence is defined as the extent to which the study as a whole makes sense (Yardley, 2008). Reflexivity of the researcher was included in the methods section and the interpreter too was interviewed to increase awareness of reflexivity in the interpretation of data. The research remained true to the principles of IPA at all stages of the process. Coherence was strived for by producing numerous drafts of the final study according to feedback received from the research supervisor.

Finally, impact and importance was determined. Yardley (2008) brings our attention to the principle that research is meaningless unless the findings have a potential to make a difference. This research is hoped to form the basis for positive change in policy, practice, further education and continued professional development and research in the area of family care giving and professional disability disclosures. The research was deemed to be of importance to the researcher, the literature and crucially the participants, as evidenced by their willingness to participate.

3.18 Chapter Summary

This chapter demonstrates the methods employed in this study, the rationale for these and the reflexive position of the researcher. This chapter provides a grounding for the results section and the proceeding discussion which is informed by the IPA methodology.
4. 1 Chapter Introduction

The results in this section are informed by the analysis of the interviews of eight mothers of children with disabilities living in the South of Romania. This section will present a summary of the master and superordinate themes. The themes will then be described according to the IPA methodology. The chapter begins with a figure to demonstrate the themes and their connections.
Figure 4.1: Demonstrating how the master theme of “going forward” impacts on uncertainty and disempowering bureaucracy, all of which impact on lack of understanding.
4.2 Overview of Results

Four master themes emerged from the data. All mothers recalled various exchanges with professionals which began with their interactions during the disclosure process of their child’s disability. How they made sense of these encounters was heavily influenced by the uncertainty they experienced during the disclosure experience. A major challenge for many was their annual experience at the Disability Commission\(^7\), where they described experiencing disempowering bureaucracy which had long term implications for the adjustment and readjustment for these mothers to parenting their child. For many, this experience coupled with the many challenges of daily life was exasperated by caring for a child who had additional support needs. Parents were challenged by their lack of understanding of their child and the lack of understanding demonstrated by others: family, friends, professionals and society. To make sense of daily life, mothers all identified ways of “going forward” with their children. These strategies allowed mothers to overcome the challenges they faced thus ensuring the best level of care they could provide to their children.

Finally, mothers described their love for their children and highlighted their appreciation of being given the novel chance to have their voice heard as part of the research process.

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\(^7\)In order to access state support, parents and children must annually attend a Disability Commission in their local county to officially register their child’s disability. They submit reports from state specialists (which must be renewed annually) to the Commission and the Commission decides the child’s ‘degree’ of disability. From this, the Commission give an intervention plan for the parent and child.
4.3 Uncertainty

A master theme emerging from mothers stories was that of uncertainty. Most mothers described being uncertain about the circumstances surrounding the disclosure of their child’s disability. The consequential management of the child’s disability by professionals caused parents to question the competency of professionals. Each mother had different experiences with professionals which impacted on how they adjusted to the uncertain future facing them in the wake of the unexpected news. They faced uncertainty both when assimilating the news and deciding on how to proceed with their lives. To make sense of this master theme, the superordinate themes will now be described in more detail.

Figure 4.2: Uncertainty: Master theme and associated super ordinate themes

4.3.1 Accidental Discovery

There was much uncertainty surrounding mothers experiences during the disclosure process. These early experiences shaped the manner in which mothers perceived professionals and affected how they currently understand their child.

Anca was the only mother whose child’s disability was revealed shortly after birth. Four mothers recalled the accidental discovery of their child’s disability. These mothers heard about their child’s disability while seeking help for other health problems experienced
by the child or a sibling. The remaining mothers recognised delayed child development which prompted them to seek help. Viorica spoke of the accidental disclosure of her son’s disability at the age of 8 years, following her visit to hospital with her son for a hernia operation when the specialist told her she:

“Should treat him for his behaviour, unknowing that he had being diagnosed with another diagnosis” (Viorica).

At the age of 2 years her son had fallen and banged his head. Two days later he experienced a seizure and later was diagnosed with epilepsy. Although he didn’t experience any further seizures, Viorica was advised to treat him with multiple medications in the intervening years, one of which prompted a near fatal reaction at the age of 6 years. At this point she discovered that the medication was not intended to be administered to children under the age of 16 years. Viorica eventually received the diagnosis of autism for her son at 8 years of age. It was at this point the diagnosing doctor remarked:

“She was surprised, why had this medical error happened? Because it was clear that he doesn’t have epilepsy” (Viorica).

For Viorica, the uncertain experiences prior to disclosure caused her to question and distrust medical professionals. Upon the receipt of the eventual diagnosis, the understanding approach adopted by the professional resulted in feelings of relief for Viorica and fostered a curiosity in her to learn more about her son. Viorica applied this curious approach towards the management of her child’s behavioural and learning needs.

The experience of poly prescribing of medication is one which is evident in many of the mothers stories. Georgeta was uncertain as to which medication had prompted her child to turn “purple”, resulting in the hospitalisation of her child at 4 years old. At that time he was
taking “8 or 9 types of medication”. Upon the receipt of the diagnosis at 4 years, the specialists remarked “that the medication was not good because he had problems with the throat”, which contributed further to Georgeta’s uncertainty surrounding the competency of professionals. Iulia also wondered about the implications of the handling of medication during her child’s admission to hospital following a fever:

“They gave him a treatment that from my point of view wasn’t good- to stop the convulsions. Because of that he had a cardiac arrest” (Iulia).

The ambiguous circumstances surrounding the mismanagement of medication or unclear communication around the purpose of administering medication contributed towards uncertainty for these mothers. This prevented mothers from viewing professionals in a competent light. The mothers acceptance of multiple medications for their children reflected a different approach to intervention than that experienced in Ireland, with a strong reliance on the medical model evidenced in these mothers stories. The journey towards disclosure was significant for many as it was a critical time for readjustment and an opportunity to form opinions on the professionals with whom they met. As the interviews unfolded, there was a suggestion by some mothers that the process left a lasting impact on their ability to positively adjust and readjust.

4.3.2 “A Special Person”

A common theme for all mothers was the impact left by the professional who disclosed the disability to them upon how they made sense of the news. For Stela, she experienced conflicting emotions resulting from her experience at disclosure, based on the conflicting information doctors revealed to her. She recalled one specialist:
“Told me that he will not be able to recover and that he will be a vegetable for his entire life” (Stela).

Stela had experienced many conflicting prognoses from professionals and she was still actively using searching for a cure to maintain a sense of hope. This provided a balance for her ability to ignore or question those who described her child using negative dehumanising terminology.

Madalina also had experience of her daughter being described by professionals using dehumanising terminology. Madalina’s doctor did not reveal the disability immediately because he feared she would abandon her child. When the disability was disclosed, the doctor prompted her to remember:

“I knew I put you to the test in the hospital. I put you together with orphans... and I saw that you love children and you didn’t leave your child there to get a home” (Madalina).

Although unconventional, Madalina accepted the doctors reasoning behind the late revelation of the diagnosis. Madalina’s unique resiliency as demonstrated by her strength in overcoming domestic violence in the past helped her to challenge the doctors to communicate the diagnosis to her “using terms I could understand”. Her ability to be assertive and self sufficient facilitated her ability to advocate for her child when the doctors suggested that her child needed an operation “on the head when she was 2 years old”. She sought advice from other sources and discovered:

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8 Transcript notation: ..... indicates some text omitted; [ . . . ] indicates name removed; ... indicates pause in speech
“90% chance was that she would have died. So, instead of allowing him to make a medical experiment on her, God gave her to me like this, God will heal her. So I left her like that” (Madalina).

Three of the other mothers interpreted a lack of hope about their child’s disability arising from the information the doctors communicated to them, resulting in anxiety about the future. Georgeta was told “to take him home because I cannot do anything for him”. Mihaela was told “he is not affected so much but it is still an illness that will evolve”. Tatiana recalled “they told me they cannot guarantee that he will reach the age of 10 but now he has 12 years”.

Three mothers- Stela, Iulia and Georgeta, recalled the communication of the disability by the professional was “simple”, “hard” or “it was told directly”. No mother signalled that their partner was present at the time of disclosure. Stela questioned the researcher as to why her husband should have been involved in the process. The researcher felt that mothers did not expect their husbands to be involved, and didn’t expect anything other than being told “directly...face to face” (Georgeta).

Anca remembered a sense of solidarity with the professional who revealed her child’s disability to her:

“After one month the doctor who took care of him told me in a very beautiful way-that he will be a special child. He will need a lot of love and attention [mother crying]” (Anca).

Anca felt this rapport was made possible because of the story the doctor told her. The doctor's mother had been in a similar position to Anca when he was born, as he too had many health complications as a baby and his mother too had to fight for his survival. This personalised
approach to disclosure helped the development of a rapport between Anca and the doctor, and helped Anca to accept the news. She felt her doctor was a “a special person”. She recalled how his empathetic communication style helped her and her husband:

“He was a special person, he helped a lot me and my husband, we were very young at that time, he knew how to talk” (Anca).

For Viorica, when she eventually received her son’s diagnosis, she felt her doctor encouraged her to be hopeful:

“A lot of love, a lot of money and affection. He will recover 80, 90 percent.” (Viorica).

The empathetic approach taken by her doctor offered her hope for the future, although the forecast for the child’s recovery was unlikely. Viorica used this to maintain hope when stressors accumulated.

The above extracts clearly demonstrate the individual differences in approaches adopted by professionals when communicating the diagnosis to the mother. Of interest to the researcher was the sense gleaned from some mothers that they did not feel that there was an alternative to the manner in which the professionals communicated the news. The manner in which the news was communicated had long lasting connotations for the mothers as they coped with caring for their children.
Memo Box 1: Reflections during analysis on Madalina’s interview

During analysis I was reminded of the shock I felt to hear Madalina describe breastfeeding abandoned babies in the maternity ward (it is illegal to place children under 3 in state care, anecdotal evidence suggests there are wards in many hospitals for ‘abandoned babies’, as babies are being abandoned (Cojocaru, 2008), but because of the law- there is no where to place them). The revelation by the doctor that he had not only put Madalina ‘to the test’ by putting her with the abandoned babies but also hidden the disability from Madalina as he didn’t know what she could do, shocked me further. Although well meaning, and his approach was accepted by Madalina, I struggled to see how such unethical and risky practice was justified by the professional and accepted by the parent. It must be noted that my reflection upon this event was impacted by Madalina’s positive outlook and energetic presentation throughout the interview which intensified during times when she recalled overcoming a multitude of challenging events in her life. In making sense of the approach, I reminded myself of the reality of the lack of services for children who are abandoned or children with disabilities in an attempt to understand why the doctor approached the disclosure process in this manner.

4.3.3 “The sky fell on my head”

Once the diagnosis was disclosed all of the mothers described experiencing a period of turmoil while making sense of the news, as a normal reaction upon hearing such unexpected news. All mothers recalled their initial reactions of disbelief and of the end to the lives they had expected:

“When I found out, she had 9 months. And imagine the sky fell on my head. I couldn’t understand that, she was a sparkling kid. I couldn’t foresee that she would have this problem” (Madalina).

Although during disclosure the parents had been in contact with professionals, the aftermath was a time of uncertainty, blame and disempowerment. Mothers realised that they
faced a life where they themselves were possibly going to assume the role of main caregiver and that they would receive minimal support from external or state agencies. The disclosure for everyone was a huge shock, instigating a sense of fear and a search for a different reality:

“I was scared. I went to all the hospitals at one point and all of them told us that he cannot be recovered” (Georgeta).

Like Georgeta, many other mothers sought opportunities for their child to “recover, to be normal” (Viorica). Mihaela felt the lack of information given during disclosure about her son’s disability caused her to postpone accepting the reality of the situation. Based on the information received, she invested hope in finding a cure by using medication:

“Because of lack of information I thought that it was an illness that can be cured. And I was grasping my hope through medication. Because I had access to medication” (Mihaela).

The ad hoc manner in which Mihaela acquired information about her son’s disability marked the beginning of a cycle of continual readjustment as she struggled to understand her child. For Stela, it was her helplessness and disappointment that caused deep distress:

“It was very hard because he was the first child. The pain is very big. And how do I say, the fact that I cannot do anything to help him” (Stela).

This helplessness was not only felt by mothers. Madalina remembered her doctor admitting that a motivation for concealing the disability from her at birth was because:

“I couldn’t tell you, I didn’t know whatever you could have done” (Madalina).

Most of the mothers experienced the realisation that they had to adjust with minimal support from others. Madalina used a metaphor to describe this moment for her:
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“Mi-am luat inima in dinti” [Translation: “I took my heart in my teeth” meaning to take courage] (Madalina).

This use of metaphor reflects the decision shared by many mothers to take courage and to move on with facing the reality of the situation in the absence of other options.

The doctor who diagnosed Viorica’s son with autism was a university lecturer and she invited Viorica’s son to a university so that students could learn from him as a case study. There were other children and parents present, which offered Viorica the unique chance to consider her situation in comparison to others around her:

“I arrived at that time at the conclusion, the illness is not asking you if you are rich or poor, if you have a certain type of education or certain type of job” (Viorica)

For others, knowing that there was very little professional support available to them caused many to adopt the attitude that this is their life, therefore they must accept it. Exasperated by a lack of formal support from professionals and a lack of understanding of their children, many parents chose to accept “that we will have a hard mission in life” (Anca).

4.4 Disempowering Bureaucracy

This master theme encompassed the feelings of disempowering bureaucracy experienced by mothers during the compulsory annual visit to the local Disability Commission. Some mothers were disempowered by the stigma surrounding the process of initial registration and the lack of options leaving them with little choice but to register their child. They were frustrated with the inconsistent nature of the obligations they had to meet to attend the Commission and felt neglected as a result of the stringencies imposed by the Commission. Their interactions with those running the Commission were marred by a lack of
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professionalism. This contributed towards their view of the system in general as being unfair and disconnected from the reality of the struggles inherent in their home lives. The experience resulted in feelings of disempowerment, stress and anxiety as mothers prepared to live and relive this experience on an annual basis.

Figure 4.3: Disempowering Bureaucracy: Master theme and associated super ordinate themes

4.4.1 “It was the hardest”

Mihaela and Stela recalled the lack of alternatives which forced them to register their child with the local Disability Commission. For Stela, she had resisted registration but was forced to succumb for financial reasons. This forced choice was experienced by Mihaela also, resulting in a feeling of a loss of independence as her financial dependency was now linked to the state:

“You have to accept it because you don’t have any other choice” (Mihaela).

Iulia recalled the late registration of her child which she carried out grudgingly, he was
“One year and five months when I got the handicap certificate, which I got reluctantly” (Iulia).

Stela did not register her child until he was 7 years old. She admitted that she purposively delayed his registration because they hoped as a family that he would get better. Stela felt, that of any of the challenges they had met before that point, that “it was the hardest” as it forced her to accept that her child was “with a disability”. Stela’s sense of stigma and the fear of losing social acceptability contributed towards this delay, reflecting her awareness of how society at large perceived those with a disability

“We considered that the certificate would be a sort of a ‘bad’ spot for him. And I didn’t accept the fact that I had a child with a disability” (Stela).

Stela’s decision to delay the diagnosis was reinforced by her parents:

“My parents said at that time- let’s hope that he will get better, he will not walk on the street with the certificate on his forehead” (Stela).

This quote shows the awareness of Stela’s parents of the stigmatising effect of labelling which contributed towards her difficulty in registering her child. It demonstrates the value Stela placed on her parents opinion and support when making decisions for her son.

4.4.2 Inconsistency

Every mother felt disempowered and neglected as a result of the bureaucracy and inconsistency experienced during the Commission. They felt that the Commission was purely a paper filling exercise, and that the true child and family needs were repeatedly not taken into consideration. Mothers felt that the inconsistent efforts of the Commission to fulfil its
duty in providing financial supports to families was unacceptable. This caused mothers to question whether the effort expended to attend the Commission was worth the ill treatment experienced. The bureaucratic process offered insights into the process of assessment for the families, which left Mihaela feeling neglected by the format:

“Generally, this Commission in [...] are looking mainly to the documents, so it is about the IQ that is given by the specialist doctor. It’s a lot of, how should I say-bureaucracy” (Mihaela).

Iulia described the arduous paper trial that was necessary to obtain before attending the Commission:

“When you are going there on an annual basis to the Assessment Commission, first we are going to the neuro psychiatrist, the doctor- to write down all the diagnosis that the child has. We go to this Commission where we receive the level of the disability. They look, they see his evolution and then the result- they write down the severe handicap level 1” (Iulia).

This deficit based approach to disability contributed towards mothers view of professionals as form fillers. Feelings of isolation arose for mother through their awareness of the social divide between families and professionals. Parents complained about the lack of individualisation within the Commission and how they felt pressurised to submit all the relevant paperwork:

“They are copying the diagnosis from one paper to another. They are not examining him” (Georgeta).

Madalina felt the overemphasis placed on paperwork resulted in a lack of attention to the child:
“They are asking too many things. So they see the case, but they don’t judge each case individually. They just say bring all the documents and if you don’t have the full documents then they just throw it away” (Madalina).

Parents can avail of financial support if they register their child’s disability. If their child’s disability is severe, parents are eligible to become a personal assistant for their child. This should mean the receipt of additional financial support- although the finance given is still insufficient. The inconsistent nature of this payment caused anxiety and distress for families as they struggled to meet even the basic needs for their children.

“Doesn’t matter if you have that money on paper if I don’t receive it” (Tatiana).

Stela experienced conflict as she knew that attending the Commission allowed her to stay at home to care for her son, but the inconsistency of the payments was a stressor:

“It would help me more if they would give us the salaries on time, a thing that is not happening. For example now I didn’t get the salary since March” [3 month gap] (Stela).

Iulia was angry that she received less money than someone who adopted or fostered a child with disabilities. Mihaela felt that although being hired as a personal assistant was helpful, the role was exhausting and as carers, they were undervalued:

“24/7, 7 days a week...no holidays, no vacations” (Mihaela).

Madalina summarised her anger, and her statement reflected the frustration felt by the other mothers because of the bureaucratic and inconsistent process:
“And I told her, don’t send me on the roads to get these documents- the child has 14 years, I cannot carry her. Even for a certificate for good, to finish it. If you don’t go to get the papers, you are not allowed to see the Commission. It is hard. I fight. This is it. This is Romania” (Madalina).

4.4.3 Unprofessional and Impractical

The bureaucratic process highlighted to parents the social divide between them and the State system. This social divide was felt to be widened by the impracticalities imposed on mothers to meet the requirements of the Commission annually. The unprofessional attitudes of those the mothers faced during this process contributed towards distress for mothers and their children.

Anca, Viorica and Stela all experienced unprofessional attitudes from staff members residing over the Commission. The lack of understanding of the professionals reflected their orientation towards the medical model. For mothers this demonstrated to them how distanced professionals were from the challenges of raising a child with a disability. Anca recalled her most recent visit to the Commission, when the professionals were:

“Pretending that they are writing something, they did not look at [...]”.... That doctor didn’t raise her head to look into [...] eyes” (Anca).

Georgeta too found that those at the Commission generally:

“Don’t speak with you, they are just making the papers. They don’t communicate with anybody, they don’t communicate” (Georgeta).
Viorica had requested an exemption for her son so that he would not have to physically attend the Commission but her request was denied. She knew that the environment would provoke anxiety for her child and worried about how they both would cope. The professionals told her:

“To give him something to cool him down. When I told them that I had just started one week to give him the medication and it was enough time to have affect, they said- don’t you see that he is very nervous?” (Viorica).

Viorica felt frustrated by the trivialisation of her child’s behaviour by the professionals and their lack of insight into the importance of systematically following treatment plans. The simplistic view adopted by those at the Commission highlighted to parents how removed they were from understanding the struggles they faced.

A huge impracticability for parents were the unreasonable steps necessary in order to obtain the correct paperwork for the Commission. Tatiana highlighted the strain arising from the difficulty of travelling to another city in order to meet specialists to update the child’s diagnosis. She relied on others for transport as her sons were unable to cope with travelling on a bus. Madalina relied on public transport to bring her child to these meetings with specialists and was conscious of the different attitudes from the public while she made this journey:

“I have to carry her on the trolley. I am going on the metro. Some people who are pitying you are helping you, those who don’t, don’t help you” (Madalina).

Mihaela felt traumatised by the lengths she had to go to fulfil the requirements of the Commission. She felt isolated as she felt others did not understand how difficult it is:
“I should tell you how it is to queue hours with a sick child to get to the doctor... the kid is getting crazy on the hallway. When you manage to enter to the doctor’s office, in 5 minutes he is assessed, they put the diagnosis and they give the treatment...it is traumatising because the kid doesn’t have patience” (Mihaela).

In an attempt to make sense of the process, Georgeta questioned the researcher as to whether this experience was common for parents in other countries or if it was unique to them in Romania. Despite the attitudes of those in the Commission, Madalina had not blamed the professionals as she felt that they are under pressure to conform to national regulations. Mothers blamed the system and not the individual professionals for their experiences.

4.4.4 “Terrified”

The collective impact of preparing for and attending the Commission provoked anxiety for all mothers. The stresses associated with being present on an annual basis caused huge dread for mothers in the knowledge that their children were getting older and an uncertain future faced them. The resultant inadequate support received by mothers caused feelings of anger. Mothers felt belittled by the system when they compared the massive effort they made to meet the Commissions requirements to the minimal support they consequentially received.

The actual attendance at the Commission is one which caused intense anxiety for Stela, causing her to question her faith. She did not identify with others attending the Commission:

“Many times I am asking myself why I am there because there are kids that...how should I say, that push me on the ground, who are from broken families and there are
parents who are sick. I see so much suffering it makes me feel very bad. I am asking myself, why God decided to be like that” (Stela).

Mihaela was disillusioned with the system and her isolation left her feeling depressed as she worried about the future:

“I can say it is hard. I can say I got into depression too. I can say that at my age I perceive the life differently, in order words- it is very hard. And I don’t know what the future holds for me and it frightens me. Because we don’t have any help from the state. I am sorry to say that” (Mihaela).

Madalina feared her next visit to the Commission. The social distance between her and the professionals whose requirements she had to meet to attend the Commission reminded her of her powerlessness in the process:

“Now they don’t care, they are not interested. They are asking Commission after Commission, they are asking to go to the hospital, to put a lot of analysis, more and more. I am terrified that I have to go now to the Commission” (Madalina).

Iulia was angry with the minimal support she received and viewed it as unacceptable and unfair, when compared to those who adopt children with disabilities as:

“They receive everything I said before, plus money for food, for treatment, for detergents, clothes” (Iulia).

Anca was angry as she felt that this illusion of support reflected the larger divide of appearance versus reality surrounding the implementation of disability laws in Romania.
“Romania has a lot of laws to protect families, children... There is a special law number 448 which states all the rights of people with handicaps. But we are a lot behind the EU community, because this law is not applied” (Anca).

The experience for Anca was disempowering. During the Commission, along with receiving an official disability certificate mothers received a recuperation plan which includes recommendations for the child but also the family such as counselling for parents. However, the plan did not offer any means of meeting these recommendations. By struggling to fulfil these recommendations alone, mothers are reminded of what was required in order to function but disempowered when they realised they cannot access the support needed alone. These challenges negatively impacted on mothers wellbeing.

4.5 Lack of Understanding

This master theme explored the manner in which the lack understanding of the child permeates all areas of family life and caused many challenges for mothers. The lack of understanding of parents, friends, family, professionals and society hindered mothers’ coping. Mothers’ perceived lack of control over decision making further mystified their child’s disability as they resorted to relying on behavioural indicators to guide medical decisions. Their lack of understanding of their child added to the feeling of situational helplessness previously described.

Figure 4.5: Lack of understanding: Master theme and associated super ordinate themes

“You are awaking alone”

“It’s a sad life”

Lack of control
4.5.1 “You are awaking alone”

A prominent theme for all mothers was the distress they felt because of their lack of understanding of their children. Most mothers spoke of their despair and confusion as they struggled to understand their children. This lack of understanding left them bewildered as they were unsure of how to help their children. Three mothers anticipated that the challenges they faced would increase as their children grew older. They felt their lack of understanding about how the disability would progress reflected the impact of the lack of information provided by doctors.

“That’s the problem nobody talks about it. Nobody says anything about his illness. And also they don’t inform us about each illness” (Georgeta).

For Viorica she felt that her child was too dependent upon her and she worried that this limited his independence. She was aware of this dependency and expressed a desire to increase his independence. However, she repeatedly found herself compromised in her dual role of mother and educator, as her sons’ teachers struggled to understand her child. They constantly turned to her for guidance thus putting pressure on her to act as both educator and advocate and this increased her son’s dependency upon her presence:

“They told me to stay outside to see how he will behave. So only after a half an hour they called me back” (Viorica).

Stela’s lack of understanding about her child’s disability was deeply distressing for her. She constantly questioned his behaviour and the mismatch between what she experienced with her child and what she understood about her child’s disability.

“Himself having a certain degree of disability, level 1 with cerebral palsy through this I understand that he is a vegetable? But he understands me. For example ‘water’.
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When I am giving it to him to drink- he tastes it first to see if it’s cold or warm. If it’s warm, he moves his head, he wants cold. I ask him if he wants a chunk [of bread] he looks at it and he opens the mouth. And I’m asking him- do you want bread? And again he moves his head away. When I’m calling his name he is looking at me. He knows the members of the family, whoever is each of them. A kid with cerebral palsy can do that?” (Stela).

It is not only the parents themselves who didn’t understand their child, but there was a lack of understanding of others: friends, family, spouses, professionals and society at large. The summation of this lack of understanding was feelings of despair, confusion, blame and isolation for mothers. Anca felt the lack of understanding of others lead to isolation and loneliness:

“People are scrutinizing... The mothers are taking away their children from [...] saying that “he is sick”. The friends get aloof. I lost my husband. Because he wanted to setup a different family. And you are awaking alone” (Anca).

Four mothers spoke about the impact of the lack of understanding of their husbands upon their marital relationship. Tatiana felt her husband was ashamed of his sons. Madalina experienced a severe level of domestic abuse which did not decrease with the birth of her daughter. Madalina’s then husband believed the disability was familial and she feared the impact of the abuse upon her young daughter. Viorica’s husband was unsupportive as he blamed her for her sons disability. She felt a duty to stand by her husband to maintain the family unit and hoped that her husband would realise his place in the family:

“He must understand in a family there is a father, a mother, a child and in my case another child. And each person in the family has their own responsibility” (Viorica).
Anca had a heightened awareness of the difficulties facing her and her child. For her husband, she felt his inability to understand and accept the situation caused him to wish for a different life. Although her ex-husband remained supportive, at the time of disclosure Anca felt that it was her duty to “release” her husband from her and her son:

“We divorced, I made the decision. Because I considered I should give him the freedom to live as he wanted” (Anca).

The lack of understanding of those in society was one which caused anger, social distancing and shock for mothers. Mihaela talked about how she felt judged by others as she perceived that they were blaming her “because you are unable to educate him, no not educate him, not able to treat him properly”. Viorica felt that society felt that “children who are able to walk are perceived as healthy”. The gap resulting from the invisibility of the disability was difficult for both mothers as they felt they were being judged by others. Anca spoke about the forwardness of some towards her son, which was deeply distressing as she challenged others preconceptions and the stigma of disability:

“Some people look at you with compassion, others are asking themselves “what is she doing with that?” I met a lady who told us that she knows a doctor who could give to my son an injection and I could get rid of him” (Anca).

The rejection of Mihaela’s son from mainstream school because of his inability to cope with the subject matter reflected the implementation of an individual model of disability within the mainstream education system. Her son, now in special education, was not making progress with his education. Mihaela attributed this to the lack of understanding and training on behalf of the teachers about how to manage her son’s learning needs. These repeated
negative experiences and lack of understanding of self and others were emotionally draining for Mihaela, as she relied on instinct to try and manage her son:

“...Still I am trying to get him closer to the kids, I don’t know how bad is his disability, but he is not playing with other kids. Also he is not playing with toys. I think I can say that he is a boy that is living in his own world” (Mihaela).

4.5.2 Lack of control

Four mothers described the frustration they felt when making care related decisions for their child. These mothers experienced a loss of control over care related decisions, with the decisions being influenced by professionals, a lack of money or the regulations as defined by the Disability Commission. Two mothers described how they learnt to use their child’s behaviour as an indicator for making decisions and also the impact of discovering new information as an aid to guide their decisions.

Three mothers described how a lack of money restricted the therapy they could access for their children. Parents knew that there were better therapies available for their children and this was disempowering for them, as they didn’t have the money to access it:

“There is no money to rehabilitate your child. And then you are alone and helpless” (Mihaela).

“Only a few years ago the ABA therapy started. But I couldn’t afford it” (Viorica).

Anca highlighted her frustration with the Disability Commission as she felt her decisions for care are decided according to her ability to access the means and not led by the needs of her child:
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“On that piece of paper are just some recommendations- to perform recuperation. They don’t care about if you can go with the child, if you have the means, if you have enough money. And they don’t give you advice to go to a certain rehab centre” (Anca).

Mihaela was frustrated as she sensed her decisions were restricted by the perimeters of the Disability Commission, as they only accepted documentation from state specialists:

“There is a difference. The state hospitals, they are assessing you quick, they don’t give any importance to the child. They are doing their job just to get the salary. But if you are going to a private hospital, the doctors are going there to do their job and to have results” (Mihaela).

This belief held by Mihaela about the inferiority of state services was mirrored by Viorica, as she perceived state care as inferior to the level of care needed by her child.

“And I don’t want to have [...] in an asylum when people will neglect him. My opinion is that it would make it worse on him” (Viorica).

This belief of the inferiority of state services and lack of control over treatment options caused five of the mothers to perceive the state as neglectful, due to the lack of treatment options within their county, and in the country as a whole. This frustration was expressed by Anca:

“In Romania there are only rehab centres where you can take your child once or twice per year. In our county- in [...] county there is nothing. Nobody cares how these children are living (Anca)”
Some mothers were angry at the lack of control they had within the assessment process with specialists. Georgeta and Mihaela felt the process was too brief and because they were not part of the assessment process they were powerless to impact on the decisions made.

“I don’t know what to say. I wasn’t there with the child. I don’t know what they are asking them, they are held only for 5 minutes. Last time when he was there he asked him his name, the colours and the days of the week. Very short here with us”

(Georgeta).

Stela was angry because of the manner in which she was treated by doctors as she struggled to have her voice heard:

“I said to him that my son loves the cars. I wanted to say that he loves something! He enjoys something! He feels something. He is not a vegetable. And he said to me-

“Aaah, I like cars as well”. For him, the child was with a handicap” (Stela).

In the absence of clear directions for the administration of medication, Viorica, Mihaela and Stela became accustomed to using their child’s behaviour to guide how effective they perceived medication to be:

“The medication gave him adverse affects, side reactions, that medication should not have been administered to a child of 6 years old, that medication should have been administered from 16 years and above. So I decided to stop the treatment” (Viorica.)

Anca considered the sharing of information as important in guiding decisions for families in similar situations:
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“It would be ok if our life experience could be shared with the parents who are coming after us and they could face the same situations. This is why I consider your research, as I said one year ago, is welcomed, so at least for other people [it] will be much easier than it was for us... And I hope that together, by telling to the others the problems we are facing, trying to change the laws, being more open to the society, all the things could get better and better” (Anca).

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**Memo Box 2: Reflections during analysis of Stela’s interview**

During Stela’s interview I became aware of the struggle to remain in the role of ‘researcher’. I found it difficult not to believe her suspicion that the injection given to her son as a child caused his current state. After the interview I reflected on the powerlessness I felt when she asked me for help. I felt her request for help demonstrated her vulnerability. During our informal chat after the interview, she told me about bringing her child to see a group of Italian Bioresonance scientists who visited the city. She asked them to assess her child. They connected her son to many electrodes which were attached to a computer. After a period of time, the words “Affected by a phenomenon such as a diabolic creature” appeared on the computer screen. Personally feeling shocked and angry, I was left wondering how she could cope with such a statement. I reflected upon the balance between her vulnerability in her desire to find answers and her ability to overcome such inhumane and shocking encounters with “professionals” and “scientists” and how this would impact upon her emotional wellbeing.
4.5.3 “It’s a sad life”

Most mothers described the daily struggles which negatively impacted on their emotional well being. Mihaela and Viorica worried about what the future held for their children. Viorica feared that the burden of responsibility for the care of her son would pass onto her older son. She worried if a potential wife of her older son would be supportive of such an arrangement. Mihaela felt “it’s a sad life” and she was unable to gauge what the future held. Her negative outlook was influenced by negative forecasts from professionals:

“I would like from the bottom of my heart to bring him down with his feet on the ground, I don’t know how to explain that. But I hope when he will be big, a grown up, he will be able to take care of himself. Nowadays I believe he cannot be helped by anything, not by medication, not by rehab. And the doctors told me there is not much that we can do. I don’t know what else to say “(Mihaela).

Iulia and Stela carried with them an acute awareness of the sacrifices they have made to adjust to caring for their child. Stela gave up her full time employment to care for her child. Iulia felt she led a double life, one that was split between home and rehab centres which were located in other counties far away from her home. She felt she had no choice but to restrict the size of her family in order to take care of her son:

“He is the only one and the first one. After that I had an abortion. He was very small, I heard about his problems so I decided not to have it. And after that I didn’t try to have a child” (Iulia).

Madalina emotionally recalled a huge family sacrifice she made upon the birth of her daughter. No longer able to tolerate the harsh physical abuse from her husband, she made the decision to leave her husband, but to leave the care of her eldest daughter with him. That
decision was still hugely distressing for her – “my soul as a mother is aching”, as she acknowledged that her oldest daughter had a difficult childhood being reared by her ex husband. However she felt this sacrifice was necessary as she felt a need to protect her youngest daughter, who in her eyes was innocent.

Viorica was told that her son had depression and that he needed to be medicated for this. She blamed herself for his depression:

“I remembered, I think I should not speak about the boys illness when he is there. Because the depression he got was because of me, my mistake. In the moment I was meeting different persons, not to everybody, certain persons, they have asked me, what was the problem with [...] and I was telling them. I made the mistake to speak when he was there. And autistic persons have extraordinary hearing” (Viorica).

In contrast, Stelas’ lack of understanding of her child’s disability coupled with the minimal information provided by professionals and the pain of not knowing the cause of her son’s disability was an ongoing burden for her:

“When I have an argument with him, he is turning his back to me and he is upset. I don’t know where he has this reaction, knowing that he has cerebral palsy. This is the biggest pain for me. Because I don’t know the reason why he is like this. Who made the mistake? Us in raising him? Or the doctors. This is the burden that I will carry with me all the time” [participant crying](Stela).

4.6 “Going Forward”

This theme explored mothers desire of “going forward” with their children and the range of internal and external factors that contributed toward this. Most mothers shared many themes
which facilitated them to overcome daily challenges of caring for their child and in
overcoming specific situational challenges. “Going forward” was strongly influenced by the
support of others, the strength derived from the children themselves, parental acceptance,
adaption, future orientated optimism, help seeking behaviours and parental activism. These
themes will now be described in more detail.

Figure 4.6: “Going forward”: Master theme and associated super ordinate themes

4.6.1 “We don’t lose the hope”
A strong theme was the manner in which many mothers spoke about their acceptance of their
child’s disability and how this helped them to progress with their lives. For some, this
acceptance occurred gradually and was facilitated by the support of others or their
understanding of the finality of the disability.

“I am not afraid. Even if she is like this, she is dear to me and my soul is aching. We
have to encourage each other, power and trust. The psychic has to be higher up. We
go forward. Yes. This is me. I am a fighter” (Madalina).
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For other mothers they maintained a positive future orientated outlook by placing hope in doctors predictions or by focusing on future goal setting for events that signified the progression of family life together. Given the unique nature of Stela’s sons’ disability although she accepted “This is it the destiny, the faith. And you have to go forward”, Stela hoped that advances in science would contribute in the future to an improvement in her sons life. She told the researcher about how she used this hope to make the decision that her, her husband, and her son would take part in a research study:

“If they find out the gene that provokes his suffering, then they should find a treatment to treat that gene. I agree, we gave the blood. And now we are waiting. It will take years. But we don’t lose the hope even now. We tried everything we heard in order to help him” (Stela).

Most mothers grasped opportunities to seek help when they arose which helped them to maintain hope for the future. As detailed in an earlier memo box, this request for help was experienced by the researcher first hand.

Viorica described how she used opportunities to learn new skills which she could continue in the absence of the professional. These help seeking behaviours were opportunities for mothers to access new information to aid their understanding of their children:

“I am thinking that in other countries they are speaking, they are communicating information. Here they are not doing it. .... Yes that’s why I came here. To see, to see other things.. I don’t find the words.. the solutions” (Georgeta).
4.6.2 Support of Others

All mothers discussed the value they placed on the informal support coming from others as a facilitator to coping with daily care for their children. Supportive relationships came from the children’s fathers, grandparents, siblings, neighbours or from the mothers friends.

Six mothers described the active support their mother or mother in law gave by providing hands on care for their child, despite the fact that many of these parents are aging. Tatiana described the positive active support provided by her 80 year grandmother, as she helped with exercising and feeding her children. Knowing that her mother and mother in law were available to help with care giving duties facilitated Iulia to carry out her daily tasks:

“Yes. When I need to go for shopping, to the doctor, someone stays, my mother in law, my mother, stays with him. Yes” (Iulia).

Fathers were mentioned by many mothers as being a source of support. Most fathers did not take an active role in child rearing, but fathers were available to four of the mothers to provide emotional support. Stela sought and received reassurance and support from her husband whom she felt understood the full time nature of the care she felt was necessary to provide for her son:

“But he is not getting upset because he understands me and we try to understand each other, so each of us would let things from ourselves. He has to understand that I am staying all the time with [. . .], during the day, during the nights. I am more irritable and he allows me to vent myself and he understands my status. It didn’t affect us in another way” (Stela).
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As previously mentioned, the lack of understanding of others contributed towards stress for mothers. However, many mothers felt that their neighbours were supportive and understanding of their situation:

“Very good. Very good. They don’t despise me that I have a child with handicap-to push me aside. To say that she is with handicap. No” (Madalina).

Georgeta referred to the absence of problems from neighbours as an indicator that within the community, their children are all the same.

“I don’t have any problems with neighbours, they are children between themselves, they are having small play arguments in the park (Georgeta)”

Some mothers mentioned their wonder at the empathy shown by their other children towards their child with a disability. This unique understanding eased parents worry for the future as they felt their other children may continue to provide home care for their son or daughter:

“I don’t think she was affected. At least she doesn’t show me. Because when she says to me, that when I am not anymore, she will take care of her brother” (Mihaela).

4.6.3 “I am not ashamed”
Six mothers expressed how they acquired strength through their decision to increase the awareness of others about their children through their engagement in advocacy activities or by challenging others preconceptions about disability. One mother was proud of her decision to sue the mayor of the city because of the delay by the County Council in paying the personal assistance monies. Many mothers spoke about their decision to bring their child into
the community, reflecting their awareness of the stigma attached to disability and their desire to challenge this:

“If I want to go on the street with my kids I am not ashamed” (Tatiana.)

“From time to time I am going with him shopping- so he is my child, I am not ashamed with him” (Viorica).

“I am going with her to the church, I am not ashamed” (Madalina).

Some mothers were proud to be viewed by others as role models for overcoming adversity:

“They give me as a good example, that I am strong, despite the sufferings and the problems, that I have a smile on my face and I’m trying not to show my sufferings. And in the moment when they face a problem, they say to themselves, if they, like both of us, are able to go over so many problems, why couldn’t they” (Stela).

Another facilitator for coping was the application of daily routines by mothers. The implementation of these routines facilitated mothers to adapt to caring for their child. For Stela, adhering to the routine strengthened the bond between her and her son:

“Despite the fact that I am doing the same thing every day. He is waking up, I am washing him, despite the fact that he is as tall as I am. I put him in diapers, I have to wash him when I am taking the diaper off. Otherwise he will have sores if I would not do that. I brush his teeth- me again. I am doing his toilet, I am feeding him. Without each other... we cherish each other” (Stela).
By adapting their behaviour towards their children or adaption of the physical environment where they live, mothers found novel ways to facilitate caring for their children. Tatiana created a resourceful strategy to help her care for her youngest son:

“With the youngest one it’s more difficult because I have to change the pampers, I have to change the trousers. And now I have to go to the tailor to have a sort of one piece trouser plus blouse because he is taking down his pampers. So that’s why I want to do this one piece. In that case he will not be able to remove his diaper” (Tatiana).

4.6.4 “Every mother wants to bring her child home”

Mothers described how their identification with the role of mother helped them assume responsibility as primary caregiver for their child. Four mothers spoke about the manner in which this role helped them to adapt to caring for the physical needs of their child. This identity allowed them to identify negative thoughts and suppress them until they could find an appropriate outlet to express them. Through her use of humour, Anca jovially described how she attends to her son’s needs:

“He cannot eat by himself, he cannot use his arms, he cannot walk, he cannot sit on his bottom, he cannot talk. Everything that he needs is given by me…. He is totally dependent on his mother or somebody else - but I couldn’t find another person so far” [mother laughs] (Anca).

Anca’s strongest desire was to care for her son at home, and she feels this was a normal response of any mother:

“There was no wonder that [. . .] arrived at home. This was our strongest wish. Every mother wants to bring her child home” (Anca).
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For Stela, her need to maintain close physical proximity to her son given the intensity and frequency of her son’s seizures was justified through her role as mother and primary caregiver. Maintaining close physical proximity to their children was helpful for mothers to reassure them that their children were safe:

“First of all to be alongside him. It’s the only thing I can do to be alongside him”

[mother cries] (Stela).

Madalina and Tatiana described how their beliefs in cultural practices helped them as mothers to proceed with daily care. Madalina’s strong religious beliefs gave her strength as a single parent to care for her daughter. Madalina included her child in a ritual in the church whereby the priest walked over her daughter. Madalina attributed an improvement in her daughter’s health to her strong religious beliefs and found her faith to be rewarding and strengthening for her:

“He healed my daughters crises, she doesn’t have any longer seizures. I put her to.. in the church, the priest walks over the child, so from 9 years to now she didn’t have any seizure. I didn’t give any treatment to her. And I went with God forward” (Madalina).

Tatiana also placed importance in cultural practices as a factor which positively improved her son’s disability:

“We went to another doctor, a naturalist doctor. And he gave us a dust- powder, it held many ingredients. I remember only “pork brain”. I gave that powder and I think it may be because of that he got better. Before he had many calcification spots and now he has only two, on the left and on the right. And the doctor was surprised when she saw the MRI results” (Tatiana).
4.6.5 “He is a special kid”

Each mother revealed that their individual coping style was shaped by their life experiences. This affected their sense of self and they were encouraged by the love they felt for their child, which was reinforced by individual child’s characteristics. Anca spoke of the special daily rituals between her and her son that facilitated care:

“So before he goes to sleep mommy tells him that she loves him, that he is a special child. And he goes to sleep quietly” (Anca).

Madalina recognised the inherent resilience of her daughter as a factor which gave her strength:

“Aaah. Her love. Her love. Very much. She calls me in the yard. I put her in her trolley. She is checking me. She is calling me ‘heeeey, heeeey’. She is calling grandpa when someone goes by. Her strength, her resilience keeps me as I am” (Madalina).

Stela spoke of the interdependent bond between her and her son, and how this strong bond maintained her to provide home care for her son:

“I cannot sleep the whole night without him. I can hear him, I feel him, I feel when he has a crisis. I cannot rest myself. I must feel him close to me, to my heart. I want to hear him breathing. I cannot stay without him” (Stela).

This strong bond revealed an insight into Stela’s tenderness for her son and how this bond allowed her to view her son as normal. Her unique insight into the responsibility arising from the mother-child relationship ensured that she was committed to providing long term care for him:
“I didn’t send him to a centre because I cannot stay without him. He represents too much for me. He is a special kid. He’s a special kid, not a kid with special needs, he is special by himself. He is a very good kid despite the fact that he is very ill. And for sure he couldn’t resist in a centre. Probably he wouldn’t be alive now at this time. And I couldn’t send him there because his blood is out of my blood. He’s not an object, it is not like if you are buying from the shop and if it’s not good you are taking the object back. He is everything for us. And us- we are everything for him” (Stela).

While some parents perceived themselves as strong, more mothers preferred to identify others in similar positions as strong. By identifying with this group of individuals, parents attributed these strengths to themselves:

“Most of the families who have children or persons with disabilities that are getting over 18 years old are raised and kept at home. With sacrifices, I may say, huge. I admire these type of people and I respect them a lot, taking into account that society ignores us. They are special people. And the reasons why they are keeping their children, teenagers and persons at home? It is love, the love for their children. They couldn’t conceive life without their child” (Anca).

This ability to attribute strength facilitated them in managing and overcoming the many struggles they faced daily. In the end, it was the child that maintained the parent. Anca felt that “It is a paradox”, that although mothers may be more susceptible to additional struggles because of the disability of the child, it was their children that reinforced them to carry on. Their child’s happy disposition and the strong mother-child bond strengthened the ongoing provision of care. Also, the ability of many to view their children as symbols of overcoming adversity all ensured the continual provision of care for their children:
“I considered [ . . . ] as a wonder that appeared in my life. Although it is very, very difficult, I never lost the power to take care of my child” (Anca).
Chapter Five: Discussion

5.1 Chapter Introduction

Eight mothers of children with multiple disabilities were interviewed about their experience of caring for their child with disabilities at home. An interview schedule was constructed to answer the six research questions. The questions focused on, what was the experience of the disclosure process for parents of children with ID in Romania? What impact, if any, did this experience have on mothers care related decisions? How did the disclosure process impact upon parental coping? What impacted upon how parents make decisions for their child? What was the impact of caring for a child with a disability on parental relationships in the family, community and in society? This study aimed to discover parents understanding of disability legislation and its impact on the family. Finally, the study asked parents what were their experiences at the annual Disability Commission.

Four master themes of uncertainty, disempowering bureaucracy, a lack of understanding and “going forward” emerged from the mothers’ accounts. This chapter discusses their experiences and positions them within current disability literature. The chapter will present the implications of these findings for clinical practice, policy, education and continued professional development and future research. The chapter will close with reflections on the research process before presenting the strengths of the study in tandem with areas requiring further development.

5.2 Uncertainty

The analysis of the eight interviews revealed four main themes. The first theme arising from mothers interviews was uncertainty. For most mothers, uncertainty arose from the delayed
and/or accidental manner in which they discovered their child’s disability which resulted in the delayed disclosure of the disability. Worryingly, four mothers discussed the nature of the accidental discovery of their child’s disability. The accidental nature of the revelation, and in one instance the unveiling of the concealment of the disability by a medical professional compounded the unexpected nature of the shock experienced upon disclosure. This contributed towards parental distrust in the competency of professionals.

Suspicion of concealment of disability is not unique to this study and previously reported instances have been given as examples of bad practice in the process of disability disclosure (Baird, McConachie & Scrutton, 2000). It is known that stress can arise for parents during the disclosure process and that this stress will increase according to the delay at which the child’s disability is discovered (Most, Fidler, Laforce-Booth, & Kelly, 2006). After the disclosure, parents stories revealed a tendency by professionals to prescribe medication as a form of intervention for the child, indicating a dominance of the medical model of intervention. Mothers’ unquestioning acceptance of this practice indicates the status accorded to the professional as expert (Case, 2000). The resultant acceptance of professional opinion and advice suggests the existence of a professionally-centred model (Espe-Sherwindt, 2008). This model has been criticised for its failure to recognise the importance of the family (Espe-Sherwindt, 2008). For many, the consequence of this unquestioning position was the nearly fatal reactions of some of the children to these medications. These events further contributed towards parental uncertainty and the events disempowered mothers by reminding them of their lack of knowledge surrounding their child’s condition and the management of their medication.

The manner in which professionals disclosed the disability to mothers was used for many as a reference point to form judgements about the competency of professionals. Many
mothers experienced professionals using dehumanising terminology to describe their children which was upsetting and gave mothers little hope for the future. Earlier research has identified a lack of hope and uncertainty for parents of children who receive a diagnosis of intellectual disability of unknown aetiology (Watson, Hayes & Radford-Paz, 2011). Parents adopted different coping styles in response to the portrayal of their children using similar dehumanising terminology. Similar to previous research (Graungaard & Skov, 2006), one mother strived to disprove professionals assertions based on the incongruence between the professional prognosis and the mothers understanding of her child’s behaviour. This perspective has been evidenced in other studies, whereby the parent attempts to disprove others view of them or their child as ‘victims’ (Broberg, 2010). As parents struggle to advocate for their child in the face of the application of dehumanising terminology, they felt powerless (Sheets, Baty, Vázquez, Carey & Hobson, 2012). Some professionals used this power imbalance to their advantage to maintain the expert or dominant role within the parent-professional relationship (Dale, 1996).

Three mothers spoke of the professionals communication as being direct or simple. Parents in Bosnia and Herzegovina also experienced a harsh communication style which impacted negatively on their emotional wellbeing (Bećirević & Dowling, 2012). Previous research suggested that the indifferent attitude of professionals during the disclosure process is one which can persist throughout the family life cycle (Schall, 2000). Mothers in this study did not indicate that the absence of their husbands during the disclosure process was of significance to them. Previous research highlights the paternalism of expectations upon fathers in the care giving process. Service providers are less likely to demand co-operation from fathers than mothers (McLaughlin, Goodley, Clavering, & Fisher, 2008). This research
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draws attention to the manner in which paternalistic views may be reinforced by services and handed down within societies.

For mothers, although on the receiving end of harsh terminology, they did not feel in a position to judge professionals based on the behaviour of the professionals. Many felt that the direct approach adopted by professionals was the only way in which to disclose the disability. This is at odds with previous research whereby parents had an expectation of professionals to foster a co-operative relationship with families, as a means for empowering them to provide care to their child (Graunagard & Skov, 2006). This lends further support to the view of professionals being viewed as experts by families (Espe-Sherwindt, 2008).

In Romania, support for families of children with disabilities is minimal. Unlike previous research (Hatton, Akram, Shah, Robertson & Emerson, 2003), the manner in which the disability was disclosed in this study did not impact on mothers future engagement with professionals. This may be because all mothers were obliged annually to meet professionals in order to maintain disability benefits. Therefore, regardless of parents opinions of the disclosure process, they were obliged to annually engage with specialists. Similar to the system of disability assessment in Bulgaria, the child and parent are obliged to attend an annual Disability Commission in order to access any form of support (Mladenov, 2011). Before they attend the Commission, mothers were required to meet state specialists to update their child’s disability papers. In this study, the information and approach adopted by professionals impacted upon parents expectations and understanding of their child but it did not affect their engagement with services as this was obligatory.

For one mother, her positive experience at disclosure was aided by the empathetic approach and professional rapport established by the disclosing professional. This experience corroborates with previous research which showed that despite the stressful nature of the
disclosure process, it can be less traumatic if professionals adopt an empathetic approach (Graungaard & Skov, 2006). This process is enhanced by the ample provision of information and a good communication style (Sloper & Turner, 1993).

The period after disclosure marked the beginning of a cycle of adaption and re-adaption for mothers as they reframed their understanding of the child. Unclear communication about their child’s disability hindered some parents’ acceptance of the disability, causing a large degree of uncertainty for some. As a normal reaction to an unexpected event, parents were disappointed and shocked to hear of the disability. Similar to previous research (Hatton, Akram, Robertson, Shah & Emerson, 2003) some parents identified a lack of information from professionals as delaying the adaption process. Many mothers had difficulty adapting to the news and searched for different diagnoses.

Eventually, all mothers spoke about the gradual realisation of their situation that allowed them to accept their reframed lives and persevere with caring for their child with minimal or no formal support. This lends credence to the idea that families go through a process of modification of their life plans in the light of a new reality (Graungaard & Skov, 2006). It also reinforced the desire by some parents to utilise behavioural adaption strategies and ‘get on with it’ (Pelchat, Levert & Bourgeois-Guérin, 2009), with the disclosure of disability marking a point of transformation for families (Watson, Hayes & Radford-Paz, 2011).

5.3 Disempowering Bureaucracy

The second theme was the disempowering bureaucracy experienced by mothers while preparing for and attending the annual Disability Commission. Mothers spoke about the
distress and lack of control they felt when making the decision to register their child’s disability. The process was made more difficult by the attitudes of professionals they met at the Commission and the distress felt by mother and child by physically having to present themselves annually at this Commission. Mothers ruminated about the challenges they faced in fulfilling the requirements of the Commission. The inconsistency of the financial support received from the Commission was deeply distressing. It highlighted the gap between what disability policies promised for families and the disappointing reality of the lack of provision of these supports in practice.

One mother spoke of her awareness of stigma as a deterrent for registering her son’s disability. Previous research has shown that the parent is in a unique situation when they have access to the outside perception of disability and an awareness of the prejudices linked to this (Goodley & Tregakis, 2006). They use this information as a reference system to guide their expectations of others’ reactions to their child (Broberg, 2010). In this way, the mothers reluctance to register her child may have been influenced by an awareness of prejudice towards disability, an awareness which from her account, appeared to be reinforced by her parents.

Some mothers recalled their exit from the workforce in order to meet the daily needs of their child. No longer having the security of two salaries, families were forced to register at the Commission for financial support. It is known that extra support needed by a child with a disability can result in additional financial strain being put on caregivers (Runswick-Cole, 2007). The parents perception that they lacked an alternative to registering their child’s disability, and their consequential feeling of their loss of independence because their financial stability was then linked to the state caused them to feel disempowered (Graungaard, Skov & Andersen, 2011). One mother spoke about the relentless nature of the personal assistant role.
The 24/7 nature of the level of care required left little time for parents to engage in other activities (Breen, 2009).

Most mothers were disgruntled by the huge effort expended to meet the requirements of the Commission. Mostavi (2011) spoke about the difficulty arising from the finding that staff members at the Commission were not fulfilling their job requirements, with the sheer large quantity of evaluations being processed being given as an indication of the quality and the excessive bureaucracy associated with the Romanian system. The efforts expended did not compare with the inconsistent nature of the payments or supports received as a result of attending the Commission. The tireless efforts and associated strain of accessing support has been described by mothers in similar situations as being akin to ‘running a small business’ (p38, Kingdom & Mayfeld, 2001). One mother was angry that carer’s who adopt children with disabilities received more support. This feeling of parental care being devalued contributed towards feelings of unequal treatment (Murray, 2007). The view of the registration process as being resource consuming has been evidenced in similar research carried out in Norway (Graungaard, Skov & Andersen, 2011).

Mothers in this study recalled the negative attitudes of professionals residing over the Commission. Parents felt that professionals avoidance of direct contact with their children or their trivialisation of their child’s behaviour was a further indication that professionals in this instance were far removed from the daily struggles that are inherent in caring for a child with multiple disabilities. In one study which looked at the relationship between parents of children with autism and professionals, they found an incongruence between the areas professionals addressed as challenging and those identified by parents. Professionals tended to focus on externalising behaviours while parents were more concerned about challenges in the areas of play and social skills (Dillenburger, Keenan, Doherty, Byrne & Gallagher, 2010).
The importance of listening to parental concerns has been highlighted especially in order for the professional to be able to plan and implement effective interventions (Dillenburger, Keenan, Doherty, Byrne & Gallagher, 2010). This lack of understanding on behalf of professionals further contributed towards parental stress.

Many mothers were unable to rationalise the manner in which the Commission made judgements’ surrounding what documents they had to present, or whether their child had to attend the Commission. Despite being granted an exemption from her child having to attend, one mother found that being confronted at the Commission with other families with children with disabilities was deeply distressing and caused her to question her core beliefs. The changing nature of these demands was very stressful for parents as they struggled to anticipate what requirements would be imposed in the knowledge that their children were getting older and therefore their need for support was increasing. The experience reminded parents of the disappointing gap between what disability policy promised and what the families received, and reinforced the belief that the state was neglectful towards their needs. This novel study has illuminated the deep distress resulting from parents obligation to attend a local Disability Commission with their child.

5.4 Lack of Understanding

For mothers, their ability to cope with caring for their child is challenged by their own lack of understanding of their child and the lack of understanding of others. Parents struggled to act as advocates and awareness raisers for their child with the minimal knowledge they had, and this struggle took its toll on their personal relationships and emotional wellbeing. The majority of these challenges are related to socio-structural constraints which acted as barriers to coping (Green, 2007).
Most mothers identified their despair and confusion as being connected to the lack of information about the specifics of their child’s disability. Without this information, mothers were unsure about the progression of the disability and how to anticipate whether the challenges they faced would increase. One mother blamed professionals for not equipping her with the information she felt she needed in order to ease her anxiety in this area. Taanila, Järvelin and Kokkonen (1998) found that the more information parents received upon disclosure, the better prepared parents felt towards being able to manage their child (also supported in Taanila, Syrjälä, Kokkonen & Järvelin, 2002). The provision of appropriate information is important in order to manage the ‘crisis of information’ experienced by many families as they are faced with the disclosure of a disability (Guralnick, 1997).

This lack of understanding extended to partners, who struggled to accept their children or to understand that their wives were not to blame for the child’s disability. This lack of a shared understanding, or the failure to replace the ‘lay persons’ knowledge led to a lack of shared parental understanding of the disability. Similar to previous research, this consequentially contributed towards a gap in the parental support system (Hatton et al., 2003).

One mother struggled to consolidate her multiple roles as educator, caregiver and advocate. While grateful to be accepted to provide assistance to her son in school, she worried that her constant presence was creating a dependent relationship between herself and her child. Her awareness of the strengthening of this dependent relationship placed her in a compromising position as she felt that the teachers lacked knowledge regarding the management of her son in the classroom. In the absence of adequate support from the teachers, she felt the need to be present and was relied upon by the teachers.
For all mothers, a general lack of understanding of those in society caused mothers to feel isolated and stigmatised. All parents spoke of being activists for their children, but their ability to tolerate others unfavourable glances or upfront shocking remarks eroded their emotional wellbeing and reflected a lack of awareness of disability in society. It is possible that these mothers were exposed to what Goffman (1963) called “courtesy stigma”, whereby an “individual who is related through the social structure to a stigmatized individual” (p30, Goffman, 1963) themselves feel stigmatised. This can impact upon mothers emotional wellbeing and has been found in previous studies of mothers of children with disabilities (Green, Davis, Karshmer, Marsh & Straight, 2005). Previous research has highlighted the importance derived from acting as an activist in the mothering role (Ryan & Runswick Cole, 2008). However, this study gave insight into the struggle that arose for some parents in these dual roles and the long term toll it had on mothers emotional wellbeing.

An ongoing challenge for parents was their limited ability to exercise control over treatment related decisions. Their control was limited because of three main factors: a lack of finances, the limits imposed by the Commission and the struggle to have their opinion heard during the professional consultation. This struggle to be heard is a universal difficulty which is present even in countries where early intervention services are well established such as the USA (Sices, Egbert & Mercer, 2009). The lack of a partnership within the assessment process is a source of great upset for parents as they felt powerless to impact upon treatment decisions, which runs counter to the principles of family- centred practice (Rodger, O’ Keefe, Cook & Jones, 2012). Parents options for treatments were limited due to a lack of finances, an experience not uncommon for parents of children with disabilities (Bećirević & Dowling, 2012). However, in this study, as mothers resided in one of the five poorest economic regions in Romania (Alexandrescu, 2010), it is likely that financial difficulties are more pronounced.
for this group. It is suspected that there is a higher prevalence of people with ID in low and middle income countries which also contributes towards decreased access to formal supports (Emerson, Yasamy & Saxena, 2012).

Parents were obliged to have their child assessed by state specialists to meet the requirements of the Disability Commission. Some parents felt that the services they received through the state system were inferior to those received within the private system. It is possible that the early experiences of professionals as incompetent in combination with the lack of professionalism exhibited by professionals towards parents at the Disability Commission contributed towards these beliefs. For some mothers, these negative interactions resulted in a depressive affect. Due to a lack of information imparted by professionals, one mother blamed herself for her son’s depressive state. Feelings of self blame and depression are found in the literature as examples of negative coping strategies when parents are adjusting to a diagnosis (Poehlmann, Clements, Abbeduto & Farsad, 2005). In this research, the impact of external factors such as a lack of information must be considered when looking at the negative emotional affect these mothers experienced.

Some mothers spoke of the difficult family sacrifices they made in order to ensure the continued care for their child with a disability. One mother recognised the decision not to have any more children in the light of the high support needs required by her child. This is at odds with previous research carried out with mothers of children with pervasive developmental disorder, who cited a lack of social support and acceptance of the disability as the main factors impacting on the decision to have more children (Kimura, Yamazaki, Mochizuki & Omiya, 2010). Similar to previous studies (Stoneman, 2005), many parents spoke about the use of differential parenting as being challenging for them as they struggled to decide if they were doing the right thing by their other children. This challenge has been
found in previous research, whereby parents managed feelings of guilt arising from the lack of time they had to give to their typically developing children (Dyson, 2010).

5.5 “Going Forward”

Throughout mothers life stories, they spoke with passion about “going forward” with their children. They identified strategies and factors which facilitated them to fulfil their role as mothers. Mothers spoke about how the informal support of others helped them to adapt to caring for their child. Many maintained an optimistic outlook for their child’s ability and progress. All mothers identified the strength and satisfaction their derived from acting as a positive role model for overcoming adversity and by acting as advocates and agents for change on behalf of their child. Mothers’ positive identification with the role of mother and their faith in cultural practices facilitated coping. Finally, all mothers spoke of the love they held for their child and how each child brought joy and balance to their lives.

Some mothers noted that their realisation of the longevity of the disability facilitated their acceptance of the situation. Some mothers described their hope for their child’s independence in adulthood, while another mother described her hope in finding a cure for her son as he had a rare diagnosis of unknown aetiology. Seeking opportunities for accessing help and support for their child was a proactive coping strategy which maintained hope. It is known that adaptive coping has been facilitated by hope and optimism for parents (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2012). Parents’ willingness to participate in the research is testimony to their desire to understand more about their child and their future-orientated outlook.
Six of the eight mothers received active support from their own mothers with the care of their child. This massive input of the second generation had a positive impact on daily coping. This reflected family practices in Romania, whereby there are close connections between the nuclear and extended family which can be relied upon not only in times of crisis, with grandparents playing an active role in the rearing of grandchildren. When the child has a disability, this role does not appear to change. Mothers all spoke of the comfort they derived from knowing that their mother was available to watch their child, as well as the emotional and financial intergenerational support provided (Trute, 2003). The positive impact of grandparents upon the care of children with disabilities while limited, has been seen in previous research (Mitchell, 2007).

Similar to previous studies, this research supports the finding that the division of caring activities between husband and wife was unequal, with men providing a role of emotional support to their partner as opposed to helping with direct caring duties (Pelchat, Levert, & Bourgeois-Guérin, 2009). In this study similar to previous research (Pelchat, Levert, & Bourgeois-Guérin, 2009), mothers felt that it was their role to fulfil these duties, but this feeling was also affected by personal, social and relational factors. Five mothers confirmed the availability of their partners for support, despite the fact that one of the mothers who cited receiving this support was divorced from her husband. The desire for fathers to be involved in their children’s lives has been found in the UK, with an increasing recognition that sustaining the involvement of fathers could lead to lifelong positive outcomes for the child (Towers, 2009).

Siblings were a strong source of informal support for mothers, with many mothers marvelling at the innate empathy displayed by their typically developing sons or daughters towards their sibling. Like all families, these relationships differed but all mothers reported
no difficulties between siblings. These positive relationships reflects the current theme in sibling research which strives to replace the view that a sibling with a disability will impact negatively upon their brothers or sisters, with the realisation that positive relationships will coexist just like that experienced between typically developing siblings (Stoneman, 2005).

All mothers saw themselves as fulfilling an important role of social advocate or activist for their child. For some, this was through their desire not to hide their child away. Cross cultural research of children with disabilities in Korea has shown that mothers are aware of others negative attitudes towards their children. Similar to that found in this study, these parents showed an understanding of others reactions, and a desire not to hide their children from society (You & McGraw, 2011). Similar to the findings in Ryan and Runswick-Cole (2008), parents experiences of advocacy and activism sat upon a continuum and formed a large part of their identity of mother, which gave them purpose and strength. Parents derived strength from their position as role models for overcoming adversity. These feelings of pride empowered parents to continue with their solution orientated approach, similar to that seen in previous research (Broberg, 2010). Parents in the Broberg study (2010) acknowledged the additional demands placed upon them and gave themselves credit for having the persistence to meet these demands. It is probable, that the associated positive feedback acted as a source of encouragement for parents (Broberg, 2010) to keep “going forward”.

The benefits of the application of meaningful routines to facilitate care has long since been established (Skinner & Weisner, 2007). In this study, parents found the application of daily routines useful to facilitate care duties, with one mother viewing her use of routine in her care giving duties as being “like a job” as a useful strategy to facilitate care. Discovering family routines and complimenting them is an important part of facilitating the natural
ecology of the family (Maul & Singer, 2009). Mothers employed numerous other problem- 
focused coping strategies to facilitate coping, such as adaption’s to the home environment.

Four mothers highlighted their identification with the role of mother. This identification allowed them to adopt proactive approaches towards the provision of care. Adhering to the traditional expected role of mother allowed mothers to rationalise and justify the effort expended to care for their child as being ‘normal’ behaviour of a mother. This coping strategy gave mothers a reference upon which to base their behaviour and was a useful method when explaining their role to others. Two mothers spoke about their strong religious beliefs as providing a supportive relationship for them. These mothers also attributed improvements in their child’s disability to the practising of atypical treatments, namely a powder received from a natural doctor and the inclusion of the child in a religious ceremony.

Mothers identified others in similar positions to themselves as being “strong”. It is possible that mothers inadvertently derived strength from identifying positive characteristics in this group, which was a group with which they could identify with. Parents who engaged with parents in similar situations found it to be an important form of informal support (Olsson & Roll-Pettersson, 2012) and it is an outlet which should be encouraged.

Just like that seen in Nelson’s study (2002) mothers in this study all reported their utilisation of emotion-focused coping strategies which were motivated by positive child characteristics or their love for their child. One mother described how her view of her child as being special in a normative sense, despite his illness, strengthened the familial bond between them. She placed huge value upon their relationship and felt distress and anger at the thought that others may view theirs as a dispensable relationship. This perspective of the acceptance of the child despite the disability demonstrates the mothers simultaneous rejection of the
confines of the disability while still aspiring to enact the mothering role (Larson, 1998). This apparent contradiction whereby the mother holds two opposing thoughts about the child has been described in previous research by a father of a child with a disability as being an “emotional cross current” whereby there are emotional fluctuations between extremes, which are co-occurring (Kappes, 1995).

In line with previous research, this study lends support to the idea that the denial of the disability as tragedy trajectory is not viewed as an indicator of resistance to accepting the disability (Goodley & Tregaskis, 2006). Many mothers viewed their child not as disabled, but as special in their own sense. This viewpoint understands the impact of the disability and views mothers acceptance of disability as being normal, whereby mothers framed disability in a normative manner and thus facilitated a realistic approach to the management of daily care. The paradox of the child having additional needs while simultaneously being a great source of joy is one which is well documented in the literature (Fisher, 2005; Larson, 1998).

5.6 Reflections on the Interview Process

To facilitate understanding of the themes arising from the Interpretative Phenomenological Analysis, it is important to outline the interactive experience of the interview process. As previously mentioned, a reflective journal was kept by the researcher to reflect upon the interview process and also the three way mother-researcher-interpreter experience.

The majority of parents were initially nervous around participating. The period before the interview during which the information and consent sheets were clarified proved to be imperative to reassure mothers of the process. All mothers expressed their curiosity but unfamiliarity with the unique process. This research was guided by the belief that in order to
make a difference to the lives of these families, their voice must be heard. This aspect of the study was expressed to be highly valued by the mothers, most of whom expressed their gratitude to the researcher:

“I thank you as well. That you exist” (Madalina).

“I am glad that we spoke. That you listened to my sufferings” (Stela).

The ease with which mothers provided rich information was facilitated by many factors. The researcher had previously met two of the parents in a professional capacity. It is thought that this contributed towards open communication (Maxwell, 2005). Some mothers noted that their attendance at the opening meeting held in July 2011 was informative for them. Many mothers expressed their desire to speak freely due to the position of the researcher as a non-national, and therefore in their eyes, more understanding. This belief was based on their previous experiences of meeting Irish people:

“The Irish girls did more things than the Romanians. And they have a higher level of understanding than our Romanians. It means a lot, we appreciate it” (Viorica).

Mothers willingness to share their stories was facilitated by the newness of the process. Many mothers expressed appreciation for being given the opportunity to be heard. Most mothers cried at various points during the interview, either mid way or towards the end of the interview. The researcher monitored mothers emotional responses and offered breaks sensitively around sensitive topics. The researcher reflected on these experiences as important and concluded that they reflected mothers comfort to talk freely.

The decision to change the interpreter after the pilot interview was viewed retrospectively as a turning point in the data collection process. The interpreter used in this study was someone who was known professionally by the researcher and who held a good
knowledge of disability issues and the cultural differences between Romania and Ireland. This knowledge added to the richness of the interpretations and understanding during the interviews and analysis. The rapport between the researcher and interpreter facilitated the flow of the interviews, as the researcher felt comfortable to manage the interpreter throughout the process which ensured a consistent and good standard of systematic interpretation.

Of the eight interviews, three mothers did not provide as rich stories as the others. These mothers preferred to discuss their child’s behaviour than their own feelings. It was noted that this position may have reflected the mothers familiarity with speaking about their child while suppressing their own feelings (Osborne & Coyle, 2002). Of these interviews, one interview was reflected upon as being most challenging as the mother rearranged her seating to avoid eye contact with the researcher. This interview was shorter in duration than others and was challenging for the researcher due to the emotive content of the interview. Through discussion in supervision and reflection, it was thought that this mother was perhaps struggling to care for her children given the complexity of the child’s diagnosis and the mothers health status. These reflections were helpful when forming interpretations during analysis.

5.7 Reflexivity in Analysis
IPA recognises that research is a product of an interaction between the mothers interviews and the researchers’ interpretative framework (Smith, Flower & Larkin, 2009). In accordance with the application of IPA, the researchers framework, assumptions and position in the study must be included to determine the impact on the process and interpretation of the interviews.
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The researchers familiarity with the social service system in Romania and the support available for families was useful in preparing the researcher for the types of life experiences that would be heard during data collection. Entering this research process, it was assumed that mothers may have considered relinquishing care for their children when they discovered their child’s disability. It was also assumed that the family received little State support. The assumption that mothers considered alternative care for their child was not demonstrated for all mothers. Some mothers were surprised by such a question. It became apparent during the course of the interviews whether it was appropriate to ask this question. During analysis and write up, it was decided that decision making would take less of a prominent position than was previously anticipated to reflect the responses received. All interpretations were checked by the research supervisor who is a Clinical Psychologist and who has worked in Romania over the past five years and was familiar with the area of research.

The assumption that State support was minimal was also adapted. The State was found to be obliged to support families but this support appeared more strongly on paper than in reality. These findings were not fully anticipated and influenced the interpretation of the data as a challenge to coping.

The researchers’ experience of working in the disability sector in Romania coupled with her Psychology studies resulted in the interpretation of the data though the lens of psychological experience and literature. During the interviews it was useful to encourage mothers to expect the researcher ‘knows nothing’ as this allowed mothers to provide full descriptions of their daily lives which were rich in detail. Through the application of strategies before, during and after the process, the researcher became more aware of the multiple levels of interpretation possible in this study. In order to strive for credibility and
trustworthiness in the research process, credibility checks as outlined in Yardley (2000) were applied.

During the write up of the results chapter the researcher attended supervision meetings with an experienced IPA researcher and Clinical Psychologist to reflect on the selection of quotes to be included in this study. The researcher felt a duty to represent the mothers experiences in order to present a balance between the group experience and the powerful emotive experience captured within many of the individual interviews. The researcher found the supervision process influential in managing this, and actively recorded memo’s throughout the process.

5.8 Methodological Considerations

5.8.1 Areas for Consideration

This study reflected the analysis of eight interviews of mothers who were members of a parents support group for people with disabilities in the South of Romania. The total membership of this group is approximately 70 families. Of these, only 11 families met the inclusion criteria. Of these 11 parents, less than half actively engaged with the group’s activities on a monthly or bimonthly basis. Data received from the County Director of Social Services in the County revealed that in 2012 there were 561 children with registered disabilities currently residing with their families in the County (Appendix B). Therefore, the sample consisted only of parents who at some stage decided to register with the parents support group (registration is not an indicator of active engagement) and does not include parents who are either unaware of the group or who were unable to register.
Chapter Five: Discussion

The age group of children ranged from 10 years to 18 years. There were no mothers of children who were recently diagnosed and thus the interviews gathered offered specific retrospective maternal accounts of the disclosure process. However, this study aimed to explore parents experiences of caring for their child as opposed to establishing factual accounts of situational experiences.

As this research was carried out in one county in Romania and due to the nature of the study, the results and recommendations are not intended to reflect the experience of mothers in general in Romania. Therefore external generalisability (Maxwell, 2005) of findings is not the intended outcome of the study.

Due to time and financial constraints, it was decided that the transcripts would reflect the spoken English that occurred during the interview process. Ideally, the researcher would have preferred if the interviews would have been transcribed verbatim in Romanian and English, and checked to determine if the English spoken reflected exactly what was spoken in Romanian. Despite this, it is felt that an accurate translation was acquired. As one mother asked to validate the script, the resulting Romanian transcript as transcribed by the interpreter was compared with the English transcript conducted by the researcher. There was little difference in the versions produced and no differences of such significance that they would have influenced the interpretations produced.

This study reflected the experiences only of mothers. Caregivers who were parents of children with disabilities were invited. Mid-way during recruitment the gatekeeper was asked to remind mothers that fathers were also invited to participate. It is thought that the representation of mothers may be reflective of the division of care giving duties in Romania, with mothers taking a more active role in child rearing practices.
5.8.2 Strengths

The sample size of eight mothers is deemed appropriate, with 3-6 participants being recommended for IPA studies (Smith, Colson & Osborne, 2008). A sample of eight participants was considered to satisfy the needs of this study given the language barriers. A strength of this study was the flexibility of the interview schedule. This was adapted after the pilot to include an area of questioning which was of importance to the mothers.

The research had never before been carried out in Eastern Europe or in particular, in Romania. If real efforts are to be made to ensure the provision of care for the child with a disability at home, then it is essential the voice of the family is heard in order to enable this care to be provided. This seminal piece hopes to fill this gap and encourage others to carry out research in the area. A consideration of the experiences of these eight mothers cannot be made without surmising on the implications of their stories for clinical practice, policy, education and continued professional development and future research. Based on these emotive accounts a number of key recommendations are made which reflect the mothers voice while framing these recommendations within international best practice literature, policy and guidelines. These recommendations are not exhaustive and are presented as suggestions for reform in the areas of practice, policy, education and continued professional development and research.

5.9 Implications for Clinical Practice

5.9.1 Disclosure & Family-Centred Practice

On the basis of these eight interviews, a key finding is the position of power of health care professionals. Health care professionals are the first point of contact with mothers when they
have worries about their child’s development, putting them in a unique position to offer optimum support (Carpenter, 2007). Families reactions to disability differ and this will impact on the adaption of the family to the diagnosis. By discovering these individualised responses, professionals will be better equipped to devise and implement interventions which will compliment the family system as opposed to the application of presupposed expectations as assumed by the professionals (Carpenter, 2007).

In this study, the majority of mothers recalled at best, professionals matter of fact approach to their child, and at worst the portrayal of their child using dehumanising and unhopeful terminology. Health care professionals need to have a broader understanding of competing disability models, in order to challenge the prevailing medically orientated “disability as tragedy” model which is currently evidenced within the Romanian health care system. Health care professionals need to discard the outdated highly stigmatised view that parents will experience a lifetime of sorrow and grief (Olshansky, 1962) and encourage parents to celebrate the joy and fulfilment their new child will bring. Health care professionals are encouraged to make room for “sorrow and joy” when working in partnership with families (p242, Lindblad, Holritz-Rasmussen & Sandman, 2007).

With the large body of evidence now supporting the importance of early intervention for children with disabilities, the need for accurate and efficient diagnosis is imperative to guide the effective design and delivery of services. On the basis of the stories heard during this study, it is unknown to what extent validated assessments are being utilised during disability assessments. It is recommended that health care professionals utilise transparent and validated assessment procedures (UNICEF, 2010) similar to that outlined within the ‘Together from the Start’ guidelines developed by Department for Education and Skills and the Department of Health in the UK (2003). Examples of early intervention programmes are
evident in Romania, such as “The PREVI Project: Prevent institutionalisation of disabled children by developing centres for early diagnosis and early intervention” (PREVI, 2011).

These projects are given as examples of best practice and should be embedded into national practice. Professionals should be aware of resources centred on international best practice, such as that encouraged by the International Society of Early Intervention in Washington, USA. This society offers resources for the implementation of best practice in all areas of early intervention, with many resources available in the Romanian language.

The point of disclosure has been shown to be a crucial transformation point for parents. Professionals need to be aware of the requirement to adhere to best practice guidelines for the delivery of a diagnosis to families. Guidelines have been established in many countries such as the ‘Informing Families’ best practice guidelines in place in Ireland (Harnett, 2007) or the ‘Right from the Start’ framework in place in the UK (2003). By implementing similar guidelines, it is hoped that parental satisfaction with health care professionals will increase, thus bringing positive benefits for the child, family and their engagement and adherence to family-centred interventions.

A common thread running through mothers experiences was their lack of understanding of their child as they had not received ample information to form the knowledge needed. In line with best practice, health care professionals are encouraged to disseminate disability specific information to provide support and advice to parents. Professionals are encouraged to provide parents with information points to access further support. Possibilities include reputable internet sites, telephone help lines or local parent support groups.

Many mothers outlined their upset and trauma when recalling the unclear management of medication for their child’s disability. Professionals should be aware of the best practice guidelines as set out in the NICE guidelines regarding the administration of medication for
children and young people. NICE International are currently working with the Romanian Ministry of Health to revise basic health care packages in the country, and this and further investment in areas pertinent to the delivery of family-centred care are actively encouraged (Luiz, Lopert & Chalkidou, 2012).

Professionals are encouraged to implement family-centred practices when working with children with disabilities and their families. Of key importance is the invitation to fathers to join this process, thus recognising the importance of maintaining family cohesion and the inclusion of fathers in the planning and implementation of interventions (Towers, 2009). Mothers also mentioned their own physical exclusion from the actual assessment processes when they were asked to leave their child alone with the professional while they carried out the assessment. It is imperative that parents are present for all assessments, both for the successful delivery of assessments and to protect the safeguarding of the child (WHO, 2010a; WHO, 2010b)

5.9.2 Disability Commission

Most of the mothers in this study discussed the negative emotional impact of annually attending the Disability Commission. The Romanian system of disability registration appears to be one which is fraught with inconsistencies and one which by its nature is stigmatising. It is one of the key sources of socio-structural stress for mothers. A major revision of this process is suggested. This study revealed an incongruence between policy and practice, with an unanimous opinion that this experience is bureaucratic and inconsistent in its delivery of supports. It is suggested that in the absence of the complete overhaul of the system, some key recommendations should be implemented:
- Acceptance of assessments from professionals other than those registered within the State system.

- Removal of the requirement for the diagnosis to be revised annually.

- Removal of the requirement for the child to be physically present at the Commission.

- A grace period to be allowed for caregivers to submit relevant documents without disruption to the financial benefits received.

- Professional training for employees at the Commission to ease parental stress resulting from unprofessional interactions occurring at the Commission.

- Increased cohesion and communication between services, with information being provided at the Commission about how to access the supports that are recommended by the Commission.

- The provision of a ‘key worker’ or similar liaison person for families, to facilitate families to access appropriate information, to help families navigate the relevant systems and for the delivery of feedback or complaints to relevant departments.

- Romanian literature (Cojocaru, 2008) discusses the existence of ‘mobile teams’ which provide care to families of children with disabilities at home. The delivery of family-centred care such as this is to be actively encouraged.

5.10 Implications for Policy

There is huge disparity between policy and practice surrounding the assessment and delivery of services for children with disabilities. Furthermore, there is a gap in the implementation of policy surrounding the Disability Commission and the ad hoc nature of supports received as a result of attending the Commission.
In 2006, the National Strategy on the social protection, integration and inclusion of people with disabilities for the period 2006-2013 was introduced in Romania. At this time, the strategy stated that “Most of the people with disabilities do not currently benefit from any services” (p8, 2006). Unfortunately, this study demonstrated that of the mothers identified, this situation remains unchanged. This study raises questions over the progression of the strategy in relation to its objective around “granting support to families including one person with a disability” (p9, 2006). This study highlighted a gap between the strategy and practice. It calls for a revision of this strategy to ensure it fulfils its commitment in the areas of:

1. The performing of a multidisciplinary assessment of the individual in cooperation with their family.
2. As outlined in objective 2.1 - the assessment of the support needs of the family to be conducted in the families’ living environment.
3. The fulfilment of the commitment to develop social services to allow families to access out of home day time supports for their children.

There is a noticeable lack of emphasis in the strategy on the introduction of family-centred practices or the importance of early intervention for families. This strategy is deemed overall to be insufficient in its current form and in its implementation into practice. Serious revision of this strategy and other relevant disability policies must be made in order to support the provision of care for children within the family home.

While it is recognised that efforts have been made to establish cohesion in realising consistency in the use of disability terminology, there is still a gap between terminology alluded to in policy and that enacted in practice. Sunderland, Catalono and Kendall (2009) highlighted the duty of care held by policy makers in shaping disability disclosure. From an analysis of the diagnoses received by parents and their use of terminology throughout the
Chapter Five: Discussion

interviews, it was evident that there is much confusion surrounding the use of disability terminology by professionals and that understood by parents. The demystifying of ‘disability’ is crucial in order to facilitate inclusion of families in society and the comprehension of professionals and families alike of the meanings of specific disabilities.

5.11 Implications for Future Education and Continued Professional Development

This study reveals numerous areas of development especially in the potential of future education and continued professional development. Like similar recommendations, this list is not exhaustive and instead is offered as a catalyst to challenge current models of education to ensure the teaching of inclusive family-centred practices. It is recommended that health care professionals: family doctors, nurses and consultants are provided with opportunities to up-skill especially in the areas of competing models of disability both at undergraduate level and to form part of continued professional development.

This study highlighted the need for adequately trained teachers in the special education system. Anecdotal evidence corroborates with that displayed in this study to suggest that ID may be misunderstood by many professionals and in particular the newness of the diagnosis of autism spectrum disorder. This is unsurprising given the complex history Romania has, and in particular the recognition of psychology as a new discipline since the collapse of the Communist regime (Smith, 2002). The development of a comprehensive curriculum based on the principles outlined by the WHO (2010c) which is competency based is a useful starting point for this agenda.

The potential for awareness raising among the wider society is vast. Given the empathy displayed by the siblings of the children in this study, it is recommended that
children in mainstream schools are educated about disabilities. The media is a powerful medium for which to begin this awareness raising and one which can be utilised effectively to challenge dated discourses of disability in society.

One mother recalled training held for parents by State services and NGO’s as being of benefit. The provision of parental education programmes specific to areas of disability are encouraged, to be delivered by a multidisciplinary team and with a focus on empowering mothers to provide care for their child.

5.12 Future Research

5.12.1 Health Care Professionals

Research into the practices in other counties in Romania would be of use to explore experiences at a national level. The collection of feedback from health care professionals who disclose the news and those working in Disability Commissions would be useful to ascertain the level of training and guidelines in place to work effectively with families.

Originally conceived as a study of mothers of children with ID, during the data collection period it became clear that there were few children diagnosed with just an ID. A national study focusing on the prevalence rates of children with ID would be useful. There is a need to uncover the actual numbers of children with disabilities in Romania in order to effectively plan supports. A national study is recommended, taking into consideration families who may not be registered with local Disability Commissions but who may be identified at birth with a disability.
5.12.2 *Teachers*

This study revealed the relatively low numbers of children who were attending formal education. In order to ensure children with disabilities are being accepted into the education system, teachers must be adequately trained to support their needs. Further research is needed to ascertain the experiences of teachers in special educational settings to explore their perceptions of competence to effectively educate this cohort of student.

5.12.3 *Families*

The potential for future research in this area is vast. This study offers a snapshot of a small group of mothers in one county in Romania and by its design, the generalisability of results was not an aim of the study. As well as exploring maternal experiences, further research could explore the experiences of siblings and grandparents of living with a child with a disability, to uncover how these informal supportive relationships can be bolstered by the health care system.

Due to dramatic changes in the child protection system upon the closure of large scale orphanages, large numbers of children were returned to their families. Future research could explore the impact of the re-entry of a child with a disability into the family after relinquishment. This study would be useful to determine how effectively supported these families feel and what factors initially caused them to relinquish care.

Research looking at the experiences of fathers would be useful to highlight men’s role within the family structure. This information would be essential in order to inform family led interventions and training which equally values the contribution of all members of the family.
Chapter Five: Discussion

Most importantly, research which allows the voice of the child to be heard is recommended. Using an inclusive research approach, future research could explore the experiences of children with disabilities who live at home. By placing the child at the centre, we can be assured that their view will be considered and can be taken into account when designing and implementing future recommendations for policy, practice, research, education and continued professional development.

5.13 Chapter Conclusions

To conclude, this chapter has explored in depth the findings related to the master themes. Mothers uncertainty stemmed from the manner in which they discovered their child’s disability and the approach adopted by the disclosing professionals. Mothers reactions in the wake of the news differed, but all of the mothers came to the conclusion that they must carry on, regardless of the lack of formal support options available to them. Mothers spoke about the crippling disempowering bureaucracy which they felt when registering their child with their local Disability Commission. The struggle to fulfil the annual requirements of the Commission, the fear of the actual attendance at the Commission coupled with the negative encounters with professionals at the Commission and during assessments and the inconsistency of the supports received after the process were exhausting for mothers. Mothers were left with feelings of terror in anticipation of their next visit.

This process and the experience of disclosure all contributed towards a lack of understanding of these mothers towards their children. This lack of understanding extended to others, with mothers advocating for their child in the face of the ignorance of others, friends, family and society in general. Their lack of control over treatment decisions and options for support left many mothers feeling that “it’s a sad life”. However, all mothers
displayed their ability in “going forward” with their children. Their ability to cope was bolstered by the informal support received from family and friends in similar positions. Their future orientated outlook and efforts to challenge the stigma attached to disability were examples of self motivated positive coping strategies. Finally, mothers all spoke of the deep love they held for their children. In their eyes, their children were like no other and this unwavering love sustained them.

This study initially hoped to hear the life experiences of mothers caring for children with ID at home in Romania. It was hoped that mothers might be able to reveal to us some indicators as to why they kept their child at home. As the study evolved, it became clear that this was not a predefined decision, in fact, it was never even considered by many. Driven by a genuine empathetic desire to facilitate these mothers to have their story heard, and a hope that the process would be beneficial for the parents, the study evolved accordingly. Faced with the many challenges of being a Westerner conducting research in a Eastern European country, I undertook this study with a huge awareness of the need to well represent these mothers and their children. As an aspiring clinician, and a person, the empowering stories of these mothers has left a lasting impression upon me. I will leave the last words with them:

“If I am away one day away from her, I have something on my soul- like a heavy rock, on my soul. An anxiety is bewildering me. I cannot stay without her. I would prefer to stay with her, to have her beside me until I die. Because my soul is attached to her soul and her soul is attached to my soul”
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Appendix A: Official Romanian Statistics on numbers of people with disabilities in Romania

Evolution of the protection of persons with disabilities, on March 31, 2011

- On March 31, 2011 the total number of persons with disabilities sent to the General Directorate Protection of the Persons with Disabilities of the Ministry of Labor, Family and Social Protection, through its general directorates of social assistance and child protection and local sectors of Bucharest, was **691482 persons**. Of these, 97.5% (674431 persons) live in family care and / or live independently (non-institutionalized) and 2.5% (17051 persons) se află în instituţiile publice rezidenţiale de asistenţă socială pentru persoanele adulte cu handicap (instituţionalizate) live in residential institutions of social assistance for adults with disabilities coordinated by the Ministry of Labor, Family and Social Protection through the General Directorate Protection of the Persons with Disabilities.

**Graphic 1. The number of persons with disabilities in March 31, 2011**

<table>
<thead>
<tr>
<th>TOTAL NUMBER OF PERSONS</th>
<th>691482</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-INSTITUTIONALISED</td>
<td>674431</td>
</tr>
<tr>
<td>INSTITUTIONALISED¹</td>
<td>17051</td>
</tr>
</tbody>
</table>

¹) The number of the persons in the public residential institutions of social assistance for the adults with disabilities coordinated by the MLFS/GDPPD.

**Graphic 2. The evolution of the number of persons with disabilities, 2006 – March 2011**
Appendix B

Appendix B: Figures received from Director of Social Services in June 2012 on the number of children registered in the county with a disability

**Numar total copii cu handicap din familie- 561** (Number of children with a handicap in their families- 561)

- Gradul I = 348 (Severe)
- Gradul II= 169 (Medium)
- Gradul III= 22 (Mild)

<table>
<thead>
<tr>
<th>Fizic (physical)</th>
<th>Somatic</th>
<th>Auditiv (hearing)</th>
<th>Vizual (visual)</th>
<th>Mental (mental/intellectual)</th>
<th>Psihic (psychic)</th>
<th>Asociat (associated- 2 more disabilities)</th>
<th>Boli rare (rare diseases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>II</td>
<td>III</td>
<td>I</td>
<td>II</td>
<td>III</td>
<td>I</td>
<td>II</td>
</tr>
<tr>
<td>27</td>
<td>16</td>
<td>5</td>
<td>68</td>
<td>35</td>
<td>6</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>48</td>
<td>109</td>
<td>15</td>
<td>32</td>
<td>168</td>
<td>14</td>
<td>174</td>
<td>1</td>
</tr>
</tbody>
</table>

**Numar total copii cu handicap aflati in Case de tip familial- 88** (Number of children with a handicap in protected homes)

- Gradul I = 40 (Severe)
- Gradul II= 36 (Medium)
- Gradul III= 12 (Mild)

<table>
<thead>
<tr>
<th>Fizic (physical)</th>
<th>Somatic</th>
<th>Auditiv (hearing)</th>
<th>Vizual (visual)</th>
<th>Mental (mental/intellectual)</th>
<th>Psihic (psychic)</th>
<th>Asociat (associated)</th>
<th>Boli rare (rare diseases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>II</td>
<td>III</td>
<td>I</td>
<td>II</td>
<td>III</td>
<td>I</td>
<td>II</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>25</td>
<td>0</td>
<td>57</td>
<td>6</td>
</tr>
</tbody>
</table>

*Translations provided by the Director of Social Services, June 2012*
Appendix C: Table outlining areas of discussion at open meeting with parents in Romania

*Table C: Core areas discussed during focus group*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
<th>Prompts and expansion material</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Issues affecting home care provision</strong></td>
<td>When your child was diagnosed can you list all the <strong>people</strong> and <strong>places</strong> that helped you care for your child at home?</td>
<td>-factors affecting decision making process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-available family supports</td>
</tr>
<tr>
<td><strong>Understanding of disability</strong></td>
<td>What <strong>supports</strong> helped you to better <strong>understand</strong> your child’s disability?</td>
<td>-perceived helpfulness of supports</td>
</tr>
<tr>
<td></td>
<td>What <strong>factors</strong> made these supports better than others?</td>
<td></td>
</tr>
<tr>
<td><strong>Benefits of group</strong></td>
<td><strong>Why/ what makes</strong> you attend this group?</td>
<td>-Benefits of support groups</td>
</tr>
<tr>
<td><strong>Hospital care</strong></td>
<td>Has your child ever spent time in hospital, and if so, what was your experiences while there</td>
<td>- Interactions with professionals</td>
</tr>
<tr>
<td><strong>Maintaining care provision at home</strong></td>
<td>What <strong>people/services</strong> would you like to access to <strong>improve</strong> the care you give to your child</td>
<td>-supporting ongoing care</td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td>What were the reactions of family, friends neighbours to your child?</td>
<td>-how did they use their relationships to support you</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>How do other children in your home help with your child</td>
<td>- Positive/ negative?</td>
</tr>
</tbody>
</table>
Appendix D: Information used to prepare interpreters for participation in this study

1. **Guidelines for Interpreters**

1.1 **Reason for choosing qualitative research methods:**
   - Rationale for choosing this method
   - Purpose and background to this study
   - The conduct of the qualitative interview: understanding what information we want to elicit during the interviews
   - Understanding the research questions and central meanings. Discussion around purpose of research and potential benefits to the cultural group.

1.2 **Explaining ethical procedures:**

The interpreter is representing the researchers voice and identity, therefore also the researchers code of ethics. The interpreter needs to be aware of this at all times. Take for example the following example:

In one study conducted by a male interpreter for a female researcher, the interpreter made inappropriate sexual remarks about females to a female participant. The researcher intervened and apologised to the participants who stated they were used to such comments from men. On this occasion, as the researcher had previously explained to the interpreter about their responsibility to represent the voice of the researcher, it was decided that the interpreter would have to be replaced as they had competing ethical frameworks (Ficklin & Jones, 2009).

1.2.1 **Topics for discussion**
   - Explaining informed consent
   - Explaining need for signing of agreement & confidentiality forms
   - Reflexivity, the interpreter/ researcher. Question the researcher regarding: Interpreters background: age, professional cultural background, own life experience, their relationship with the participants, what issues they regard as important in relation to the topics being addressed, and the subject of the study (Temple & Edwards, 2002).
### Table D: Interpreter selection information

<table>
<thead>
<tr>
<th>Item</th>
<th>Benefits</th>
<th>Caution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matching the interpreter to the participant in terms of socio-demographic characteristics</td>
<td>Research participants see interpreter as trustworthy and can help rapport and put participants at ease</td>
<td>Can limit depth of the responses as there will be taken for granted assumptions between the interpreter and the participant that the researcher is unaware of. How do you decide what characteristics to match researchers and participants on?</td>
</tr>
<tr>
<td>Choosing interpreter who has strong connections to the participants</td>
<td>As above</td>
<td>Status of the interpreter in relation to participant may be of relevance. This perceived/real status may affect participants responses making them more inhibited. Interpreter may selectively choose what to interpret, as interpreter may feel that some responses may reflect badly on their ethnocultural group.</td>
</tr>
<tr>
<td>Choosing interpreter who has knowledge of cultural background of participant and researcher</td>
<td>Can explain terms unfamiliar to the researcher</td>
<td>May rephrase a participants responses to make them more socially or politically acceptable to the researcher which will affect the validity of the data. E.g. In one study an interpreter translated a response as ‘in China, the parent needs to be strict... very strict.’ The interpreter went onto say ‘the participant thinks that the Canadian way of parenting is that parents really love their kids’ even thought the participant had actually said: ‘in China, we can hit and yell at the kids to discipline them’</td>
</tr>
</tbody>
</table>

1.3 Lessons learnt from previous research
- Refrain from softening responses from participants when summarising responses.
- The researcher should ask the interpreter if there is any additional information from participants before progressing onto the next interview question. This allows the interpreter time to remember any additional information.
- The researcher and interpreter should feel like students in that they emphasise their desire to learn about the participants experiences.
- The interpreters can provide additional depth to the material by explaining particular issues and relationships during the course of the interviews and afterward to the researcher. For example, on some occasions, the interpreter may include additional information to ensure that the researcher has understood what was meant (and highlight to the researcher when this information is additional to what the participants have said).
- The need to maintain conceptual equivalence. Conceptual equivalence is where the interpreter provides a technically and conceptually accurate communication of a concept spoken by the participant. Sometimes, a word or phrase may not exist in another language. In these cases the interpreter must strive to provide a translation.
which maintains the key concept, using their knowledge of the subject matter and applying this to the context that they are in (Squires 2009).

1.2 During the interview

- You must not show participants how you feel about what they say, beware of showing this through facial expressions or body language. This is important as you do not want to influence the participants in any way by showing either approval/ disapproval for their story.

- In English the researcher asks the question which is translated by the interpreter to the participant.

1.2.1 Steps in interpretation

The interpreter provides 1st person translation of parents’ responses to the researcher.

The interpreter translates probes from the researcher to the participant.

The interpreter provides 1st person translation to the researcher.

1.2.2 What to do if someone becomes emotional

Follow the lead of the interviewer:

- Interviewer will assure the participant it is ok to be emotional , encourage participant to keep talking or take a break if they prefer. Do not ignore the emotion (as they may avoid sensitive topics from then on). Should aim for an atmosphere within which the participant feels comfortable enough to talk about emotional topics (Flyan, 2005).

1.2.3 After the interview

Researcher will summarise what was spoken about for the participant. Researcher through the interpreter should seek feedback from participant to see if you have interpreted correctly - offers opportunity to check validity (Fylan, 2005).

Provide contact information.

1.2.4 Once the participant has left

Researcher will record field notes on:

- The context of the visit
- Nonverbal behaviours of the participant: e.g ease of discussion, participants affect.
- Personal impressions of the interview:
- Feelings ideas and phrases that stood out as meaningful

Appendix E: Email providing Ethical Approval from the University of Limerick Research

Ethics Committee

From: Anne.OBrien  
Sent: 16 May 2012 09:15  
To: Barry.Coughlan  
Cc: Triona.Collins  
Subject: EHS29021277

Dear Barry, Triona

Thank you for your amended Research Ethics application which was recently reviewed by the Education & Health Sciences Research Ethics Committee. The recommendation of the Committee is outlined below:

**Project Title :** EHS29021277  Parents experience of caring for their child with a disability at home in Romania. An exploratory study.

**Principal Investigator :** Barry Coughlan  
**Other Investigators :** Triona Collins  
**Recommendation :** Approved

Yours Sincerely

Anne O’Brien  
Administrator, Education & Health Sciences  
Research Ethics Committee
Appendix F: Letter confirming Garda vetting for access to vulnerable participants
Have you ever been convicted of an offence in the Republic of Ireland or elsewhere?

No [ ] Yes [ ] Please provide details

<table>
<thead>
<tr>
<th>DATE</th>
<th>COURT</th>
<th>OFFENCE</th>
<th>COURT OUTCOME</th>
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</table>

DECLARATION OF APPLICANT

I, the undersigned who have applied to study at University of Limerick, hereby authorize An Garda Síochána to furnish to University of Limerick a statement that there are no convictions recorded against me in the Republic of Ireland or elsewhere, or a statement of all convictions and/or prosecutions, successful or not, pending or completed in the State or elsewhere as the case may be.

Signature of Applicant: __________________________ Date: ________

Print name: __________________________

To be completed by University of Limerick only

Authorized Signatory: __________________________
(Ms Jackie O'Shaughnessy, Office of the President, University of Limerick)

PLEASE PRINT ALSO (Jackie O'Shaughnessy)

Registration Number: AS ____________

To be completed by the Garda Central Vetting Unit

According to Garda records there are no previous convictions recorded against the above named applicant:

OR the attached convictions appear on Garda Records:

OR the attached prosecutions are pending:

NOTE: Checks were carried out by this office based on the information supplied.

The convictions supplied may apply to the subject of your enquiry.

Please verify information disclosed with the applicant.

Signed: __________________________ Member I/C __________________________

G.C.V.U. __________________________
Semi structured Interview Guide

Introduction
Researcher will welcome participant, introduce self and interpreter. Researcher will explain the background to the study and allow for any questions. Researcher will go through the information sheet, and allow for any questions. The researcher will explain the purpose of the interpreter agreement form. Participant, interpreter, and researcher to sign the agreement form. Participant to sign consent form. Researcher will turn on audio recorder and commence interview.

Background information/ rapport: Could you tell me a little about your son/daughter?

RESEARCH AREA 1: Parents experience of the disclosure process
1. Can you tell me about how you felt when you were told your child has a disability?
2. During this time, what was your experience of meeting and talking to the professionals (prompt- doctors, psychologist, social workers, nurses)?

RESEARCH AREA 2: The impact of the disclosure process on coping and care related decision making.
1. From your memories of these meetings, how did those experiences impact on your decision to mind your child at home?
2. How did your meetings with the doctors impact on how you coped with your child on a daily basis?

RESEARCH AREA 3: Impact of disability on the family
1. Tell me a little about how the disability of [ . . . ] has impacted on the lives of his / her brothers/ sisters?
2. How has the diagnosis impacted on the relationship with the child’s father?
3. Tell me a little about how having a child with a disability impacts on your relationship with your neighbours? Friends?
RESEARCH AREA 4: **Factors influencing the decision making process regarding choice of care**

1. Tell me about some of the things that influenced your decision to keep your child at home?
2. Was there anything making that decision more difficult/or easier?

RESEARCH AREA 5: **Parents experience of coping with their child**

1. What are the things that make caring for a child with a disability on a daily basis most difficult?
2. Caring for a child with a disability on a daily basis can be difficult, what are some of the things that help you to cope with these difficulties?

RESEARCH AREA 6: **Impact of legislation on care**

1. Tell me about your experience at the annual Disability Commission?
2. What is your experiences with the professionals at that commission like?
3. Are you aware of any laws/policies that help you care for your child?
4. If yes, how do they impact on how you care for your child?

Closing remarks and arrangements for transcript validation

Thanks
Appendix H: Letter of Support for this study from the Irish NGO The Comber Foundation

8th February, 2012

Education of Health Sciences Research Ethics Committee
Faculty of Education & Health Sciences
University of Limerick.

Dear Sir/Madam

This letter is to confirm that the Comber Foundation, Ireland are aware of the study entitled “Parents experience of caring for their child with a disability at home in Romania. An exploratory study” being undertaken by Ms. Triona Collins under the supervision of Dr. Barry Coughlan of the University of Limerick.

I have met with Ms. Collins and Dr. Coughlan on several occasions and am satisfied for this research to be undertaken to support our partnership with a group of local parents who have a child with a disability who resides with them in their family home. The Comber Foundation are satisfied that the research supports our current objectives of deinstitutionalisation and prevention of institutionalisation for persons with disabilities and their families and are happy for the research to proceed.

Should you have any queries or require further clarification please do not hesitate to contact me.

Yours sincerely,

___________________________
Ms. Fiona Dowling
Executive Director

Charity registration numbers: CHY 10070  NI: XN 91215
Appendix I: Letter of Support from University of Bucharest, Romania

26th April, 2012

Education of Health Sciences Research Ethics Committee
Faculty of Education & Health Sciences
University of Limerick.

Dear Sir/Madam,

This letter is to verify that we in the Department of Special Education in the University of Bucharest are aware of the research study that is to be undertaken by Ms. Triona Collins, postgraduate researcher, under the supervision of Dr. Barry Coughlan, University of Limerick.

In the absence of an Ethical Committee in the University of Bucharest we are happy to verify that the researchers have applied and received favourable approval from the National Supervisory Authority for Processing Personal Data. This is the national body responsible for granting approval to allow for the collection and processing of personal data that is gathered through research conducted with human participants.

Should you have any queries or require further clarification please do not hesitate to contact me.

Yours sincerely

______________________________

Dr. Doru Vlad Popovici
Head of Department of Special Education
Faculty of Psychology and Special Education
Appendix J: Permission from the Romanian National Authority of Monitoring the Processing of Personal Data

In atention:
Domnul Dobroș Bogdan

Stima domn,

Vă facem cunoscut faptul că declanșăm notificarea pe care să o transmită Autoritatea Națională de Supraveghere a Prelucrării Dateelor cu Caracter Personal, pe propria răspundere, semnată și stampilată, în format electronic la autoritățile de supraveghere sub nr. 574 din 21 martie 2012.


Această notificare are ca scop să se asculte opinia autorității de supraveghere, în conformitate cu legislația României.

Completarea/schimba notificării nr. 22995, ca urmare a apariției unei schimbări în activitatea operatorului, sau la solicitarea autorității de supraveghere, se va face prin intermediul unui formular electronic, la adresa site-ului oficial al AUNS (www.auns-pocp.ro), secțiunea “Notificări”.

Notificarea este obligatorie în cazul în care operatorul nu este în conformitate cu legislația sau cu directivele și recomandările care sunt cuprinse în anexa. Prezența notificării, care efectuează domnul bogdan, nu modifică informațiile din anexa.

Această notificare este realizată în conformitate cu legislația României. Prezența notificării, care efectuează domnul bogdan, nu modifică informațiile din anexa.

Stima domn,

Vă adesea să se asculte opinia autorității de supraveghere, în conformitate cu legislația României. Prezența notificării, care efectuează domnul bogdan, nu modifică informațiile din anexa.
Appendix K: Information sheet for participants (English)

Parents experience of caring for their child with a disability at home in Romania. An exploratory study

We would like to invite you to take part in our study. Before you decide we would like you understand why the study is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. Ask questions if there is anything that is unclear.

What is the purpose of the study?

This study will look at Romanian parents experience of caring for their child with a disability at home in Romania. It will look at parents experience of finding out their child has a disability, how parents cope, and how they make decisions about care for their child. To date there has been no known research in this area in Romania. This study aims to give a voice to you, the parent, to give you the opportunity to share your experience of caring for your child.

Why do you want me to take part?

You have been chosen as you are a parent of a child with a disability, and your child lives with you at home. In total, 12 parents will be interviewed.

Who is organising and funding the research?

The study is organised by Triona Collins, a research student at the University of Limerick, Ireland. The study is being supervised by Dr. Barry Coughlan, a Clinical Psychologist in the University of Limerick. The researcher is not receiving any money for this study.

What will happen to me if I take part?

If you take part in this study, you will be asked to

1. Sign a consent form to say that you are participating in the study.

2. As the researcher does not speak Romanian, there will be an interpreter who will translate what is being said. You will be asked to sign an agreement between you, the interpreter, and the researcher to confirm that the interpreter agrees to treat all information heard as confidential.

3. Have a face to face interview for a maximum period of two hours with the researcher and an interpreter. The interview will be audio recorded, to make sure that what is written down in the study matches what was said in the interview.

4. After the interview, using the audio recording, the interpreter will write what you have said and send it to you to verify.

Can I change my mind about taking part?

Yes. It is up to you to decide to take part in the study. You are free to leave the study at any time without giving a reason. No information you may have shared up to that point will be
used in the study. This decision will not affect the care or support you, or your family receive now or in the future.

**What are the benefits in taking part?**

Your participation will help develop an understanding of parents experiences of caring for a child with a disability at home. A potential outcome would be that your experiences will help develop improvements in clinical practice and service provision for you and your child.

**Is there any risk to me if I take part?**

There is no risk to you in taking part in this study. However, you may feel some emotional distress when sharing your experience with the researcher.

**What happens to the information?**

The audio recordings and any written information will be kept under password on the researchers computer, or in a locked cabinet which will not be accessible to anyone apart from the researcher. The data will be kept for 7 years, after which time the information will be destroyed.

**If I take part will my involvement be kept confidential?**

All information gathered in this research is **confidential**. This means, that at no point will the research team tell anyone that you have taken part. You will not be named in the study, and you will not be identifiable from the information you have given. Your name will not appear on any records.

*Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.*

**What happens at the end of the study?**

The results of the research will be made available to all participants. The study may be published in research journals or presented at conferences.

**Who has reviewed this study?**

This study has been reviewed and given a favourable opinion by the University of Limerick Ethics Committee. A Research Ethics Committee is an independent group of people who review research to protect the dignity, rights, safety and well-being of participants and researchers. Approval has been granted from The National Supervisory Authority For Personal Data Processing in Romania to process the information.

**What if I have more questions or do not understand something?**

If you would like further information please contact Triona Collins, Foundation Building, FG- 176, University of Limerick, Limerick, Ireland or email triona.collins@ul.ie

*If you have any concerns about this study and wish to contact someone independently and in confidence you may contact University of Limerick Ethics Committee tel: +35361202700*
Experiența părinților români în îngrijirea la domiciliu a copilului cu handicap

Studiu experimental

Ne-am dori să vă invităm să luați parte la studiul nostru. Înainte de a decide, am dori să înțelegeți de ce se face studiul și ceea ce ar implica pentru tine. Cercetătorul va trece prin fișa de informații cu tine și va răspunde la orice întrebări pe care le ai. Puneți întrebări dacă există ceva care nu este clar.

Care este scopul studiului?

Acest studiu se va ocupa de experiența părinților români în privința îngrijirii la domiciliu a copilului lor, cu handicap. Se va ocupa de experiența părinților de descoperire a dizabilității copilului lor, cum fac față părinții și modul în care ei își decidii cu privire la îngrijirea copilului lor. Până în prezent nu se cunoaște existența vreunei cercetări în acest domeniu, în România. Acest studiu își propune să ofere o posibilitate de exprimare pentru dvs, ca părinte, și o oportunitate de a împărtăși experiența dvs de îngrijire a copilului.

De ce doresti ca eu sa particip?

Ați fost ales deoarece sunteți parintele unui copil cu handicap și copilul locuiește cu dvs. În total, 12 părinți vor fi interviuvați.

Cine organizează și finanțează cercetarea?


Ce se va întâmpla dacă particip la acest studiu?

Dacă luați parte la acest studiu, vi se va cere să:

1. Semnati un formular de consimțământ de participare la studiu.
2. Deoarece cercetătorul nu cunoaște limba română, va exista un interpret care va traduce ceea ce se spune. Vi se va cere să semnati un acord între dvs, interpret, și cercetător pentru a confirma faptul că interpretul este de acord să trateze toate informațiile auzite, ca fiind confidențiale.
3. Veti avea un interviu fața în fața timp de maximum două ore cu cercetătorul și interpretul. Interviul va fi înregistrat audio pentru a vă asigura că ceea ce este scris în studiu redă fidel ceea ce s-a spus în interviu.

4. După interviu, folosind înregistrarea audio, interpretul va scrie ceea ce ați spus și va v-a trimite o copie scrisă pentru ca dvs sa o verificâți.

Pot sa ma razgandesc in privința participarii mele la studiu?

Care sunt avantajele participarii dvs?
Participarea dvs va contribui la dezvoltarea înțelegerii experienței părinților in privinta ingrijirii copilului cu handicap, la domiciliu. Un rezultat potențial ar fi faptul că experiențele dvs vor contribui la îmbunătățirea in mai mare masura a furnizării serviciilor clinice pentru tine si copilul tau.

Există riscuri in privinta participarii mele la acest studiu?
Nu există nici un risc în participarea dvs la acest studiu. Cu toate acestea, se poate sa resimtiti un stres emoțional in timpul discutiilor cu cercetătorul.

Ce se întâmplă cu informațiile?
Înregistrările audio și orice informații scrise vor fi păstrate cu o parola pe calculator cercetătorului, sau într-un dulap încuiat, care nu va fi accesibil nimănui in afara de cercetător. Datele vor fi păstrate timp de 7 ani, după care informațiile vor fi distruse.

Dacă voi lua parte la acest studiu, implicarea mea va fi păstrata în mod confidențial?

Tot ceea ce spuneti / transmiteti este confidențial, dacă nu ne spuneti ceva care indică faptul că dvs sau altcineva sunteti sub amenintarea unui pericol. Vom discuta acest lucru cu dvs înainte de a spune oricine altcineva.
Ce se întâmplă la sfârșitul studiului?

Rezultatele cercetării vor fi puse la dispoziția tuturor participanților. Studiul poate fi publicat în reviste de cercetare sau prezentat la conferințe.

Cine a analizat acest studiu?

Acest studiu a fost revizuit și a primit aviz favorabil de la Comitetul de etică al Universității din Limerick. Un Comitet de etică a cercetărilor este un grup independent de oameni care analizează argumentele unei cercetări pentru a proteja demnitatea, drepturile, siguranța și bunăstarea participanților la cercetare și ale cercetătorilor. Aprobarea procesării informațiilor a fost acordată de Autoritatea Națională de Supraveghere a Prelucrării Datelor cu Caracter Personal, din România.

Ce se întâmplă dacă am mai multe întrebări sau nu înțeleg ceva?

Dacă doriți informații suplimentare, vă rugăm să o contactați pe Triona Collins, la adresa Foundation Building, FG- 176, University of Limerick, Limerick, Ireland sau pe email triona.collins@ul.ie
Appendix L: Participant Consent Form (English Version)

Consent Form

Thank you for considering taking part in the study entitled:

“Parents experience of caring for their child with a disability at home in Romania. An exploratory study”

If you have any questions please ask the researcher before you decide to take part. You will be given a copy of the consent form to keep and refer to at any time.

Please put an X to confirm the following:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I confirm I have read and understood the information sheet for the above study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have had the opportunity to ask questions and have had these answered satisfactorily.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that my participation is voluntary and confidential and that I am free to leave the study at any time without giving any reason, without my rights, or my child’s rights being affected.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that if I withdraw from the study the information collected up to that point will be destroyed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that my involvement in the study will not affect the relationship with any organisation or person that offers services that I, or any member of my family, use or potentially will use in the future.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I give permission for the interview to be audio recorded and am aware that all information I give will be treated confidentially and anonymously.</td>
<td></td>
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</table>

Signature of Participant :........................................... Date:.............................................
Participant Consent Form (Romanian Version)

**Formular de consimțământ**

Vă mulțumim pentru ca luati în considerare participarea în studiul intitulat:

"Experiența parintilor romani in îngrijirea la domiciliu a copilului cu handicap

Studiu experimental"

Dacă aveți întrebări vă rugăm să le adresati cercetătorului înainte de a vă decide să participați la studiul. Vi se va da o copie a formularului de consimțământ pe care sa o păstrați și la care sa va referiți în orice moment.

Va rugam sa puneti un X pentru a confirma următoarele:

| Confirm ca am citit și am înțeles fișa de informații pentru studiul de mai sus. |
| Am avut ocazia să pun întrebări și am primit răspunsuri satisfăcătoare. |
| Înteleg că participarea mea este voluntară și confidențială și că sunt liber să renunț la participarea la studiu în orice moment, fără a mă justifica, fără ca drepturile mele sau ale copilului meu să fie afectate. |
| Înteleg că, dacă ne retragem din studiu, informațiile acumulate până la acel punct vor fi distruse. |
| Înteleg că implicarea mea în studiu nu va afecta relația cu orice organizație sau persoană care oferă servicii de care eu, sau orice membru al familiei mele, beneficiaz sau posibil voi beneficia în viitor. |
| Dau permisiunea ca interviul să fie înregistrat audio și sunt conştient de faptul că toate informațiile pe care le dau sunt considerate anonime și confidentiale. |

Semnătura participantului: .............................................. Data:.........................................................
Appendix M: Interpreter- participant- researcher consent form (English Version)

Interpreter Agreement

This agreement is undertaken between the researcher, the interpreter and the participant.

In signing, all parties agree that

1. The participant understands that the translator will have access to the data during the transcription process and that all recordings and written scripts will be processed anonymously by the interpreter/translator.

2. The interpreter will treat all information from the participant as confidential and shall not disclose it to anyone other than the researcher.

3. No information translated will be otherwise shared with any third parties, nor will the interpreter or researcher make any personal copies of the data.

Signature of Participant :........................................ Date:..................................................

Signature of Researcher: ........................................ Date:..................................................

Signature of Interpreter: ........................................ Date:..................................................
Acord cu interpretul-traducator

Acest acord este efectuat între cercetător, interpret și participant.

Odata semnarea acordului, toate părțile sunt de acord că:

1. Participantul înțelege că traducătorul va avea acces la date în timpul procesului de transcriere și că toate înregistrările și documentele scrise vor fi procesate în mod anonim de către interpret-traducător.

2. Interpretul va trata toate informațiile furnizate de participant ca fiind confidențiale și nu le va dezvalui altor persoane cu excepția cercetătorului.

3. Nicio informație tradusa nu va fi furnizată unei terțe părți, si nici interpretul, nici cercetatorul nu își va face vreo copie a acestor date.

Semnătura participantului: ........................................ Data: ........................................

Semnătura cercetătorului: ........................................ Data: ........................................

Semnătura interpretului-traducator: .......................... Data: ........................................
Appendix N: Copy of participant transcript with initial noting and emergent themes

<table>
<thead>
<tr>
<th>Exploratory Comments</th>
<th>Original transcript</th>
<th>Emerging themes</th>
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<tbody>
<tr>
<td><em>Doesn’t wait for a question! Order of events - status first.</em> I am separated with him. Life organised in relation to relationships. I have chosen an older house with my child (joint decision was made) to make it home. Goal orientated, that will belong only to me. Independent.</td>
<td><em>And we’re ready.</em> Can I start? So I am separated with him. I have chosen an older house with my child and I am living there. And now I am trying to do a home and that home will belong only to me this year.</td>
<td>Life defined according to relationships. Future orientated.</td>
</tr>
<tr>
<td>I was separated... because he was drinking abusive relationship, I chose my own way, to be alone, not to be terrorised, abused, reject old life, chose to be solo, free from terror. I fight alone self reliant, life of fights, with husband in life constant battle if you don’t fight God is upstairs. He judges us. Impact of religion, strong faith, God is helping me. Supportive relationship, helps cope with daily life.</td>
<td>I was separated three years ago because he was drinking. I chose my own way, to be alone, not to be terrorised, abused. I fight alone. I am fighting everything alone. If you don’t fight God is upstairs, he sees us, he judges us. The truth will come forward. God is helping me.</td>
<td>Self-reliant. Self as survivor? Self as guided by God.</td>
</tr>
<tr>
<td>The problem see’s handicap as problem it’s a special case unique different from others?</td>
<td>The problem is the child is with a handicap, level 1. It’s a special case. She has cerebral palsy, that’s the diagnosis, spastic tetraparesis, with extrapyramidal elements. The causes were before and during the birth, focal epilepsy and left hip dislocation. [Interpreter reading disability certificate: unable to work independently. Profound mental delay. IQ &lt; 15. Microcephaly.]</td>
<td>Awareness of uniqueness of child’s condition.</td>
</tr>
<tr>
<td>The child uses language, no name given, with the help of God I am going forward alone. Movement alone in life but has faith as crutch. Life as journey. Going forward I am fighting repeated use of word battle not expecting easy path.</td>
<td>The child has 14 years old. With the help of God I am going forward alone. I am fighting. This is all I can say. Ok and do you have any other children? I have a girl 22 years old. She’s lives in Italy. She is there with a boy. She said she will marry with him but one never knows. That’s all. Yes. Ok. And does anyone else live with you and your child in the family home? Nobody lives with me. When I am finishing the home in the Autumn I am going to live with myself and my</td>
<td>Self guided by God. Value’s marriage.</td>
</tr>
<tr>
<td>She said she will marry... but one never knows hopes for daughter.</td>
<td></td>
<td>Future orientated and self reliant.</td>
</tr>
</tbody>
</table>
| Nobody lives with me home as symbolising fresh start? | daughter.
Ok, and where are you living at the moment?
Aaa A village in Giurgiu County
Ok, with your child?
Yes, it’s a girl.
Ok, so you are living in the countryside?
Yes
Great thanks for that background information. It’s very useful. Ok, I’d like to ask you about your experience.
Ask me a lot I will answer eager to engage, open

| metaphor the sky fell on my head end of the world, her old world couldn’t understand that, she was a sparkling kid disbelief, child was ‘sparkling’ couldn’t foresee problem contrast problem and sparking shock disbelief questioning life? I want to every doctor denial, searching for meaning, return to life before diagnosis I said it’s not true doubting diagnosis as normal reaction – getting 2nd opinion walk at 5 year, 2 years she is gonna speak, told me just to encourage me false medical predictions, motive to maintain hope, angered her led to distrust, not good approach sobbing crying emotional impact of diagnosis metaphor Miriam I am first in 2011 I took courage, emotion focused coping and is said God we go forward with you religion as coping, supportive factor, and in the end, those days of adjustment are over god gave me strength, made me stronger. I thank him. I’m on my way, I am always discouraged. In the end I said it is my child, I have to fight. I didn’t have a good relationship with my husband. He came home and he was shouting, the child listened. He understood that it was something in the family. So I said to myself I had to do different things on different days. So it lasted for 8 years: terror and pain. I said stop. I am going one way you are going on |

| metaphor the sky fell on my head end of the world, her old world couldn’t understand that, she was a sparkling kid disbelief, child was ‘sparkling’ couldn’t foresee problem contrast problem and sparking shock disbelief questioning life? I want to every doctor denial, searching for meaning, return to life before diagnosis I said it’s not true doubting diagnosis as normal reaction – getting 2nd opinion walk at 5 year, 2 years she is gonna speak, told me just to encourage me false medical predictions, motive to maintain hope, angered her led to distrust, not good approach sobbing crying emotional impact of diagnosis metaphor Miriam I am first in 2011 I took courage, emotion focused coping and is said God we go forward with you religion as coping, supportive factor, and in the end, those days of adjustment are over god gave me strength, made me stronger. I thank him. I’m on my way, I am always discouraged. In the end I said it is my child, I have to fight. I didn’t have a good relationship with my husband. He came home and he was shouting, the child listened. He understood that it was something in the family. So I said to myself I had to do different things on different days. So it lasted for 8 years: terror and pain. I said stop. I am going one way you are going on |

|欲求 to be heard |
|Shock and disbelief |
|Searching for cure |
|Functional defense: Denial |
|Learning to ignore misguided advice |
|Self guided by God |
|Positive reframing: religion |
|Lack understanding from husband |
|Value empathy |
### Appendix N

<table>
<thead>
<tr>
<th>Social support: in laws</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self as fighter</td>
</tr>
<tr>
<td>Positive reframing: religion</td>
</tr>
<tr>
<td>acceptance</td>
</tr>
<tr>
<td>Pride in overcoming negative relationships' self as survivor</td>
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<tr>
<td>Desire to display accomplishments</td>
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<tr>
<td>Desire to be heard</td>
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**Blame her? It lasted 8 years. Terror and pain entrap cycle of terror. I said stop. Stand up for yourself. Challenge the husband. I am going one way again. Movement his relative took care of me. In their home. They understand familial support from husband and not alone. They didn't chase me out unusual to announce own.**

*It doesn't matter that you are a stranger. They rejected him and they chose me. Feel special, saved? They communicate with me all the time despite passage of time, still good relationship.*

*I am fighting life as battle, still fighting need defend myself. Not giving up always alert and ready thanking to God source of guidance and encouragement. I am not afraid even if she is like this soul aching total acceptance, unequalled love.*

*Encourage each other mutual encouragement power. And trust descriptive wouldn't associate power with encouragement. Psychic higher up movement religious comutations higher as near to God? Go forward movement constant reference to movement to move linked with progression, success, fighter was always personality characteristic? Adapt at overcoming adversity? Put everything behind me and I kept going forward separate challenges, conquer, overcome, don't ruminate, moving on hell she was in hell? Don't have any problems new care free life way. Fought very good happy with decision no regrets. Didn't marry 2nd relationship wiser. More cautious. I stayed 8 years. I left in control. Pished I am up all the levels/ comparison contrasts he is degraded. I am evolving comparison with him, pitiful, evolving, changing, adapting, growing superior? Making my home showing not a no one house as sign status material wealth independence — not dependent on any man get something he remains comparison left behind. Sense achievement metaphor took courage took a chance.*

*Open, keen to talk*  
*Ambiguous*  
*Explain to me, wanted explain in our terms medical jargon own terms not understood by the other, as in her. Didn't the other way. His relatives took care of me. They took me in their home. They understood the situation. They didn't want to chase me out. They said you are coming, stay with me. It doesn't matter that you are a stranger and that he is our own blood. They rejected him. And they chose me. And they communicate with me all the time. It is like I'm their relative. And now I am fighting. I am thanking to God give me strength and faith. And I am a fighter. And I am going forward with them. I am not afraid. Even if she is like this, she is dear to me and my soul is aching. We have to encourage each other, power and trust. The psychic has to be higher up. We go forward. Yes. This is me. I am a fighter. I was always...even when I had the fights with my husband, I put everything behind me and I kept going forward. I said go to hell and I went on my way. I didn't have any problems. So this is the way I fought. It was very good. Yup. I didn't marry with him [?]. I stayed with him for 8 years and I finished it. I am going this way, and you are going that way. He is pitted. And I am up with all the levels. He is degraded because he is drinking. I am evolving. I am making my home, I am showing that I am not a no one. I will get something but he remains in his world. I took my heart in my teeth [Interpreter: we have this saying it makes you take your courage.] Thank you. You are welcome. Can I bring you back to that initial experience... Put to me any questions and I will answer. I would like to...to that initial experience of hearing your child had a disability. What was your experience of the doctors?**

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<table>
<thead>
<tr>
<th>Approach it in a client-centred way. I told them using terms I understand assertive, challenge professionals.</th>
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<tbody>
<tr>
<td>Medical explanation: I gave her treatment didn’t have expected result, treatment ineffective, what was result? Operated on, on the head, outdated procedure? Medical model no to sign the paper, alive or not scary for mother; reject cause of risk of death, simplicity of life, sign paper, bureaucracy. I asked the doctor...other doctors...friends seek information, make informed decision, not treatable, why then offer operation? Could have died. Level repetition of life down to chance, uncertainty, unpredictable, 90% died, strong possibility death, what were benefits? Life quantifiable. Medical experiment, child as experiment for doctor, not sure of how treat? Perception doctors to undervalue good gave her, like this, heal her left her justification, religion as support, meaning making for situation happy remain in God’s state.</td>
</tr>
<tr>
<td>She was a doll, small comparison to doll image of beauty always loving her unflattering love I left couldn’t stand to stay life intolerable with ex-husband fought very much constant battle I cried disappointed grief for loss of relationship often crises, take her away, what am going to do life hard crises, despair at thoughts of losing her. Starting to be faithful, search for meaning, support then. She healed my daughter as miracle worker, transformation in child, situational coping the priest walks over the child. I didn’t give any treatment unusual religious custom no medicine, miracle cure? went with God forward, strength, reassurance. Takes change was my pleasant memory because like doll I was playing with her happy retrospective memory of those times. Child as perfect, fun, happy times all time. Smiling reinforcing child characteristics fighter like her mother, personal compassion, calling God when seizure happened, paying attention, comfort responsive rel. see results.</td>
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<tr>
<td>My memory is with her. They explained to me, they wanted to explain to me using their own terms but I told them- please explain to me using terms that I could understand. They told me this, the skull is smaller by 15cm smaller and the brain doesn’t have room to develop. I gave her treatment but she didn’t have the expected result. And they told me that she should be operated on, on the head; when she had 2 years old. I said no to sign the paper if she is alive or not after the operation. I asked the doctor, my GP, other doctors I saw, friends from rehab- it is not treatable. She could have died or she could have lived. So 90% chance was that she would have died. So, instead of allowing him to make a medical experiment on her, God gave to me like this, God will heal her. So I left her like that.</td>
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**Ok**
At 5 years she was a doll. Small, I am always loving her. I left at 8 years I couldn’t stand to stay there. I fought. Very much. I cried. I was disappointed. Days when there were often crises. I was thinking- if you are going to take her away, what am I going to do. I started to be faithful, we are orthodox, we believe in God, in Jesus Christ. That he healed my daughter crises, She doesn’t have any longer seizures. I put her to. in the church, the priest walks over the child, so from 9 years to now she didn’t have any seizure. I didn’t give any treatment to her. And I went with God forward. Yes. She was my pleasant memory. Because she was like a doll. I was playing with her, she was asking, calling me ‘hey’. All the time she was smiling. A fighter. I was calling god when she was having the seizures and he was paying attention to me. Yes. |
| Challenging doctor as expert |
| Assert control over treatment options |
| Seeking information |
| Challenge doctor as expert |
| Child characteristics facilitate coping |
| Positive adaption |
| Atypical cultural practices |
| Child characteristics facilitate coping |
| positive reframing; religion |

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Appendix O: Figure taken from mind mapping tool “The Brain” which was used to organise themes

- CHALLENGES TO COPING
  - Anger at lack of recognition
  - Appeal for understanding
  - Belief that father deserves a different life
  - Challenging attitudes/stigma
  - Isolation magnified by lack of services
  - Loss and loneliness

- FACILITATING COPING
  - Acceptance
  - Activism
  - Attitudes change
  - Balance maintained by child
  - Belief in others' best efforts
  - Empowered by Higher Being
  - Group identity
  - Idealised solutions
  - Information
  - Interdependency
  - Life as mission
  - Love
  - Mother child rituals
  - Positive reframing of situation
  - Role as a mother
  - Schedule
  - Self as stronger than others
  - Social support
  - Value understanding

- FACTORS AFFECTING CARE RELATED DECISION MAKING
  - High Understanding
  - Information

- SITUATIONAL CHALLENGE TO COPING: COMMISSION
  - Inconsistency
  - Inflexibility
  - Lack of attention disempowering
  - Lack of professionalism
  - Lack of service causes stress
  - Support as bureaucratic
  - Systemic issues

- SITUATIONAL CHALLENGE TO COPING: DISCLOSURE
  - Life as mission
  - Overcoming adversity
  - Self as influential in influencing others
  - Shared experience as unifying
  - Special Doctor