Exploring parents’ and teams’ perspectives of the models in Early Childhood Intervention Services: A grounded theory approach

Thesis submitted for the Degree of Masters of Arts

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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: _____________________

Noelle Fitzgerald
All names cited in the Results Chapter are pseudonyms, in order to protect those who participated in this study.
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Abstract

The aim of this study was to explore parents’ and team-members’ experiences of the multidisciplinary approach (MDA) and transdisciplinary approach (TDA) operating in Early Intervention services for children with disabilities from birth to six years of age. A review of the literature was conducted and issues were identified for exploration. Data were collected by semi-structured interviews and focus-group discussions with parents and team members, to investigate experiences of the approaches in the delivery of services for children. The study sample included parents ($N = 19$) and two Early Intervention teams ($N = 10$). Data were analysed using a qualitative grounded theory research methodology. The empirical qualitative data informed the development of the tentative models based on a grounded theory approach. The theory developed and consisted of a set of plausible relationships proposed among themes and sub-themes. The results revealed that both models contained client-centred values for parents, such as enabling a child/family-centred model and facilitating parent empowerment. The study concluded that parents valued mostly team guidance and the teams’ ability to promote optimal development for children. The delivery of a key working system was also seen as worthwhile. The Early Intervention teams favoured a TDA when it supported and operating effectively. The TDA was found to be holistic, family-centred and to enhance relationship quality with families. The results also highlighted a number of obstacles, such as misuse of time, inefficient delivery of services, lack of support and confusion shifting from one approach to another. In conclusion, it is recommended that for best practices, clear guidelines and agreed standards need to be developed for the approaches applied to Early Intervention Services. In order for any approach to be successful, roles and responsibilities of parents and teams must be defined to ensure best practice. In addition, further time and effort is needed to ensure a smooth transition from one model to another. Future research suggestions included investigating children’s developmental gains participating in either the MDA or TDA and conducting further qualitative research to obtain the views from more Early Intervention Services, Early Intervention service managers and key workers.
Chapter One: Overview of Thesis

1.1 Introduction

Understanding of and provision for children with special needs in Ireland has improved in recent years, underpinned now by policy and a legislative framework. Having reviewed the relevant literature, it is evident that much remains to be achieved to ensure that children with disabilities in Ireland receive appropriate services in order to reach their true potential. There has been little research published exploring parents and/or team experiences of the models operating in Early Childhood Intervention services in Ireland. A few studies have, however, focused on specific characteristics of the models in practice, such as the key working service (Mullins, 2008) or family-centred approach (James & Chard, 2010).

The term Early Childhood Intervention (ECI) is used throughout this document. The term ‘early’ means during the early years which, for the purposes of this research, includes infants and children up to the age of six. This has been done to avoid any misunderstanding with the concept of Early Intervention, which is defined as a programme that attempts to improve child development during the period from birth to six years of age with the expectation that these improvements will have long-term consequences for child development and well-being (Barnett, 1995).

As there is limited research examining the different models in ECI services, this study aims to reflect on both parents’ and teams’ experiences of ECI services. The goal is to highlight the experiences of key stakeholders and identify any issues that may arise in the existing services. In particular, it looks in detail at the older (multidisciplinary) and newer models (transdisciplinary) which are currently in operation. By investigating experiences of the models, this may lead to the development of more efficient and effective strategies to help children with disabilities in Ireland. The holistic development of a child with special needs requires good quality early services and, as the research implies, providing appropriate practices to children and their families as early as possible is essential to give them a good head start in life.

In this study, the definition of children with special needs is consistent with the report of the Special Education Review Committee (SERC) (Ireland, 1993). Reference to children with a range of disabilities was intended to include children with mild, moderate, severe or profound general learning disabilities, children with motor impairment, children with sensory impairment, children with language delays and disorders, children with autistic spectrum
disorder, children with emotional/behavioural difficulties and children with multiple disabilities (Kelleher et al., 2006).

1.2 Background
Research during the 1960s and 1970s showed that the earlier children received Early Intervention, the better their outcomes. Research also showed that families who were supported earlier were more empowered to advocate for their child later on (Guralnick, 1997a). From 1990 to the present, Ireland has seen an unprecedented interest in the development of young children with disabilities. Numerous reports and policy documents have highlighted the need for providing appropriate services to children with disabilities. In recent years, the Education for Persons with Special Educational Needs Act 2004 (EPSEN) and Disability Act 2005 were passed in Ireland; this made provision for young children with special needs a statutory right.

In a broader light, international literature has also emphasised the need to support the development of children with disabilities through effective Early Intervention programmes. The effectiveness of Early Intervention has been supported and research is now concerned with the specific needs of children and their families. In this regard, the literature points to the challenges involved in delivery of intervention practice to meet the diverse and complex needs of children and their families (Wolery & Bailey, 2002; Odom et al., 2004; Guralnick, 2005a).

1.3 Early Childhood Intervention
The aim of Early Childhood Intervention is to support and empower the family to best promote children’s development and to optimise their access to, and use of, services which are involved (Guralnick, 1997a; Wolfendale, 1997; Soriano, 2005). ECI programmes attempt to improve child health and development from birth to six years of age, with the belief that these improvements will have long-term benefits for child development (Wise et al., 2005). After nearly 50 years of research, there is evidence, both quantitative and qualitative, that ECI increases the development of the child, improves the functioning of the family and reaps long-term benefits for society. For example, the child’s increased developmental and educational gains and decreased dependence upon social institutions, the family's increased ability to cope and the child's increased eligibility for employment, all provide economic as well as social benefits (Shonkoff & Meisels, 2000; Guralnick, 2004).
The ‘whole-child’ perspective is at the centre of policy development and service delivery. Early Intervention helps a child in key developmental areas such as physical development, language and speech development, social and emotional development, adaptive development and cognitive development. There is a need for further examination of the structures currently in place and a need for structures to be strengthened and co-ordinated more effectively to empower professionals and parents, at a local level, who are directly involved with the delivery of services to children (Department of Health & Children [DoHC], 2000).

1.3.1 Models in Early Childhood Intervention
The concept of a multidisciplinary and transdisciplinary team model in Early Intervention has long been established. Both models reflect Early Intervention professionals' view of human development which regards a child as an integrated and interactive whole, rather than as a collection of separate parts (Golin & Ducanis, 1981).

On multidisciplinary teams, professionals from several disciplines recognize the importance and relevance of the other team members, but work primarily independently (Woodruff & McGonigel, 1988; Bruder, 1997; Carpenter et al., 1998; Ogletree, 2001). While the family is a member of the team, the role they play in decision-making is secondary to that of the professionals (Younggren, 2003). On transdisciplinary teams, teams are composed of both parents and professionals from several disciplines. They attempt to overcome the confines of individual disciplines in order to form a team that crosses disciplinary boundaries and thereby maximizes communication, interaction and cooperation among team members (Bruder, 1994). Included in this model is the key worker system, whereby a key worker is a named person who is available as a contact/link for a family of a child with a disability to the services (Mullins, 2008). Studies have found that families who have a key worker show positive results in terms of relationships with and access to services and overall quality of life (Glendinning, 1986; Liabo et al., 2001). The role of the key worker referred to, however, is not always the same and literature on the role of the key worker appears to be relatively new and scarce in Ireland (Mullins, 2008).

1.4 Outline of Thesis
Currently, there is confusion as to which model, or what characteristics of a model of ECI, should be implemented in the delivery of services to children with disabilities. In addition, there is a dearth of research investigating whether a key worker system should be developed
on an Early Intervention team. For the purpose of this study, it was recognised that the Multidisciplinary Approach (MDA) and Transdisciplinary Approach (TDA) are in operation in two services in Ireland. This study aims to provide insights in relation to the provision of ECI practices by exploring parents’ and team members’ experiences of the approaches in practice. This present study will place emphasis on best practice models within the field of Early Intervention. It also intends to make recommendations in relation to future research and future practice in the provision of services for children with disabilities in an Irish context.

1.5 Perspectives

Furthering provision of ECI services requires parents and team members to discuss their successes and failures when considering the service’s use with children in ECI services. While early childhood settings are at the heart of the research, the experiences of parents and team members are vital in shaping how future services will be generated and provided for children with disabilities.

Parents have a unique knowledge of their child and families have important information to contribute and a key role to play in determining how effectively the services provided have met their and their children’s needs (Department of Education & Skills [DfES], 2003). Listening to parent’s views is, therefore, a very important aspect in the development of services. Evidence in the literature suggests that parents are experts in disability research (Carpenter, 1997; Law et al., 2003; Davies, 2007). Studies have also shown that parents want to work in conjunction with services to get the best outcomes for their child; hence, a main focus of this study is to explore parents’ lived experiences of the approaches in ECI services to enable decisions to be made about further practices.

In addition, information is needed to support and facilitate professionals on how to enact collaborative processes and work toward shared goals for children with disabilities. ECI professionals work with parents to help their child develop knowledge and skills and reach their potential. Teams are being expanded to include a more comprehensive network of service providers including psychologists, speech therapists, occupational therapists etc. Thus, the present study will supplement the current literature by providing exploratory experiences regarding the models in ECI from team members’ point of view. It will investigate team members’ perceptions of the models in operation. This is a fundamental aspect to ensure the best possible practice for children with disabilities. It is essential that the future of Early Intervention services are founded on core principles and this requires
substantial exploration of the ways in which Early Intervention services are provided in Ireland today.
Chapter Two: Review of Literature

2.1 Chapter Introduction
This chapter gives an overview of the current research in the area of Early Childhood Intervention. In particular the chapter discusses the influence of child development theories, the policies and legislations of ECI and the delivery and provision of ECI services for children with disabilities in an Irish context. The journey to ECI is also reviewed, together with an extensive review of the models currently in practice in Early Intervention services.

2.2 Early Childhood Intervention
“For most parents the birth of their child is a joyous time, however, nearly 4% of parents receive distressing news about their child’s health”

(Barnett et al., 2003, p. 184)

In 2004, Ireland’s population exceeded four million and approximately 10% of this population was composed of children from birth to six years of age (Central Statistics Office [CSO], 2005). In 2002, for the first time, the number of people with disabilities in Ireland was measured. The report confirmed that 2,029 children aged 0 to 4 years have a disability and another 7,017 children aged 5 to 9 years have a disability (CSO, 2002).

The field of ECI for children with disabilities is emerging and growing worldwide. The main goals of ECI are to encourage families in supporting their child’s development, to promote children’s development in key areas (e.g. cognitive, social, physical, emotional), to promote social inclusion and to prevent the emergence of future problems (Wolfendale, 2000; Rush & Sheldon, 2001; Pretis, 2005). Park and Peterson (2003) found that positive and rich experiences during early childhood can have positive effects on brain development can help children to acquire language, develop problem-solving skills, form healthy relationships and acquire different abilities. In addition, research and practice have proven that ECI can produce both short and long-term benefits for children with disabilities, their families and society (Carpenter, 2001b).

ECI services serve a very wide variety of children. The age at which children begin ECI is a concern because research has demonstrated the importance of providing these services in early years of life, from birth onwards. Under the Individuals with Disabilities Education Act ([IDEA], 1997), a child is to receive ECI services because he or she “is experiencing developmental delays in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and
adaptive development; or has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay”.

The main historical theories dealing with child development have had an influence on the development of ECI (European Agency for Development in Special Needs Education [EADSNE], 2005). Some of these include the developmental approach of Gesell (1943), the operant conditioning of Skinner (1968) and the genetic epistemology of Piaget (1969). Further developments emphasised other theories, including attachment theory (Ainsworth et al., 1978), social learning theory (Bandura, 1977), social development theory (Vygotsky, 1978), the transactional model of communication (Sameroff & Chandler, 1975; Sameroff & Fiese, 2000) and human ecology (Bronfenbrenner, 1979). The most recent perspective focuses on the ecologic systemic approach whereby children’s development is viewed as holistic; this means that all areas of development are inter-related and dynamic; which implies that the environment needs to alter in response to an individual’s changing needs (Horowitz, cited in Porter, 2002, p. 9) and transactional; where development is facilitated by a reciprocal interaction between the child and his or her environment (Sameroff & Chandler, 1975).

ECI for both children and families has changed significantly over the past two decades. Programmes traditionally focused on the development of skills for the child in isolation and the emphasis was on assessing and responding to individual characteristics and learning styles of each child. The current trend, however, has been to focus increasingly on a child’s family context as the basis of their learning.

2.2.1 Early Childhood Intervention in Ireland

In Ireland there have been a number of changes in health, education, social and disability policy and legislation, which have affected the delivery and provision of ECI services for children with disabilities and their families. Despite these changes, there is still no cohesive policy or programme to co-ordinate the delivery of ECI services to this population nationally, which suggests that the quality, accessibility and comprehensiveness of the service received may vary (Foran & Sweeney, 2010). Walsh (2009) reported that 1,100 children were receiving early services with an upward trend in referrals in Ireland. Understanding the nature of Early Intervention, therefore, is significant at many levels, including the development of policies to improve services and ultimately the results of those services. There is little consistent evidence, however, regarding the effectiveness of ECI programmes and
determining which policies the government should pursue to improve the quality of programmes is often debated.

Irish research reports (e.g. National Economic and Social Forum [NESF], 2005; Kelleher et al., 2006) have continually emphasised the need for policies on Early Intervention and responses to the needs of children with disabilities (Kelly et al., 2007). These policies aim to support and empower the child, the family and the services involved. For example, the Development of Services for Persons with Disabilities, developed by the National Disability Strategy (2004), provided a framework of supports for people with disabilities. The Strategy builds on a strong equality framework, which is reflected in several pieces of equality legislation (Health Service Executive [HSE], 2007). The HSE aims to provide dynamic, progressive and high quality services for children and families. The HSE is required to develop a team-based framework of service delivery that is multidisciplinary or transdisciplinary in delivery and that promotes ongoing individual and team development, accessibility, flexibility and responsiveness to identified needs. The HSE is also required to develop services to meet its statutory duties under the Disability Act 2005 and, in particular, to provide assessment and treatment services initially for children from birth to five years of age with disability needs. In the current study, the models of ECI, funded by the HSE, are being explored to identify suitability for the child and family.

The introduction of the EPSEN Act 2004 and Disability Act 2005 are important milestones in the history of education and support service provision to people with disability in Ireland. Since June 2007, parents of a child with a disability under five years old are entitled to apply for an assessment of need. This is critical to each child and family in terms of identifying and accessing future service requirements. Many children using ECI services are eligible to apply for this assessment (Foran & Sweeney, 2010). The Disability Act 2005 deals with assessment of need and service statements. If an assessment confirms a disability the assessment report will include a statement of the nature and extent of the disability, the education and health needs which arise as a result of it and the services considered appropriate to meet the person’s needs. While these pieces of legislation, taken together, provide, for the first time, a statutory right to assessment of need and other important rights, they do not set out a vision for the future configuration of educational and other supports for people with disability in Ireland. This current research aims to fill this gap by setting out recommendations for future supports in ECI settings.
Key characteristics of the ECI services in Ireland have been identified. Galvin (2006) reported the following characteristics as favourable: a theoretical best-practice whereby the service is based on sound principles of current theory and best practice in ECI, a family-centred practice where a service is responsive to the needs of the family, a team working in a transdisciplinary way that reflects the integration of assessment, planning, progress evaluation and communication within a team, a transdisciplinary play-based assessment where play best supports the development of the whole child socially, emotionally, physically and intellectually (e.g., Linder, 2008) and the assignment of a key worker to each family to ensure there is a good match between the actual needs of the family and service provision (Cederman, 2006). Staff competence and ability are required as well as having qualifications and skills relevant to ECI. This study explores the characteristics developed in ECI service models, to determine best practice methods for future services.

Until recently, there had been relatively little research carried out on children with disabilities in Ireland. As part of the Department of Health and Children’s (2000) National Children’s Strategy, ‘Towards 2016’ was put in place to facilitate and enhance children’s well-being in Ireland. It aims to examine effects of the economic and social change and changing family structures on children in Ireland and established a multi-agency Children’s Services Committee in each county. These Committees plan to work, in partnership, to develop a strategic approach to services for children in their county. The aim is to find information on the children in each county, what each county is spending on children’s services and what outcomes are being achieved for the investment. The focus will be on achieving better outcomes for children as there is a need to better understand the practices of children in Ireland (Langford, 2007).

Foran and Sweeney (2010) confirmed that a major shortage of multidisciplinary expertise outside of ECI services in Ireland led to caregivers’ frustration and disappointment with mainstream health and educational services. This study was similar to other findings (DfES, 1999; Peterander, 2000; Kelleher et al., 2006). Kelleher et al. (2006) established that this could be due to the more family-focused work with child and relatives among specialist ECI services. Foran and Sweeney (2010) found that participants were acutely aware of the differing attitudes of mainstream healthcare professionals and professionals in the specialist ECI service. This study was, however, conducted in one specialist ECI service for children with intellectual disabilities in Ireland and therefore it cannot be assumed that the findings equate with the experiences of caregivers accessing ECI in other contexts. Where there is an overwhelming trust in the professionals in the ECI service, a similar level of trust does not
extend to generic service professionals. This reflects the findings of Cho and Gannotti’s (2005) study in which experiences with mainstream professionals at the point of diagnosis were reported negatively.

The opportunity exists within the legislation to address the needs of children from birth to six years of age. The National Federation of Voluntary Bodies identified that the National Council has a crucial role in the implementation of the EPSEN Act 2004 to significantly address the needs of this very important group. Well supported investments from the start can prevent a number of other complications that will have significant implications for children and families resulting in additional costs in years to come. This will involve the National Council identifying who is to fund such provision (e.g. the Department of Health & Children or the Department of Education & Science) and to provide a mechanism to make this a reality.

International studies suggest that between 2% and 6% of the population will present for ECI services. The European and international documents published in the last 30 years, dealing with concepts, principles and methods of ECI, show the evolution of ideas and theories. Different theoretical perspectives have contributed to the evolution of concepts and, consequently, practice. These have highlighted the progression of change from intervention mainly focused on the child to an increasingly broad approach where the focus is no longer solely placed on the child but also on the family and the community (Peterander et al., 1999; Blackman, 2003). Research is of critical importance to ensure that the development of the ECI emphasises the most efficient and effective services for our youngest children in ECI settings.

2.2.2 Coming to Terms with Child’s Disability

The journey to Early Intervention can begin in different ways for families. Studies found that some families learn that their child has a disability at or even before birth, and these families may come directly through a hospital to enter into ECI services (Hebbeler et al., 2007). On the other hand, identifying children with less obvious delays and disabilities can be challenging for both professionals and families because the nature and presence of disability only emerges as the child grows (Bailey et al., 2004). Evidence from the National Early Intervention Longitudinal Study (NEILS) suggested that the process of finding out about and beginning ECI services is a positive one for the majority of families. Previous studies have, indeed, reported that parents waited two to four years for a diagnosis (Howlin & Moore,
According to international literature, the majority of parents do not receive the diagnosis until the child is between 5 and 6 years of age (Howlin & Moore, 1997; Howlin & Asgharian, 1999; Siklos & Kerns, 2005).

The importance of ECI has been highlighted in the literature (Kelleher et al., 2006; Hebbeler et al., 2007). ECI service delivery has consistently demonstrated positive outcomes for families where the service was comprehensive and accessible (South Australian Health Commission, 1993; 1996). For instance, an earlier intervention would provide help to families in the first few months of the child's life when parents have to adapt to their parental situation, grieve their dream of a perfectly healthy child and learn to take care of their child (Pelchat, 1994; Bouchard & Pelchat, 1997). Adaptation refers to a process of grieving that helps a family achieve a comfortable balance and to promote the growth and development of individual members and the system as a whole in adjusting to a member having a disability (Walls & O’ Connor, 2004). The impact on the family of the birth of a child with a disability has been investigated in many studies over the last decades (Lazarus & Folkman, 1984; Trute & Hiebert-Murphy, 2002; Reichman et al., 2008). It is recognised that some families adapt well to such a situation (Bennett et al., 1996). On the other hand, some families have difficulty adapting to the birth of a child with a disability and are more likely to have negative experiences. When a child has a disability, parents experience the typical stressors associated with parenthood plus additional stressors unique to their child’s disability (Ainbinder et al., 1998). This study explores both the diagnosis and referral processes that parents experienced.

The disclosure of a disability is a particularly crucial moment for parents and the way they experience it has important consequences for their adaptation (Pelchat-Borgeat, 1978; Bailey & Simeonsson, 1988; Sauter, 1989). Brinker et al. (1994), as cited in Walls and O’ Connor (2004), argued that the goals of Early Intervention are to facilitate the development of the infant with disabilities and to assist the parents in their adaptation to their child. There is a great deal of research literature exploring how families adapt to having a child with a disability (Pain, 1999; Taanila et al., 2002; Olsen et al., 2003; Graungaard & Skov, 2006; Greer et al., 2006; Langford et al., 2007). In conclusion, this research has reported the influences on parents’ coping ability, such as the way in which the initial information is given and how things are dealt with immediately afterwards, diagnostic certainty, communication of information, social support, parents’ ability to focus on positive aspects of the child and the quality of services provided.

Several international studies explored parents’ experiences of and satisfaction with the diagnostic process (Howlin & Moore, 1997; Howlin & Asgharian, 1999; Siklos & Kerns,
Parents’ experiences of and reactions to the disclosure of the disability can vary considerably. A positive experience within the diagnostic process has a significant impact on a parent’s initial reaction to the diagnosis of a developmental disability (Cottrell & Summers, 1990; Leff & Walizer, 1992). Brogan and Knussen (2003) found that the main factors related to parent satisfaction were the manner of the professional, the quality of the information given and the time allocated to asking questions. This study was, however, based in a Scottish context and specifically referred to the disclosure of an autism spectrum disorder (ASD) rather than other developmental disorders. Baird et al. (2000) found that parental acceptance of the diagnosis was maximised by the content and manner of the professionals involved. They noted, in particular, the warmth, honesty and an openness about what is definitely known as well as areas of uncertainty. Goin-Kochel et al. (2006), however, found that 40% of parents were “not satisfied” with the process of receiving a diagnosis for ASD. A large scale study of 1,200 parental reports by Howlin and Moore (1997) and Howlin and Asgharian (1999), found that 49% of families in the U.K. were either “not very” or “not at all” satisfied with the diagnostic process. Brogan and Knussen (2003) highlighted two main reasons why ensuring parental satisfaction with the diagnostic process can be such a difficult task. Firstly, parents can be faced with a stressful wait of two to four years for a diagnosis and such delays in disclosure have been positively correlated with parent dissatisfaction (Howlin & Moore, 1997; Baird et al., 2000). Secondly, many parents are faced with vague and tentative diagnoses. As there is mixed results in relation to parents’ experiences of the disclosure process, the current study examines this in relation to gaining access to the ECI service.

A few studies have examined the experiences of receiving services for the child or what it is like to receive ECI services. Caregivers report relative ease in accessing ECI services and are positive about their child’s entry into ECI services (Wehman & Gilkerson, 1999; Peterander, 2000; Bailey et al., 2004) but elements of ECI programmes can cause distress and challenges for caregivers (Foran & Sweeney, 2010). Studies have shown that parents of children with disabilities have more health problems such as higher levels of depression, anxiety and emotional distress, lower self-esteem and more stress than parents of typically developing children (Waisbren, 1980; Trout, 1983; Bristol et al., 1988; Goldberg et al., 1990; Beckman, 1991; Miller et al., 1992). The current research study is, therefore, extremely valuable in that it examines both positive and negative characteristics of the Early Intervention service from parents’ points of view, which will aid in providing more accessible and more positive elements of ECI services.
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Previous research has demonstrated the importance of social support for families of children with special needs (Telleen et al., 1989; Hartman et al., 1992; Ainbinder et al., 1998). Specifically, social support can be an effective buffer against the stress and isolation faced by parents. It has been reported that when parents are able to share their experiences with other parents who are in a similar situation it may help in terms of reducing stress (Phillips, 1990; Matloff & Zimmerman, 1996; Santelli et al., 1997) and there is strong theoretical argument supporting this claim (Thoitis, 1986; Taylor et al., 1990). Kerr and McIntosh (2000) explored the impact of parent to parent support and found that parents did not obtain the level of support required from family, friends or health professionals when coping with their child’s disability. Purposive sampling was used in this study and parents of children with unique disabilities were included. These results, hence, may not be entirely generalisable to other parents or services for children with disabilities. Further research found that by moving services to a natural environment but continuing to focus only on working directly with a child, support is not provided for parents to teach them how to enhance their child’s learning (Jung, 2003). Warfield et al. (2000) reported that the provision of ECI must lead to improved family cohesion and extended networks of social support.

Research has found that parents who have participated in the intervention displayed a better adaptation to their child’s disability than parents who did not receive the intervention (Pelchat et al., 1999). Parents involved in the intervention felt less threatened by their situation. Parents were also more confident in the help they could receive from others, experienced less emotional distress, less anxiety and less depression and felt more emotional support from their spouse. There is also evidence, to the contrary, that suggests parents’ involvement in ECI programmes does not consistently produce benefits for children (White et al., 1992). One Irish study reported that a lack of multi-professional support for children and families and short length of day services was a matter of significant concern (Kelleher et al., 2006). It is important to note that 13% of children in the study reported to having an undiagnosed disability and it is therefore difficult to determine the level of multidisciplinary support is needed. Paige-Smith and Rix (2006) found that when parents were responsible for teaching programmes it caused them to feel conflict and tension. Parents’ perceptions of their involvement with the development of their child’s learning through ECI included a sense of anger, frustration, guilt, perseverance, pressure but also achievement. Parents believed that the child’s achievements reflected how much the parent had done for him or her. These findings were based on case studies and therefore causal conclusions cannot be made. In addition, the results were not representative of parents involved in teaching their child.
Research has demonstrated that infants show more progress when families are involved in their Early Intervention programmes (Shonkoff & Hauser-Cram, 1987; Shonkoff et al., 1992). The current study looks at the support families received from the Early Intervention team and identifies barriers preventing parents from participating in the ECI programmes.

2.3 Review of Early Intervention Research
In recent years, the literature has focused increasingly on the importance of Early Intervention to enhance the development of young children. Over 50 years of research support the effectiveness of intervention for young children with disabilities (Kirk, 1958; Bronfenbrenner, 1974; Bailey & Bricker, 1985; Dunst et al., 1989; Gallagher, 2000; Cederman, 2006a; Guralnick, 2008; Trohanis, 2008). The findings demonstrated that early learning and development can be affected by interventions across a number of developmental domains (Guralnick, 2005b; Bruder, 2010), although some studies had methodological limitations, such as heterogeneity of the population, lack of control groups and inappropriateness of standardized measures of intelligence for the population. Despite this, the earlier a child is identified as having a developmental delay or disability, the greater the likelihood the child will benefit from intervention strategies designed to compensate for that child’s needs (e.g. Odom et al., 2003; Guralnick, 2005a).

Historically, Early Intervention has been regarded as a service targeted for individual children but from the 1970s, there has been an increasing emphasis on parents as partners in Early Intervention programmes (Carpenter & Egerton, 2005). The literature suggests that there are a few components which are present in most Early Intervention studies that report the maximum effectiveness. These features include early assessment of children, family involvement and participation in services, appropriate levels of intensity in terms of the timing and structure of the interventions, appropriate programmes and high levels of professional expertise (Guralnick, 1997a; Wolery & Bailey, 2002). Sloper (1999) and Carpenter (1998) also identified common features of successful services, which included a holistic approach to meeting family needs, an emphasis on the importance of collaborative relationships with professionals, a consistent, single point of contact, a flexible, individualised approach, a focus on parent perception of need and the empowerment of parents.

The most successful programmes are reported to be more highly structured (Strain & Odom, 1986; Shonkoff & Hauser-Cram, 1987). That is, maximum benefits are reported in programmes that clearly specify and frequently observe child and family behaviour.
objectives, utilize task analysis procedures and regularly use child assessment and progress data to modify instruction. In addition, the intensity of the services, particularly for children with multiple disabilities, appears to affect outcomes. Intensity can be considered along a range of dimensions including the overall duration of the programme, the size of group, the nature of setting, the length of each intervention session and the comprehensive nature of the programme (Bryant & Maxwell, 1997; Guralnick, 1998; Farran, 2000; Goldenburg, 2001).

Early Intervention for children with disabilities is now recognised as essential for optimum development and a large volume of research relates to intervention and research in the early years (Bailey et al., 2004). Research literature emphasised the importance of Early Intervention for children to maximize their development and to remediate the adverse effects of their disabilities (Mitchell & Brown, 1991; Safford et al., 1994; Guralnick, 1997a; Ramey & Ramey, 1998). The importance of Early Intervention for children in hospital has been documented by the Association for Welfare of Children in Hospital (1993), Bannon (2002) and Children in Hospital Ireland (2000; 2002). Cederman (2006a; 2006b) reported on a targeted intervention for children with special needs in Early Childhood Care and Education (ECCE) settings. Many studies have shown that Early Intervention for developmentally delayed children is effective (Meisels, 1984; Shonkoff & Hauser-Cram, 1987; Dunst et al., 1989; Moeller, 2000).

Society, as a whole, may also benefit from Early Intervention programmes as increasing children's independence sharply reduces the cost of providing services (Lovaas, 1987). Every $1 spent on children in early years saved the state $7 later by reducing the interventions necessary on crime, welfare, mental health and job prospects (Barnett & Hustedt, 2005). In Ireland, the ‘Prevention and Early Intervention Programme for Children’ aims to support and promote better outcomes for children in disadvantaged areas and is being evaluated. This project and findings will have an important input to policy and service development. The research will include learning about how services are best designed, offered, organised and integrated (Department of Health & Children, 2010).

Over the years, the results of intervention programmes have been both encouraging and disappointing (Yoshikawa, 1994; Kagitcibasi, 1996; 1997; Young, 1997; Ramey & Ramey, 1998; Scarr, 1998). Research on the efficacy of early childhood programmes can be divided into short-term and long-term studies, where long-term is defined as having data for more than one or two years beyond the end of the programme (Nores & Barnett, 2009). To date, there has not yet been a consistent enough pattern of long-term success (Crane & Barg, 2003). A comprehensive review of 36 studies by Barnett (1995), for example, revealed short-
term benefits on developed abilities and, later, school competence for both types of programmes. Although the number of well-controlled studies with long-term follow-up is relatively small, findings of positive effects generally hold for both model and large-scale programmes.

A growing body of international research supports earlier intervention to secure better longer term outcomes for children (Lazar & Darlington, 1982; Berrueta-Clement et al., 1984; Schweinhart et al., 1993; Engle et al., 2007; Vargas-Barón, 2009). There are hundreds of studies reporting the short-term effects, yet relatively few of these offer data beyond the end of the programme period. While there are only a handful of long-term studies, these tend to be the strongest methodologically and have provided many of the most interesting results. Nores and Barnett (2009) analysed 56 studies reporting the effects of 30 interventions in 23 countries in Europe, Asia, Africa, Central and South America. They found that children from different contexts and countries receive benefits across all dimensions and that interventions providing direct care or education are more effective. Changes were sustained over the long-term in studies that evaluated effects at older ages. However, there remains confusion regarding what dimensions had an impact and for what reasons. The findings were broadly consistent with the results of similar reviews conducted in the U.S. (Camilli et al., 2010). These studies, however, varied in method, population, type of intervention and type of outcome measured (Nores & Barnett, 2009). Other research from the U.S. also provided evidence that intensive, high-quality ECIs have direct and persistent effects on cognitive and non-cognitive development (Blau & Currie, 2005; Barnett, 2008; Heckman & Masterov, 2007; Temple & Reynolds, 2007; Camilli et al., 2010). Indeed, for many years, the central issue in early childhood was whether positive outcomes are persistent. Now the focus is shifting to research on how lasting positive outcomes are produced and what the best quality approaches to produce such outcomes are (Cederman, 2006a; 2006b).

Researchers in the mid-1980s reported substantial success with some Early Intervention programmes for children with autism (Simeonnson et al., 1987; Dunlap & Fox, 1996; Green, 1996; Rogers, 1996; Dawson & Osterling, 1997; Whiteford et al., 2000). Research also found gains on standardized tests of intelligence (e.g., Anderson et al., 1987; Lovaas, 1987; Harris et al., 1991; McEachin et al., 1993). Such findings offer hope for children with disabilities and their families (Lovaas & Smith, 1988). Other studies indicated that ECI can be very effective for communication disorders or in minimising the side-effects of birth accidents, such as premature birth (McLean & Cripe, 1997; Perry & Pollard, 1998; Champion, 2005). Early Intervention is valuable and, within limits, the more intense the
intervention, the greater the gains; this is despite variability in outcomes within groups of children treated (Symes et al., 2006).

Critics of Early Intervention have argued that little evidence can be found for any long-term impact. For example, the long-term effects of ECI for children with Down syndrome or cerebral palsy have not identified long-term advantages for children participating in Early Intervention programmes (Gibson & Harris, 1988; Palmer et al., 1988). Another highly intensive 3-year intervention as part of the Infant Health and Development Program ([IDHP], 1990), found that cognitive benefits did not last 2 years after the programme ended (Brooks-Gunn, 1994, McCarton et al., 1997). Despite this, a broader perspective reveals that the negative findings are not nearly as consistent or pessimistic (Guralnick, 1998). Modest, long-term benefits for children participating in Early Intervention programmes have been cited (Locurto, 1991).

Guralnick (1997a) critically reviewed studies of Early Intervention effectiveness and concluded that Early Intervention programmes “work”. As previously stated, programmes which involved parents and the child were more effective (Carpenter, 2007). Many ECI programmes have recognized the critical role of parents in promoting their child’s development and some evidence shows that training parents to adopt specific communication strategies can result in language and developmental gains for their child (Sharry et al., 2005). For example, the Hanen Programme was developed as a parent training programme targeted at parents of children with language delays (Manolson, 1992) but which has also been adapted for intervention with children on the autistic spectrum (Sussman, 1999). Studies have shown that completion of the Hanen Programme has resulted in more responsive parenting styles (Tannock & Girolametto, 1992) and improved joint interaction between parent and child (Girolametto et al., 1994, as cited in Sharry et al., 2005).

Although several meta-analyses and reviews of Early Intervention have demonstrated overall positive benefits, many studies pose methodological questions (Blackman, 2002). One interpretation of this is that well-designed studies find larger and more significant effects of intervention than studies with weaker designs. Another interpretation is that the most intensive and expensive interventions were the most likely to have had significant effects. Both explanations suggest that advocates of Early Intervention should welcome rigorous evaluations. In other studies, there is the question of what is meant by ‘effectiveness’. Different research studies have had different interpretations of effectiveness. A pertinent interpretation of an effective intervention is one that acts to enhance performance or outcomes and may have a measurable impact on later life (Oliver & Smith, 2000). One of the
main features of the published literature in this field is the lack of evidence of effectiveness from the perspectives of parents, with exceptions such as Alderson (1996) and Stevenson et al. (1999). For young children with disabilities, the literature points to the challenges involved in delivering an intervention practice which can meet the diverse and complex needs of children and their families (Wolery & Bailey, 2002; Odom et al., 2004; Guralnick, 2005b). There is ample evidence to suggest a growing gap between what is known, what should be done and what is currently being done in early childhood intervention (Dunst & Trivette, 2009; Odom, 2009). There remains much to be learned about which services work best for which kinds of children’s disabilities; the present study addresses this and researches what works best for children and families with differing models.

2.3.1 Family-Centred Approach

Working with families has always been a significant part of Early Intervention. Initially, the idea was to enhance child development and support parental caregiving, reducing the need for institutional care. There is ample evidence to suggest the powerful effects that families have on their children’s development (Shonkoff & Phillips, 2000; Lynch & Hanson, 2004; Dunst et al., 2006; Dunst, 2007). These effects are the direct result of both the characteristics of the family and the interactions, experiences and beliefs of the family (Guralnick, 2005b). As a result, an outcome of ECI should be the facilitation of a family's sense of confidence and competence about their child's current and future learning and development (Bailey et al., 2006).

Since the mid-1960s, parents and professionals have fought persistently for child and family-centred approaches in ECI service provision (Odom et al., 2003; Carpenter & Egerton, 2005). A key principle is that ECI services should be developed in partnership with families and should work with them in a dynamic relationship which is characterised by development of existing family strengths and sensitivity to family needs, including siblings and grandparents (Guralnick, 1997a; 1998; 2001b; 2002; Sameroff & Fiese, 2000; Farran, 2000; Wolery, 2000; Wolery & Bailey, 2002). This approach represents a shift in the manner in which ECI services have been delivered in the past.

Families know their son or daughter better than anyone else and are most vested in the child’s future (Giangreco et al., 1999; Rosenbaum et al., 1998). It is assumed that parents spend the most time with their child and thus represent the greatest potential influence in the child's life (Shonkoff et al., 1992). For many families, a goal of paramount importance is creating a successful daily routine in which they feel competent as caregivers and their
children are competent as learners. Many Early Intervention models rely heavily on parents as the primary providers of teaching and therapeutic experiences (Spiker et al., 1993; McCollum & Hemmeter, 1997).

As research, policy and practice have come together, the focus in ECI has shifted from a child-centred approach to a family-centred approach, and the aim of services has traversed from the child alone to the child within the context of the family. Because of this, Early Intervention providers are reframing their service approach from an individualized child focus to a collaborative family-centred focus. Many researchers believe that family-centred models are more humane and dignifying to the child and their family (Wellings, 2005). Emphasis on family-centeredness permeates all aspects of Early Intervention service delivery. Bolstering this fundamental principle is the recognition that family input, family involvement and family professional partnerships promote premium intervention services. Relatively few studies have examined parents’ satisfaction with their child’s progression levels in Early Intervention services (Forry et al., 2009).

Fleming et al. (2010) conducted interviews with multidisciplinary practitioners (i.e. occupational therapists, speech language therapists) to better understand practitioners’ beliefs about implementing practices promoting family participation in services. Fleming and his colleagues noted that teams valued and strove for active family member participation. These results, however, were only a snapshot of provider practice and may not fully represent providers’ typical practices. Other research has shown that practitioners do not necessarily conduct practices in a manner that reflects family participation (e.g., McWilliam, 2000; Dunst et al., 2001). For example, several researchers have found that some intervention teams neither facilitate caregiver-child teaching interactions nor incorporate interventions within families’ daily activities and routines (e.g., McBride & Peterson, 1997; McWilliam et al., 1998; Wilcox & Lamorey, 2004; Campbell & Sawyer, 2007; Peterson et al., 2007).

In order to provide optimal service, it is important to involve families as partners in the process of service delivery (Cermak & Larkin, 2002). Collaboration, enabling and partnership are core elements of family-centred service (Hostler, 1994; Shelton & Stepanek, 1995; Rosenbaum et al., 1998). A family-centred service recognizes the essential role that parents have in sharing information about their child's strengths and goals, and in making decisions about the treatment, care and services that suit the child's and family's needs. Parents are respected by health professionals as key informants regarding their children since they have the breadth and depth of day-to-day experience. Parents of a child with a disability faces unique challenges and these challenges have been examined in many studies of parents'
adjustment to having a child with a disability and the risk and resilience factors that may influence that adjustment (Beckman, 1991; Cappelli et al., 1994; King et al., 1999; Manuel et al., 2003).

The TDA has been found to be the most effective model in developing a family-centred service. As noted by Kilgo and colleagues (2003), the TDA provides the opportunity for disciplines to work together while the family has one primary contact, which is the professional who coordinates the team. It promotes the involvement of the family as valued team members in the planning for and implementation of intervention services, thereby facilitating a parent provider relationship. The TDA views the child’s development in a holistic manner (McWilliam, 2000; Kilgo et al., 2003), which enables programmes to work with the family in providing the most efficient and effective services. Yet, there is still some debate around family-focused ECI approaches versus child-centred approaches (Odom et al., 2003). For example, evaluation of a family-centred approach is effective only if it is conducted jointly by the family and the professional which would endorse collaborative working (Carpenter & Egerton, 2005). The present study recognises that one of the major benefits of Early Intervention is that services are embedded in the relationship with the family and use family-centred practices; therefore, it was important to include parents’ lived experiences when ensuring a best practice model in ECI services.

2.4 Models in Early Childhood Intervention
In the last 30 years, research has shown the evolution of approaches used in ECI which has led to the development of new models of ECI. A major shift has been identified in the type of intervention delivered. This has mainly been from being child-focused to a broader, ecological approach; involving the child, the family and the environment. This relates to a wider evolution of ideas in the disability field, namely a move from a ‘medical’ to a ‘social’ model. From this shift, McWilliam (2003) developed a model that emphasizes five components, which include understanding the family ecology, functional needs assessment, transdisciplinary service delivery, support-based home visits and collaborative consultation to child care through individualized intervention within routines. The type of teams that typically function within ECI service delivery models for young children with disabilities have been identified as multidisciplinary, interdisciplinary and transdisciplinary. Collaborative teams are a central concept in current practices of Early Intervention service delivery to young children and their families (Talay-Ongan, 2001). The teams have a number of professionals, as well as family members, as their constituents. While there are three team
models, this study refers to and focuses on the traditional model (multidisciplinary) and the newer model (transdisciplinary). These two models are considered the preferred models to Early Intervention (Rosen et al., 1998; Shonkoff & Meisels, 2000).

Research has shown that, on average, families of disabled children have contact with at least 10 different professionals and, over the course of a year, attend at least 20 appointments at hospitals and services (Care Co-ordination Network U.K., 2001). The majority of programmes for treating children with disabilities have adopted some form of the multidisciplinary or transdisciplinary team model (Berman, 2000). Their core rationale is to bring together a range of professions to deliver more effective services than could be achieved without an integrated team. It is not, however, simply a matter of getting different professionals together and assuming that multidisciplinary team working will occur. Teams need to have an appropriate disciplinary composition, shared goals and values, a need to understand and respect the competencies of other team members, a need to learn from other disciplines, to communicate effectively with each other and to respect each other’s different views and perspectives (Mental Health Commission, 2006). Appropriate policies have become more clearly defined in terms of what represents recommended practice and how services should be delivered (Sandall et al., 2000).

Research suggested that within the Early Intervention field, new practitioners are expected to have the skills necessary to work as effective team members (Antonadis & Videlock, 1991; Whitehead et al., 1998). Krueger (1990) argued that teamwork has to be taught and cannot be learned from experience alone. A lack of relevant training experiences reported by team members would indicate that training has been seen as less critical when implementing a team-based approach. Specifically, in the Irish context, there appears to be a lack of concordance between what the HSE expects in terms of performance, as a team, and what is expressed in the job descriptions for the various team roles. In fact, reference in job descriptions to ‘working relationships’ with other team members is rare (deBúrca et al., in press). Since professionals from various fields are involved in the delivery of services, it has become essential for professionals to collaborate their efforts (Ebersöhn, 2007). This process of collaboration has evolved over the years from multidisciplinary teams to transdisciplinary teams, where team members share a common conceptual framework (Ferreira, 2004).

The steps in the Early Intervention process remain fundamentally the same across the models, from multidisciplinary to transdisciplinary, as team members share the tasks of assessment, intervention and service delivery. Each of the team models accomplishes these tasks differently, with varying degrees of collaboration and family-centred practice (Trivette
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*et al.*, 1997; Sameroff & Fiese, 2000; Guralnick, 2001b). The models reflect a consensus about the principles on which interventions should be based and about the components of effective programmes. The agreed principles are that Early Intervention must be evidence-based, must support the child's development in the context of the child's family and community, must integrate the contributions of multiple disciplines and agencies and must constitute a comprehensive programme which is tailored to meet the needs of an individual child and their family (McGough & Ware, 2007). The following provides an overview of the oldest and newest models in practice.

### 2.4.1 Multidisciplinary Approach

A multidisciplinary team is defined as professionals and individuals working independently of each other, and each member of the team performs a separate assessment and writes an individual report, including discipline specific goals (Woodruff & McGonigel, 1988; McGonigel *et al.*, 1994; Orelove & Sobsey, 1996; Bruder, 1997; Gargiulo & Kilgo, 2000; Rush & Sheldon, 2001). Multidisciplinary teams share and co-ordinate information and tasks are accomplished individually, according to the skills of the team members. Decisions are taken by the whole team by taking into account individual opinions. In the MDA, the roles of each team member are clearly defined and professionals from different disciplines work with the same children, however, they function quite separately (Woodruff & McGonigel, 1988). Peterson (1987) described the interaction among members of multidisciplinary teams as "side by side, but separate" (p. 484). Multidisciplinary teams evaluate and assess the child, which enables the development of a report on the abilities and strengths of the child, and provides information to develop interventions (Dyer, 2003). Treatment is then performed in an isolated setting for remediation of the weaknesses noted during the assessment (Rush & Sheldon, 2001). One of the qualities of effective teams, according to Briggs (1997) and Jones (2002), is empowerment, as in the transforming phase of teamwork; all members should be informed and empowered equally.

The impact of multidisciplinary collaboration with families is largely seen as positive. Cederman (2006a) found that parents had positive experiences of being involved with the ECI team. These findings may not be generalisable as the results emerged from qualitative research exploring parents’ experiences of one specific ECI service. A large European study surveyed parents regarding co-operation and what they expected to achieve from parent-professional partnerships (Peterander, 2000). The results showed that a high percentage of
parents were satisfied with the ECI programme for their child, the work carried out by the ECI service and the professional knowledge of the therapists. This was echoed in Cho and Gannotti’s (2005) study where the experiences of mothers with professionals diagnosing their children were positive. Another example of an effective multidisciplinary team includes the community children's nursing team (Danvers et al., 2003).

Team members of multidisciplinary teams generate and apply separate interventions specific to their area of expertise (Reilly, 2001; Thylefors et al., 2005; Batorowicz & Shepherd, 2008). From an individual team member’s perspective, this model may be comfortable, as it grants autonomy for team members to implement their individual ideas without need for coordination and compromise with other team members (Ogletree et al., 2001). It may also appear efficient, as time is not needed for consultation, allowing individuals to deliver services expeditiously (Ogletree et al., 2001). When team members work in isolation, however, they are likely to conduct assessments and collect information that fails to address the holistic nature of an individual (Anderson et al., 2000). There may be disagreement between team members about which interventions are most appropriate or how these should be implemented. As evaluations are conducted separately, there is little or no way for professionals to come to consensus or to provide each other with feedback on the results of their evaluations. In addition, children are described by developmental domain rather than holistically, creating a division among team members and fragmented service delivery. Parents often received separate and fragmented reports, which at times were not in agreement with each other. This model resulted in overlaps and gaps in services as it failed to see the child as a whole (Woodruff & McGonigel, 1988; McGonigel et al., 1994; Rush & Shelden, 2001).

Bringing people together usually entails bringing differences together. Sheehan (1996) described the differences as often being a “clash of cultures” (p. 76) characterized by differences in values, language, problem-solving strategies and other elements of professional behaviour. Different disciplines contribute separate and often competing philosophies, diagnoses of need and models of the way the world works (Knapp et al., 1994). However, each discipline alone is not capable of addressing challenges related to the whole individual, complex families and communities. Thus, cooperation and coordination are required between professionals and services (Poulin et al., 1994). Negative experiences of multidisciplinary teams have included professionals being disrespectful about children, being insensitive about their feelings, treating them in a business-like manner and not taking enough time during a session.
Another concern about the multidisciplinary model is the lack of communication between team members that places the burden of coordination and case management on the family. Effective communication and sharing of information are essential to successful multidisciplinary team working and are the basis for many recommendations and policies promoting collaborative working (DfES, 2003). Teams can learn from each other about ways of improving communication although evidence suggests that there remains a need to improve communication, between community, professionals and the family (Cameron et al., 2000; Teare et al., 2001; Watson et al., 2002; 2007).

Some participants reported that conflict relating to professional judgement or clinical decision-making within multidisciplinary teams led to moral distress. The findings indicated that, while multidisciplinary teams appear to function well on the surface, situations that give rise to moral distress are not always acknowledged or dealt with effectively. Furthermore, in the absence of open and transparent discussions that allow professionals the opportunity to address their concerns adequately, unresolved moral conflict can impact on the quality of clinical decision-making (Deady & McCarthy, 2010). While the current Irish policy document ‘A Vision for Change’ (2006) cites multidisciplinary teamwork as key to the functioning of the service, Deady and McCarthy’s (2010) study indicated that there are difficulties with current multidisciplinary practices when morally challenging situations arise. Currently, within the Irish mental health services there is an absence of formal guidelines to direct the practices of multidisciplinary teams. Consequently, decision-making frameworks have developed in an ad hoc manner; some teams foster mutual respect and encourage the sharing of moral concerns while others undermine and inhibit participation. Consequently, individuals find they require moral courage in order to act on their convictions (Deady & McCarthy, 2010).

While the multidisciplinary team model may be easier for individuals on the team, it does not respect the relationship-based nature of Early Intervention. In addition, it leaves the family as an outside member of the team and does not encourage coordination and integration across disciplines (Bruder, 1997). Consequently, the multidisciplinary model is professionally driven rather than family-centred. If it is effectively implemented, on the other hand, team working improves service provision and leads to better standards of care, lower levels of stress for parents, job satisfaction for staff, better communication, pooling of skills and resources and mutual support for agencies as well as for the child and family (Borrill, 1999; Cameron et al., 2000; Watson et al., 2002; 2007).
The most common form of teaming in the Irish disability sector remains multidisciplinary teams but there is some movement towards interdisciplinary working (Walsh, 2009). Yet, research has shown that the interaction among team members in the multidisciplinary approach does not foster services that reflect the view of the child as an integrated and interactive whole (Linder, 1983). This can lead to fragmented services for children and confusing or conflicting reports for parents. In addition, children with severe disabilities have considerable difficulty employing skills that they have acquired in an isolated setting to more typical activities and environments. Based on this fact alone, isolated instruction to remediate specific skill deficits has little if any practical value for the child (Downing & Bailey, 1990). One model which avoids the pitfalls of multidisciplinary service is the transdisciplinary model. The transdisciplinary model takes this one step further to include members collaborating and working together during intervention (McWilliam, 2000).

One study, similar to the present research study, compared the multidisciplinary and transdisciplinary team models for treating children with disabilities. Berman et al. (2000) found that there was more team member participation during the transdisciplinary meetings than during the multidisciplinary meetings. Staff members provided more information about the child and, moreover, there was more participation in group processes and more goals were proposed. Team members believed the TDA was better to assist them in addressing the needs of children with developmental delays, in understanding and integrating information and in developing interventions. One explanation for this finding is that the TDA emphasizes the use of a common language which is critical to the optimal functioning of assessment teams (Fisher et al., as cited in Berman et al., 2000). This study did not include parents when referring to members of the transdisciplinary team. Research has suggested that parents are an integral part of the process and to further maximize treatment interventions parents must be included as part of the transdisciplinary team. Research has also shown that greater participation is associated with increased team cohesiveness and effectiveness (Yank et al., 1992). One limitation of Berman’s study was the unavailability of parents as members of the transdisciplinary team. Research has suggested that parents are an integral part of a child’s life and, therefore, the current study recognises this limitation and has included experiences of both parents and team members.

2.4.2 Transdisciplinary Approach
The TDA was first identified in the mid 1970s and was originally designed for assessment of infants at high risk of disabilities (Hutchison, 1978). The newer transdisciplinary model
Chapter Two: Literature Review

moves away from existing multidisciplinary framework and focuses on play-based assessments and an emphasis on group-based interventions rather than interventions being solely undertaken on a one-to-one basis (Downing & Bailey, 1990). This is seen as an improvement from the MDA, as it represents the highest degree of collaboration, family-centeredness and holistic service delivery. Research has recommended a TDA to service delivery for all ECI services, without a sufficient body of empirical evidence (Linder, 2001). Similarly, widespread use of the model has occurred without a strong body of practical evidence to document its validity (Myers et al., 1996). Therefore, the current study aims to explore the TDA in further detail and identify positive and negative characteristics to substantiate further use of the approach.

The main goals of this approach are to promote integrated assessment and to develop an integrated intervention plan that is carried out by all team members (Berman et al., 2000). The purpose of the TDA is to minimize the number of people that the family must be in contact with on a regular basis while continuing to meet all the needs of the child (Rush & Shelden, 2001). Tuchman (1996) identified this model as providing the best service to families as they integrate the principles of co-ordination and family-centred services to a greater extent. Transdisciplinary teams are composed of parents and professionals from several disciplines (King et al., 2009). The following professionals are usually represented: Early Intervention specialist, psychologist, occupational therapists, speech therapists, psychologists and social workers (Orelove & Sobsey, 1996). Shonkoff and Meisels (1990), Sloper (1999) and Carpenter (1997a) identify the features of successful services which include a holistic approach to assessing and meeting family needs, an emphasis on the importance of collaborative relationships with professionals, a consistent, single point of contact, a flexible, individualised needs-led approach, a focus on parent perception of need and the empowerment of parents.

There are many definitions for transdisciplinary working which all differ slightly in their focus and specific features (Bell, 2010). The guiding philosophy underpinning the TDA is that team members make a commitment to teach, learn and work together to implement coordinated services (United Cerebral Palsy National Collaborative Infant Project, 1976; Fewell, 1983; Peterson, 1987; Woodruff & McGonigel, 1988). Transdisciplinary team working has been described as a “deliberate pooling and exchange of information, knowledge and skills and the crossing and re-crossing of traditional disciplinary boundaries by various team members” (Foley, 1990, p. 274). The theory underlying a transdisciplinary service is that areas of development, such as cognitive, social-emotional, communication and language
and sensori-motor development, are interrelated (Linder, 2008; in press). For example, a child’s speech crosses all four domains. Speech falls into the communication and language domain, who one talks to and how one talks falls into the social-emotional domain, what one says falls into the cognitive domain and how one pronounces words may be influenced by motor skills and thus the sensori-motor domain (Losardo & Notari-Syverson, as cited in Linder, in press). Thus, as the assessment and intervention procedure is holistic in that it addresses all areas of development and takes into account their inter-relationships, the TDA should be more effective than treating each domain independently of the others (Linder, 1990; 1993; in press).

Most programmes serving children with multiple disabilities use multidisciplinary or interdisciplinary service models. The transdisciplinary model, however, is more applicable because of its emphasis on the sharing of skills and information across disciplines and on collaboration among service providers in general (Woodruff & McGonigel, 1988; Mayhew et al., 1999; Gargiulo & Kilgo, 2000; Ewing & Jones, 2003). Over the years, a robust body of research has been published on the theoretical basis and rationale for the TDA (McCormick & Goldman, 1979; Woodruff, 1980; Albano et al., 1981, Baine & Sobsey, 1983; Giangreco, 1986; Woodruff & McGonigel, 1988; Orelove & Sobsey, 1996). To date, there has been little research examining the delivery of the TDA within an ECI context; thus, this study includes both parents’ and team members’ lived experiences in order for services to be planned in the most effective manner for children with complex and multiple disabilities.

Transdisciplinary team assessment meets standards of best practice in ECI and aims to provide more family-centred and integrated services to meet the complex needs of children with disabilities (Hanson & Bruder, 2001; Carpenter, 2005; King et al., 2009). Unlike traditional standardised methods, flexibility is allowed in the assessment process and, therefore, children with disabilities may be more fairly evaluated to determine strengths and areas of need (Kelly-Vance et al., 1999; Ebersöhn, 2007). The assessment process is also sensitive to the child and family, as well as being dynamic, functional, flexible and collaborative (Stepans et al., 2002). On transdisciplinary teams, assessments are performed in collaboration of all team members (Beukelman & Mirenda, 2005). During the assessment process, parents contribute to the information gathered and the questions asked encourage the observation of qualitative aspects of how the child performs certain tasks. Planning with families helps ensure questions are answered, family members understand their role and decisions are made about the assessment process (Child Development Resources, 1995). This allows families to decide how they would like to prepare, select assessment procedures,
provide familiar toys or activities, observe their child in varied situations, share information about their child’s behaviour, identify child’s strengths and express concerns related to development (Linder, 1993). It provides for an ecological and holistic assessment, while avoiding the redundancy inherent in individual assessments (Thousand & Villa, 1992).

Many of the criticisms of standardized assessment methods, such as lack of predictive validity and limited usefulness (McCall, 1983; Bagnato & Neisworth, 1992), have been addressed with the use of the TDA. Transdisciplinary methods provide a more naturalistic environment that is favourable to observing the skills and abilities of young children. For example, many Early Intervention services have begun using play-based assessments (Farmer-Dougan & Kaszuba, 1999; Linder, 2008) as play is a key contributor to every aspect of childhood development (Skaines et al., 2006). The use of a play-based approach resulted from problems with the quality of assessments provided by traditional standardised assessment methods when used with young children. The developmental literature suggested that play provides a ‘window’ to a child’s developmental ability (Vásquez, 2006). Research has also shown that play encourages cognitive skills (Piaget, 1962; Vygotsky, 1967; Smilansky & Shefatya, 1990), social-emotional development (Connolly & Doyle, 1984) and communication and language abilities (Heath & Mangiola, 1991; Pellegrini, 1981, as cited in Linder, 2008).

After conducting assessment activities, all team members engage in discussion of the child’s needs across all disciplines; team members share information among each other so that the boundaries of each discipline begin to be removed and each member of the team gain skills in other discipline areas (Locke & Mirenda, 1992; Reilly, 2001; Beukelman & Mirenda, 2005; Thylefors et al., 2005). All team members communicate their observations and conclusions to make decisions about functional outcomes and ECI supports and services in one integrated report (Bergen & Wright, 1994). Discussions are rich due to knowledge gained from working with other professionals (Beukleman & Mirenda, 2005). Batorowicz and Shepherd (2008) reported that team member’s work together to establish the goals and intervention plans following assessment. The TDA showed better team cohesion, cooperation, satisfaction and ability to work as an integrated and effective unit (Mullins et al., 1997). This included better team participation (Rosen et al., 1998; Popich et al., 2006) and communication (Lisa et al., 2001) compared with multidisciplinary teams.

Although descriptive data are not available to document the increasing usage of the TDA, there is evidence to suggest that the method of play-based assessment is relatively widespread. A survey of school psychologists revealed that play-based assessment was one of
the most frequently cited alternative options (44% of the time) used in conjunction with, or instead of, standardized measures in the assessment of infants and preschool children (Bagnato & Neisworth, 1994). This increased use of transdisciplinary, play-based assessment may be related to the desire for family involvement and team co-operation in the assessment process as well as concerns about the validity of standardized assessments with young children.

In the literature, research has advocated the TDA (Hutchinson, 1974; McCormick & Goldman, 1979; Lyon & Lyon, 1980; Woodruff, 1980; Orelove & Sobsey, 1996). It has been recognized as a best practice for Early Intervention (Woodruff & McGonigel, 1988; Bruder, 2000; Guralnick, 2001a; Tebbett, 2006) and many services adopt some form of TDA (Berman et al., 2000). Some of the benefits of the implementation of the TDA included more active parent participation (McCormick & Goldman, 1979; Woodruff, 1980), increased professional knowledge and skills through collaboration among team members (McCormick & Goldman, 1979; Orelove & Sobsey, 1996), increased mutual respect and professional growth among team members (Ottenbacher, 1982; Baine & Sobsey, 1983), shared responsibility for problem solving and decision making and more equal distribution of responsibilities (McCormick & Goldman, 1979). In addition, communication, interaction, and cooperation are maximized among team members in the TDA (Johnson et al., 1994; Davies, 2007).

One of the key characteristics of a transdisciplinary model is the overlapping of roles, whereby team members commit to teaching, working and learning across disciplinary boundaries (McGonigel et al., 1994). This concept is called ‘role release’; a process by which one team member transfers information and skills specific to their discipline to another team member who is of a different discipline (Rainforth et al., 1992; Kaczmarck et al., 2000). This results in less intrusion to the family, increased communication among team members and consistency in the implementation of the intervention plan. ‘Role expansion’ involves training in the concepts and language of another discipline. Both these concepts involve a certain amount of trust between professionals in order that roles are released and expanded to allow people to take each other’s places. Doyle (1997) and Lacey and Ouvry (2000) argue that ‘role release’ and ‘role expansion’ are key to effective collaborative working. This is a demanding process and professionals must first feel secure in their own roles and have confidence in their own abilities (Hart, 1991). Some professionals may find these experiences very threatening as Brown et al. (2000) point out that the erosion of roles is both opportunistic and threatening.
Ryan-Vincek *et al.* (1995) found that there were many similarities between the theoretical argument of the TDA and its application in practice by ECI teams. For example, teams reported their preference for parent participation in the diagnoses, assessments and interventions and for integration of programme goals into naturally occurring activities which is consistent with transdisciplinary theory. Discrepancies between theory and practice were evident in some areas, however, such as the limited degree of role release practiced by transdisciplinary teams and the practice of conducting assessments outside of the child’s natural environment. The TDA is different from the other models, where occupational power, status and professional recognition are key issues (Anderson *et al.*, 2000).

Initial research efforts have provided an empirical data base in support of a transdisciplinary service delivery model for children with disabilities, however, additional research is needed to further substantiate the model in practice. When critical components of the model were omitted, distorted or taken out of context, the probability of developing misconceptions and subsequent misuse increased (York *et al.*, 1990). York *et al.* (1990) clarified some of the major misconceptions regarding a TDA. One of the misconceptions was that writing *Individual Developmental Plans* (IDP) entailed gathering priorities from each disciplines’ perspective. Team members, however, should reach a consensus to select a single set of priority goals for each child. There is one collaborative IDP which specifies goals and objectives. Another misconception of the TDA was that therapists working in a TDA may lose their professional identity (King *et al.*, 2009). Some believe that a hidden agenda of a TDA is to reduce the number of therapists required. This is not the case when therapists share, teach, contribute and become involved in programmes (York *et al.*, 1990). Other team members commented about how much they value such therapists and how input and collaboration has benefitted children and families. Nonetheless, one major difficulty when shifting from a traditional model of service delivery to a transdisciplinary model is the comparatively uncertain role that team members must assume for themselves (Downing & Bailey, 1990). In the traditional model, roles are defined by job descriptions and responsibilities are designated to each team member. Whereas, in the transdisciplinary model, roles and responsibilities are more blurred. This can cause confusion and misunderstanding. In addition, practitioners may lack the peer support and professional development experiences they require to be effective in a transdisciplinary role (Maher *et al.*, 1998).

The proposed benefits of TDA have not been fully realised because confusion exists about what a TDA is, why it can be beneficial to children, parents and team members and how it can be successfully implemented (Carpenter & Egerton, 2005). “Transdisciplinary” is
a construct that has been widely accepted by the field of Early Intervention (Linder, 1990; 1993; in press; Losardo & Notari-Syverson, 2001; McLean et al., 2004; Sandall et al., 2005). As the transdisciplinary model became vogue, a variety of approaches were inaccurately labelled “transdisciplinary”. The construct is often misinterpreted to simply mean the use of professionals or service providers from two or more developmental disciplines (Linder et al., in press). Most recently, Linder and colleagues (in press) established the construct validity of the term as applied to early childhood disability, it showed that a deficit in one developmental domain will frequently contribute to deficits in other developmental domains. For example, if the two deficits operate in conjunction with one another, then separate assessment and intervention by different disciplines cannot get to the root causes. It is the joint discussion between the professionals that makes the assessment or intervention “transdisciplinary”. The use of “transdisciplinary” does not, however, guarantee that transdisciplinary influences will be identified, and the idea of the TDA is not simply to deal comprehensively with all of the child’s deficits, but rather to additionally identify the causal linkages between deficits. It is important to highlight that professionals in cognition reported influences more strongly than experts from other domains. Therefore, further examination of these influences is warranted in order to determine their authenticity and to determine why they are not generally recognized by experts in non-cognitive domains.

There is a lack of research regarding the TDA in operation in Early Intervention Services. Some challenges have been reported, such as that the model requires ample time and shared commitment from all team members to accomplish the fundamental values encapsulated within the model (Younggren, 2003). In addition, the acceptance of the model has been based too much on judgments, without adequate empirical testing of its validity (Myers et al., 1996). Reported advantages of the approach, such as time efficiency (Gallagher, 1988) seem to be based on face validity rather than empirical validation.

In considering the implementation of the TDA in Ireland, the model assigns one team member as the key worker, where he or she receives training from other team members and uses training with parents and other primary caregivers to support and empower their confidence and competence in promoting their child’s learning and development (King et al., 2009). Although this aspect of the model requires further and considerable time and effort, it is worth striving for to provide optimal family-centred Early Intervention services. The shift from older models of service to newer models reflects the changing understanding of children, of families and of disability (Wall & O’ Connor, 2004).
2.5 Key Worker System

A key worker must be identified as the primary point of contact for the family and can be any professional already working with the family and plays a lead role in guiding them (Cederman, 2006a). A number of different terms are used to describe the role, for example: key worker, care coordinator, link worker and family support worker. For the purpose of this study ‘key worker’ is the term used.

Over the past ten years, it is evident that people have used different key worker models. In the U.K., different models of key working services and models of practice have proliferated. Key workers can have a single role as a key worker or a shared role in which they may have additional professional responsibilities. Where there are financial constraints, the latter model is more common (Carpenter & Egerton, 2005). In Ireland, the literature on the role of the key worker appears to be relatively new and scarce (Mullins, 2008). Key worker services are limited to non-designated key workers whereby professionals work with a few families in addition to their normal professional role. Even when families have someone they see as a key worker, it tends to be on an ad hoc basis undertaken at the initiative of an individual professional (Mullins, 2008). Mullins’ findings are, however, limited as key working was explored in families of children with a disability from 6 to 18 years of age. Therefore, it is important to explore the key worker in a wider context by including children in early years of 0 to 6 years.

In Ireland, the most comprehensive description of a key worker was reported by Cederman (2006a; 2006b). The study examined the quality Early Intervention for children with special needs. Cederman found that the key worker was the primary contact providing information to the family. In her study, which adopts the transdisciplinary model, the key worker consults with the child’s teachers, mediates activities and routines for the child, integrates learning targets for the child across the domains, trains others to implement programmes into the child’s daily routines and provides information on resources linking families and community services. This encompassing description appeared idealistic in practical terms but is possibly one that can be aspired to in the Irish setting. It is not clear whether Cederman was referring to designated or non-designated key workers in her study (Mullins, 2008).

There is evidence to suggest that families frequently reported that they face a constant struggle in finding out about and accessing the services needed. The key worker system has, subsequently, been developed in an effort to overcome some of the barriers faced by families with disabled children (DfES/DoH, 2006). The value of key workers in providing a named
person support for disabled children has long been seen as worthwhile (Greco & Sloper, 2004; Webb et al., 2008). Studies of key workers consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being (Beecham, 2005). Key worker services are most beneficial to families when they are effectively managed and when all service partners involved are committed to the service and provide adequate funding, staffing and managerial support (Greco et al., 2005). For example, in an individual service approach, a child may receive one hour of direct therapy a week. If, however, that same hour is used by the therapist to train the family or childcare professional in how to support the child’s development across all domains through natural activities such as feeding, dressing, bathing, play, etc., then learning opportunities for that child are expanded to many more hours per day or week (Cederman, 2006a).

Benefits of the key worker include increased parental engagement and empowerment (Halliday & Asthana, 2004). Greater levels of satisfaction with respect to information provision, as reported by families with key workers, resulted in minimal problems with service coordination (Appleton et al., 1997) and higher levels of satisfaction with care coordination (McConachie et al., 1999). Other benefits include easier access to services, better relationships between professionals and between parents and professionals (Mukherjee et al., 1999; 2000; Liabo et al., 2001; Watson et al., 2002; 2007). The strongest predictor of the outcomes of Early Intervention is the relationship the family has with their key worker (Alliston, 2007), however, less than a third of families with children with disabilities have a key worker (Greco et al., 2007). Greco et al. (2007) interviewed only a subsample of families receiving the services and the results represent a snapshot in time of parents’ views of the key worker services. Families caring for a disabled child, consequently, need to have a key worker to oversee and manage the delivery of services involved in the care and support (DfES/DoH, 2004).

Research has also shown that the best outcomes for families are achieved when the role of the key worker includes providing information to families about services and supports available and accessible both locally and nationally, providing information about the child’s disability, identifying and addressing the needs of all family members and providing emotional support and help (Beresford, 1994; DoH, 2004). Greco and Sloper (2007) found that when key workers were sensitive to the needs and circumstances of the family as a whole, families experienced better outcomes overall. For instance, parents faced a number of challenges including stress and financial concerns, and experienced a greater level of stress relative to other parents. Liabo et al. (2001) found that parents’ experiences of key workers
were positive in terms of empowering parents in their role as carers, enabling services provided to be more relevant and in reducing levels of stress.

Very few studies have looked at parents’ experiences of the key worker in Early Intervention services. One recent Irish study, however, explored parents’ perceptions of key workers in an Early Intervention service and the development of a key worker service for school age children and young people aged 6 to 18 years. Mullins (2008) reported that levels of satisfaction with the key worker service were high and the role was valued greatly by the parents for whom key working was going well. Yet, it was also found that problems, such as isolation, confusion and lack of consistency were evident in relation to the role of a key worker. The study concluded that key working is a worthwhile service to provide to parents of children with a disability. The importance of using a key worker system can also be seen in services that work independently with little or no co-ordination and, therefore, result in parents receiving conflicting advice with duplication or gaps in service provision (Murkherjee et al., 1999; 2000; Liabo et al., 2001; Townsley et al., 2004). Key workers offer a solution as they co-ordinate services and act as a single point of contact for the families.

A number of studies have investigated views of staff in key worker services. Two studies showed that there was an increase in job satisfaction for those who acted as key workers (Prestler, 1998; Tait & Dejnega, 2001). Other studies have looked more broadly at professionals’ views of the key worker service and their role in it. In an evaluation of two key worker schemes, Mukherjee et al. (1999) found that half the key workers saw no differences between the key worker role and their everyday work. Key workers felt that the role produced benefits in multi-agency working and improved relationships with parents. Difficulties were also encountered, however, such as not having enough time for the role, confusion for staff and families about the key worker’s role and a lack of training and supervision for key workers. Appleton et al. (1997) reported that key workers needed more time to dedicate to care coordination and specific training for the role. Later, Abbott et al. (2005) showed that clear guidelines on the key worker role were not often available but having peer support from other professional backgrounds was helpful.

Sloper et al. (2006) highlighted the importance when planning and implementing key worker services to ensure that the role of the key worker is clearly defined and understood. Certain recommendations for effective key working practice included that training and supervision are provided for key workers, that key workers have enough time to carry out all the aspects of the role and there was a service manager to support them. The need for key worker services to focus on children as well as parents was highlighted as well as the fact that
key workers felt they needed more training in communicating and working. A group of professionals from diverse backgrounds makes a broad range of knowledge and skills available to a key worker service (Greco et al., 2005). Improved staff satisfaction for those acting as key workers is a frequent gain when key working schemes are established (Liabo et al., 2001; Townsley et al., 2004; Barton & Clark, 2005; Greco et al., 2005).

2.6 Experiences of ECI
An evaluation must be conducted jointly with the family and the professional to be effective. This would mean collaboration between professionals and parents and for both to be equally valued. This principle is important for good practice in Early Intervention (Carpenter & Egerton, 2005). Furthering service practices requires parents and team members to discuss their successes and failures when considering its use with children in ECI services. While ECI is at the heart of the research, the experiences of parents and team members are vital in shaping how future services will be generated and provided for children with disabilities.

2.6.1 Parents’ Experiences of ECI
Parents are key informants regarding their children. Parents provide information about early experiences and can describe and reflect on changes that occur over time. Family attitudes, beliefs and experiences are a cornerstone of Early Intervention. Sensitivity to family issues is paramount to optimizing the relationship between family and service providers and critical to effective intervention (Woodruff & McGonigel, 1990). For example, infants and young children are developing and learning in the context of their families and this need requires that services and supports target families as well as children (Bruder, 2000; Dunst, 2000; Bruder, 2010). Therefore, in the current research, a qualitative, grounded theory approach was adopted to provide an in-depth exploration of parents’ perspectives and to explore the meaning of their experiences for themselves and their families.

In Europe, family-centred approaches to Early Intervention have been the subject of considerable research. Maki (1994) has stressed that the aim of family-centred intervention is to empower families. Maki recommended an ecological approach in which the involvement of the family is pivotal. The purpose of the approach is to gather information about children's lives, such as their activities, interactions, experiences and peer contacts (in natural environments). Bax (2001) claimed that the effects of any programmes set up for children need to be measured in terms of parental satisfaction. Furthermore, service delivery must focus on helping establish the optimal environment at home to allow changes and generate
learning. This means that questions of service delivery need to be extremely parent-sensitive (Scrutton, 1997; Bax, 1998; Cederman, 2006a). Listening to parents’ views is an important aspect in the development of services; evidence in the literature suggests that parents are experts in disability research (Carpenter, 1997; Law et al., 2003; Davies, 2007). Hence, a main focus of this study is to explore parents’ lived experiences of the approaches in ECI services to enable decisions to be made about further practices.

Lack of collaboration with parents and dissatisfaction with services is clearly evident in studies that investigated formal support services from the parents’ perspectives (Thompson, 1998). Several researchers identified parents’ beliefs that formal support services were not truly supportive of families (Cunningham et al., 1982; Ayer, 1984; Sloper & Turner, 1993). In each of these studies, parents described experiencing unmet family needs and unhelpful service providers. Other studies focused on parents’ views of their relationships with service providers (McKay & Hensey, 1990; McKenzie, 1994). Two of these were Australian studies where parents described service providers in relation to their professional interests and perceived helpfulness (Baxter, 1989; McKenzie, 1994). Helpful service providers were perceived as those who answered questions, offered friendship and support to family members and shared information about the child’s disability and appropriate services. Professionals who indicated a genuine interest in the development of the individual child and the concerns of the individual family were highly valued by the parents in both studies. Unhelpfulness and a lack of genuine concern and understanding of the individual child and the family were also reported (Baxter, 1989; McKenzie, 1994). Similarly, an Irish study by McKay and Hensey (1990) highlighted parents’ dissatisfaction with services and unmet family needs. It was reported that 70% of parents were dissatisfied with services which stemmed from a lack of explanations regarding the child’s condition, a dismissal of worries and a lack of understanding of the problems involved in handling the child. In these studies, parents had clearly identified characteristics of services and service providers that would help them to care for their child with high support needs, however, parents continue to report dissatisfaction with services. This dissatisfaction is somewhat alarming given the supposed reorientation of services towards the documented concerns of families.

Interestingly, it is acknowledged that the parents’ perceptions of their experience may not necessarily reflect what actually occurred (Jupp, 1992; Sloper & Turner, 1993). This is of particular concern as the level of support provided during the very early days has been shown to be crucial and can affect both short and long-term coping and adaptation (Quine & Pahl,
A focus upon the parental perspective can ignore the child’s viewpoint serving to objectify the learning disabled child (Shakespeare, 1999).

Although evidence of the usefulness of a programme of services must come from a variety of sources, there is almost universal consensus that parental perspectives are a key component of any evaluation of Early Intervention services (Bailey et al., 1998; Roberts et al., 1999). While the family is a member of the team, the role they play in decision-making is secondary to that of the professionals (Gargiulo & Kilgo, 2000). Research suggested that the most effective intervention will require all responsible parties to provide the most responsive and developmentally progressive learning environment possible (Warren, 2000).

2.6.2 Teams’ Experiences of ECI

Information is lacking about multidisciplinary and transdisciplinary service delivery from a practitioner’s perspective (Ryan-Vincek et al., 1995). Practice-relevant information is needed about how to deliver ECI services. Little is known about the roles of team members, the types of services that can be offered within this approach (e.g., home visits, parent training) and how managers can provide structures, supports and opportunities to operate well-functioning and effective transdisciplinary teams (King et al., 2009). A major concern when shifting from a traditional model of services delivery, with its isolated components, to a transdisciplinary model, emphasising integrative support, is the uncertain role that team members must assume for themselves (Downing & Bailey, 1990). In the traditional model, roles are defined and responsibilities are assigned to each team member based on expectations that are clear and easy to follow. Whereas, in the transdisciplinary model, role and responsibilities are more blurred which can result in confusion and misunderstandings.

One exception to the lack of published practice models is a family-centred, transdisciplinary model of Early Intervention service delivery called “Team Around the Child” (Davies, 2007), based on work by Limbrick (2005) in the U.K. Davies outlined several model components which included philosophy, family role, key worker role, team interaction, lines of communication, staff development and the assessment process. Davies provided details to inform managers and ECI teams about how to implement a transdisciplinary service programme and ensure its key aspects are sustained over time.

Researchers have indicated a need to examine the specific team approaches in order to enhance treatment outcome (Keith, 1991; Berman et al., 2000). Thus, the present study will supplement the current literature gap by providing exploratory experiences regarding the models in ECI from team members’ point of view.
2.7 Aims of current study

It is essential that the future of Early Intervention services are founded on core principles and beliefs and this requires substantial exploration of the ways in which Early Intervention services are provided in Ireland today. The current study addresses these issues by investigating team members’ and parents’ perceptions of the models in operation. This is a fundamental aspect to ensure the best possible practice for children with disabilities.

- It is estimated that in Ireland in 2002, there were approximately 9,000 people between the ages of 0 and 9 years with a disability.

- Walsh (2009) reported that 1,100 children were receiving early services with an upward trend in referrals in Ireland.

- There is no cohesive policy or programme to co-ordinate the delivery of ECI services, which suggests that the quality, accessibility and comprehensiveness of the service received may vary (Foran & Sweeney, 2010).

- Within an Irish context, there is a lack of literature concerning the Early Intervention services and in particular, the older (multidisciplinary) and newer models (transdisciplinary) which are implemented in these settings.

- There is ample evidence to suggest a growing gap between what is known, what should be done and what is currently being done in ECI services (Dunst & Trivette, 2009; Odom, 2009).

- There remains much to be learned about which services work best for which kinds of children’s disabilities; the present study addresses this and researches what works best for children and families with differing models.

- Recommendations are made in relation to future research and future practice in the provision of services for children with disabilities in an Irish context.

- It is hoped that the research will offer a valuable insight into the approaches of ECI. It is envisaged that the findings will provide some valuable information regarding the factors influencing the development of the models and offer insight into the unmet needs of parents and teams experiencing childhood disability.
Chapter Three: Methodology

3.1 Chapter Introduction
This chapter provides a detailed account of the research approach implemented in the present study. An outline of the design of the study, participants, instruments and procedures for carrying out data collection will be provided. The chapter also describes the rationale for the choice of methods implemented. Finally, it explains, drawing on examples from the data, how theory has been generated through this process.

3.2 Rationale for Choice of a Qualitative Approach
This study used a qualitative grounded theory research methodology in the data collection and analysis. The aims of this study were: to describe and conceptualize the lived experiences of parents involved in the ‘traditional’ multidisciplinary model and/or the transdisciplinary model and to investigate the experiences of the team members working on the Early Intervention team. The aims were to enable the development of an explanatory theory of the models in the ECI services. This choice of design was influenced by the research questions and the aims of the study.

Before it is possible to discuss the rationale for using a qualitative approach, it is first important to understand what is meant by qualitative research. Qualitative research seeks to gain a comprehensive and holistic view of social life through the study of people in a wide range of natural settings. Qualitative methodologies are particularly suited to understanding individuals’ or groups’ subjective lived experiences (Fossey et al., 2002) and in developing knowledge of previously unexplored, misinterpreted, poorly understood or complex areas of human experiences, such as lived experience of Early Intervention services. These problems may be difficult to access using quantitative approaches. The researcher attempts to capture data through a process of deep attentiveness and empathetic understanding, while suspending any preconceptions about the topics to be discussed (Miles & Huberman, 1994). They asserted that the researcher is the main ‘measurement device’ in qualitative research.

In particular, qualitative research has the potential to increase our understanding of children with disabilities, their families and those who work with them. Qualitative research also has the potential for deepening our understanding of the Early Intervention challenges that children with disabilities pose. Sandall et al. (2002) argue that qualitative research is ideal for providing a ‘voice’ for the various stakeholders in Early Intervention “by listening to their voices and considering their voices within the full context of their experiences” (p. 135).
The methodological approach used here seeks to do exactly that by being diverse and evolving throughout the duration of the study.

An in-depth view is required from a small sample in order to concentrate and attend carefully to each individual’s story. Conducting this qualitatively was seen as the most appropriate technique of gaining this thorough material.

3.3 Specific Objectives of the Research Project
This study looked at parental perspectives of their lived experiences of the multidisciplinary model and the transdisciplinary model implemented in ECI services. It examined parental experiences of the key worker system in operation within the transdisciplinary model. The study also obtained the experiences of the staff working in the transdisciplinary team, as to the effectiveness of the model.

3.4 Early Intervention Services
The services investigated in the current study offer an early intervention service to children with special developmental needs in the area. The Intervention Services are a partnership of the Health Service Executive and a voluntary Body. Through transdisciplinary service delivery, the Early Intervention Team work together to establish the needs of young children with special developmental needs and devise plans and programmes to meet the needs of each child and their families. Families are integral members of the Early Intervention Service and the delivery of services. Intervention is offered through groups and individually as required and there is constant liaison with preschools and schools to facilitate the implementation of plans. Ongoing communication among all team members is essential for maintaining a consistent approach to meeting the changing needs of the child who is always considered within the context of the family. The team are aware that a child cannot be viewed in isolation and thorough assessment and intervention take place only with an overall understanding of a child’s three primary settings such as home, preschool or school and clinic or centre-based.

3.5 Grounded Theory
Given the fact that little is known about the approaches used in Early Intervention in Ireland, and that explorations of the experiences of the approaches from the perspective of parents and team members have been limited, a grounded theory methodology is used (Glaser & Strauss, 1967). Grounded theory is “a qualitative research method that uses a systematic set of
procedures to develop an inductively derived grounded theory about a phenomenon” (Strauss & Corbin, 1990, p. 24). It is one of the most widely used approaches in qualitative data analysis and is used to give meaning to the participants’ experiences and to investigate the sense of embodied, practical and active knowledge coming from the experiences of Early Intervention, as a parent or staff member.

Grounded theory research, often referred to as the constant comparative method (Glaser & Strauss, 1967), is a qualitative tradition built on compared concepts. Proponents of the method suggest that similar data are grouped and conceptually labelled followed by categorization of concepts. Categories are linked and organized by relationship, conditions and dimensions are developed and finally, a theory emerges (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990).

According to Glaser and Strauss (1967), it seeks to construct theory based on the importance of issues in peoples’ lives. It is also seen as ‘an integrated theoretical formulation’ that attempts to give insight into how people experience events (Corbin & Holt, 2005). The advantage of using such an approach is that the theory is literally grounded in the data. This type of data provides insight into thoughts and experiences that illuminate our understanding and thus enhances the emerging theory. What it also calls on is creative thinking on the part of the researcher to remain open to possibilities before deciding on one avenue (Patton, 1990).

An underlying principle of the research study involves hearing the experiences of the parent and teams as they themselves articulate them. In this way it is hoped that the research will add a new dimension to our limited understanding of Early Intervention services in Ireland.

3.6 Data Collection
Consistent with grounded theory methodology, the researcher conducted a series of semi-structured focus groups and individual interviews. Individual interviews were originally considered as a sole method of data collection. It was, however, recognised that commitment to one type of data makes the techniques of theoretical sampling very difficult to follow. In addition, relying on one technique may produce homogeneous data, which are highly unlikely to provide enough information to understanding individuals’ experiences (Richards, 2006). It was therefore decided that both individual interviews together with focus groups would be used. Although individual interviews and focus groups are independent data collection methods, their combination can be advantageous to researchers as complementary views of
the phenomenon may be generated (Lambert, 2008). Focus groups and interviews have become accepted methods used in the initial stages of valuation research (Kaplowitz & Hoehn, 2001). In addition, both methods were combined for practical or pragmatic considerations. For example, individual interviews were offered to participants unable or unwilling to attend a focus group.

Individual interviews were selected as they are the most widely used data collection method in qualitative research (Nunkoosing, 2005). Researchers choose individual interviews to collect detailed accounts of participants’ thoughts, attitudes, beliefs and knowledge about a given phenomenon (Fielding, 1994; Loiselle et al., 2007). In addition, each interviewing approach assumes a philosophical orientation (Fielding, 1994). For example, grounded theory’s underlying philosophical assumption implies reliance on semi-structured rather than structured interviews (Duffy et al., 2004). Semi-structured interviews are less intrusive to those being interviewed as it encourages two-way communication. In addition, when individuals are interviewed they may more easily discuss sensitive issues (Shelbourn, 2005).

Focus groups were chosen as group interactions may accentuate members’ similarities and differences and give rich information about the range of perspectives and experiences. Focus group data are the product of context-dependent group interactions (Hollander, 2004). The method is particular useful to explore peoples’ experiences and can be used to understand what people think, how they think and why they think that way (Kitzinger, 1995). In addition, an advantage is that friends and colleagues can relate each other’s comments to incidents in their shared daily lives (Kitzinger, 1995).

Data were gathered with parents and staff members of the Early Intervention services. For the purposes of ascertaining parents’ experiences of the models, a random sample of parents with children with a disability attending an Early Intervention service was selected. A total of 10 parents from the MDA and 10 parents from the TDA were recruited.

For the purposes of ascertaining team members’ experiences, two Early Intervention teams were recruited. A team member from each discipline on the team was selected to participate in a focus group discussion. A total of 10 team members from two Early Intervention teams were identified to participate in two focus group discussions.

3.6.1 Materials
Open ended question schedules were developed to guide the focus group discussions and individual interviews. Core questions were constructed using issues highlighted in the literature, thereby asking participants to comment on their experiences of the Early
Intervention services (see Appendix A, Appendix B, Appendix D for a set of guiding questions used in the interview schedules with parents and team members).

3.6 Phase One: Parents

3.6.1 Participants

The study’s population consisted of parents whose children are currently attending Early Intervention services in Ireland. Nineteen parents participated in the study, the majority of participants were female (79%, \( N = 15 \)), with 21% male (\( N = 4 \)). The ages of respondents ranged from 27 to 54 years (\( M = 41 \) years 5 months, \( SD = 6 \) years 2 months).

3.6.2 Instruments

Data collection took place in the form of individual interviews and focus groups, between the researcher and each participant, which ran for 40 minutes to 1½ hours in duration. Focus groups were carried out to gather information from parents. These were followed by a series of individual interviews which further explored ideas that arose from the focus groups. The focus group and interviews were designed by the researcher to tap into the parents’ experiences of having a child with one or more disability attending Early Intervention services. The questions were set to identify the facilitators and barriers to implementing the models in the service and to identify the composition of the best practice method for children with disabilities.

3.6.2.1 Focus Groups

This qualitative study used a focus group approach to collect data to learn more about the phenomenon under investigation (Morgan, 1997). Focus group interviews were chosen for the study as it was intended to seek information from participants that would potentially be sensitive (Kitzinger, 1994), and to elicit participants’ beliefs, attitudes and feelings through group processes (Freeman, 2006). Research is defined as sensitive if it requires disclosure of behaviours or attitudes which would normally be kept private and personal and which might cause the respondent to express discomfort (Wellings \textit{et al.}, 2000).

A wide variety of information can be gathered in relatively short time span due to the use of open ended questions and the moderator’s ability to explore a range of related topics (American Statistical Association, 1997). Focus groups allow respondents to react to and build upon the responses of other group members, creating a ‘synergistic effect’. This often leads to the production of more elaborate accounts of topics than are generated in individual interviews (Wilkinson, 2001). However, members of groups may fail to exchange all
information they have and groups may focus only on shared information (Levine & Moreland, 1990).

The ideal size may vary between 6 to 12 participants as this helps prevent a split in conversation (Morgan, 1997). However, Heary and Hennessy (2002) stated that group size should be smaller discussing sensitive topics. Therefore, for the present study, two relatively small focus groups were carried out consisting of a sample size of 3 and 4 parents in each group.

Although attention is increasingly placed on the combination of quantitative and qualitative methods, fewer authors (Barbour, 1998; Morse, 1999) have explicitly addressed the implications of combining qualitative data collection methods. Although focus groups and individual interviews are independent data collection methods; their combination can be advantageous to researchers as complementary views of the phenomenon may be generated.

Kitzinger (1994) found that when sensitive issues were being discussed, adults sometimes confided information to the researchers that they were not prepared to share with the group. O’ Brien (1993) claims that individual interviews may be more appropriate for the interviewer to further investigate the participant’s experience in a way that could not be done in a group setting when discussing certain complex topics (Heary & Hennessy, 2002).

3.6.2.2 Semi-structured Interviews

Individual in-depth interviews generate data in one-on-one settings. Individual interviews are the most widely-used data collection strategy in qualitative research (Sandelowski, 2002; Nunkoosing, 2005). Researchers typically choose individual interviews to collect detailed accounts of participants’ thoughts, attitudes, beliefs, and knowledge pertaining to a given phenomenon (Fielding, 1994; Speziale & Carpenter, 2003; Loiselle et al., 2007).

Grounded theory’s underlying philosophical assumption implies reliance on semi-structured rather than structured interviews (Fielding, 1994; Duffy et al., 2004). Therefore, twelve semi-structured individual interviews were carried out with parents in this study. The researcher used the same interview guide for each session and made comparisons of the interview data to determine similarities and differences. Only individual qualitative interviews can be used to undertake such investigations independent of group effects (positive and negative) (Minichiello et al., 1995). One-on-one qualitative interviews may reveal important insights in the absence of group effects and therefore, valuation researchers should typically use both (Kaplowitz & Hoehn, 2001).
Both methods, to varying degrees, facilitated learning from parents about their perceptions and were helpful to identify variables and issues. The verbatim transcripts of these interviews formed the data for the present study.

3.6.3 Sampling
The participants were recruited through the Early Intervention services. Thirty parents from the ‘traditional’ multidisciplinary model and thirty parents from the transdisciplinary model were selected to be contacted to participate in this study. Ten parents were randomly selected from each group and agreed to participate in a focus group or interview. Both methods were combined for practical or pragmatic considerations. For instance, individual interviews were offered to participants unable or unwilling to attend a focus group (e.g., Rees et al., 2003; Taylor, 2005). This type of combination led to fewer refusals or withdrawals, as individuals could choose the method that is most convenient for them.

3.6.4 Interview Procedure
The twenty interviewees were contacted by telephone and asked again if they would like to take part in an interview or focus group. Two focus groups were arranged with 4 parents in each which were held in the Early Intervention service. Twelve interviews were arranged at a time convenient to them. All participants chose to be interviewed in the Early Intervention service.

At the beginning of each focus group and interview, the researcher explained the aims of the research, how confidentiality and anonymity were going to be maintained and how the interview would be structured. During this introduction, the researcher informed interviewees that they could stop the interview at any time or could decline to answer any of the questions. The interviewees were then asked if they had any questions and their questions were answered before proceeding with the interview. Each participant then gave their informed written consent to participate (See Appendix H). The researcher also asked for consent to tape the interviews and the researcher explained that the tapes would be destroyed once transcribed. The researcher added that the transcripts would be anonymised and that consent forms, letters and transcripts would be stored separately. The interviews were arranged with interviewees to last for approximately 40 minutes.

3.7 Phase Two: Team Members
3.7.1 Participants
The study’s population consisted of staff members who currently work on a multidisciplinary team and transdisciplinary team in an Early Intervention service in Ireland. Ten team members participated in the study, the majority of participants were female (70%, $N = 7$), with 30% male ($N = 3$).

Three Early Intervention Specialists, one Physiotherapist, one Senior Physiotherapist, one Principal Social Worker, one Occupational Therapist, one Senior Psychologist and two Speech Therapists participated in the study. Two of the professionals had between two and four years experience of working in their field and eight had four or more years working in their profession.

Four of the professionals had between two and three years experience of working in an early intervention service, six had over three years experience. As regards the current early intervention service, three of the professionals interviewed had less than 12 months experience working in the service, one individual had between two and three years and a further six had more than three years working in the early intervention service.

In relation to the experiences of working on a transdisciplinary team, one professional had less than 12 months experience, another had between one and two years, another had between two and three years, two professionals had three or more years and five had more than 5 years experience of working on a transdisciplinary team. As regards education, two professionals had a Higher Diploma and two had Higher Degree, five had a Bachelor’s Degree and one had a Masters Degree.

### 3.7.2 Instruments

Data collection took place in the form of focus groups between the researcher and team members which ran for 1 to 1½ hours in duration. The focus groups were designed by the researcher to tap into the teams’ experiences of working with the different models in the services. The questions were set to learn about the experiences of the team working on the Early Intervention team, as to the effectiveness of the models.

#### 3.7.2.1 Focus Groups

Focus groups were used with team members because team members share information among each other so that the boundaries of each discipline begin to be removed and professionals gain skills in other practice areas (Locke & Mirenda, 1992; Beukelman & Mirenda, 2005; Thylefors et al., 2005).

(See section 3.5.2.1 for focus group details)
3.7.3 Sampling
The team members were recruited through the Early Intervention services. Five team members from the ‘traditional’ multidisciplinary model and five team members from the transdisciplinary model were invited to participate in this study.

3.7.4 Interview Procedure
The clinical managers of the services were contacted by telephone and asked if their team would like to take part in a focus group. Two focus groups were arranged with five team members in each which were held in the Early Intervention service. The focus groups were arranged at a time convenient to them. At the beginning of each focus group, the researcher explained the aims of the research, how confidentiality and anonymity were going to be maintained and how the interview would be structured. During this introduction, the researcher informed the team that they could stop the interview at any time or could decline to answer any of the questions. The teams were then asked if they had any questions and their questions were answered before proceeding with the interview. The researcher also asked for consent to tape the interviews and the researcher explained that the tapes would be destroyed once transcribed. The researcher added that the transcripts would be anonymised and that consent forms, letters and transcripts would be stored separately. Prior to the interview, the team members completed a demographic information sheet (See Appendix E), and verified their willingness to participate by providing verbal consent.

3.8 Consent & Ethical Issues
Ethical approval was sought from both the University of Limerick Research Ethics Committee and from the Health Service Executive regional ethics board. The following ethical considerations were incorporated into the study to ensure transparency, accountability and participant safety, anonymity and informed consent.

3.8.1 Initial Contact
From the point of initial contact by post (see Appendix F for recruitment letter) it was emphasised to participants that they had the right to refuse to take part and to withdraw from the study at any stage. The researcher stated this to every participant, throughout the entire research process. An information sheet (see Appendix G) with details of the study was sent with the initial contact letter. The information sheet outlined the aims of the study, how data
would be gathered and stored, issues around confidentiality and anonymity and any risks or benefits to the participants. These letters were followed up with a phone call and if the participant agreed to take part in the study a time and place for the interview was arranged.

3.8.2 Data storage & Management

It was explained to each participant that the interview would be transcribed and that both tapes and transcripts would be held in a locked cabinet and a password protected computer which would be accessed by the primary investigator and researcher. It was also made clear that transcripts would be anonymised and that no identifying information would be included in any documents relating to the data. The audio tapes and transcripts were to be destroyed in due course once the study reached full completion.

3.8.3 Risks & Benefits

It was made clear from the outset that no direct benefit (monetary or otherwise) would be accrued by participating in the study. Further to this, the possibility that the area of study may raise some emotionally difficult content was outlined in the information sheet and discussed again before and after each interview.

3.9 Data Management & Analysis

3.9.1 Transcription

The researcher transcribed recorded proceedings and excluded all identifying information from written transcripts. Taped interviews were subsequently erased following the transcripts. Transcripts were held electronically and password protected. All of the participants’ details were strictly confidential. None of the identifying information such as names, addresses and contact numbers was reported in the findings of the research thus ensuring anonymity.

3.9.2 Approach to analysis

Data analysis was guided by the grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Grounded theory strives to allow participants’ voices to guide and structure the interpretation of the data (Auberbach & Silverstein, 2003) and involves careful reading and re-reading of individual interview transcripts and systematic coding of salient themes. The purpose of this procedure was to generate theory from observations in real life. “By starting with data from the lived experience of the research participants, the researchers can,
from the beginning, attend to how they construct their worlds...lived experience shapes the researcher’s approach to data collection and analysis” (Charmaz, 1994, p. 68).

By reading the messages repeatedly, line by line, asking sensitizing questions (e.g., ‘What’s happening here?’), and theoretical questions (e.g., ‘How does what this parent is saying here connect to what has been said elsewhere?’), concepts were developed to capture the essence of what was being stated. Theoretical comparisons of concepts were made which involved using the flip-flop technique and systematic comparisons (Strauss & Corbin, 1998). These are methods for developing concept properties: the former involves searching for perspectives that diverge from what has already been established; the latter involves comparing incidents in the data to incidents recollected from experience or from the literature. This process of open coding was repeated, and recurrence of concepts was seen as being indicative of shared meaning, allowing for the development of higher-order categories. Once the categories were identified, axial coding was commenced in order to denote how these categories might relate to each other at a conceptual level.

3.9.3 Coding Process

Charmaz (2006) writes about the different stages of grounded theory analysis. The next aspect of the approach is termed coding the data. Mills et al. (2006) hold that coding from the data obtained in the research is the key analytical tool of the grounded theory approach. The coding of the data was conducted in three main phases.

1) Open coding:
   a) Line by line coding
   b) Focused coding

2) Axial coding

3) Selective coding

It should be noted that the analysis process was non-linear with one phase being totally discrete from the next. The process of grounded theory is dynamic and unfolding and the researcher shifts forward and backward between the phases of coding throughout the processing (Strauss & Corbin, 1990; 1998). Data is constantly compared throughout the analysis with data compared to data, data with category, category with category, and category with concept as the theory is developed.
3.9.3.1 Line by Line Coding

The first step in the analysis was the initial line by line coding, which involved labelling each line of written data with a short name that summarises and accounts for each piece of data (Glaser, 1978). Coding is how you define what the data you are analysing are about. To facilitate this process each transcript was contained in a Microsoft Word document which had three columns with the transcribed interview in the middle column. The left column consisted of the line by line codes which were sought by selecting a unit of meaning in each line of the data and selecting a word or two to represent it. Table 3.1 displays an example of line by line coding from a participant.

Table 3.1. Example of line by line coding of interview transcript

<table>
<thead>
<tr>
<th>Line by line coding</th>
<th>Transcription of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having positive experience</td>
<td>Ah yeah I’d have to say it is very positive, we were brought on line very quickly which was a</td>
</tr>
<tr>
<td>Being helped quickly</td>
<td>huge help with regard to physio[therapy] which was the initial service that we got and Sean was</td>
</tr>
<tr>
<td>Being a huge help</td>
<td>here within 8 weeks of his birth which was fantastic and the physio[therapist] here at the</td>
</tr>
<tr>
<td>Needing physio[therapy] initially</td>
<td>time was fantastic I’ll never forget her because she dealt with development issues like that like</td>
</tr>
<tr>
<td>Entering service 8wks old</td>
<td>getting over the whole shock of the experience in so far as we had no indication before he was</td>
</tr>
<tr>
<td>Having fantastic therapists</td>
<td>born that Sean was going to be special needs. She dealt with his needs very quickly which were</td>
</tr>
<tr>
<td>Never forgetting help</td>
<td>mainly physical development but she kind of encourages us to help his growth in certain ways</td>
</tr>
<tr>
<td>Dealing with disability</td>
<td>with regards to his legs and tongue and all the things that kind of give or if we could train the</td>
</tr>
<tr>
<td>Coping skills</td>
<td>growth that it would help down the road.</td>
</tr>
<tr>
<td>Getting over shock</td>
<td></td>
</tr>
<tr>
<td>Having no idea of child’s disability</td>
<td></td>
</tr>
<tr>
<td>Dealing with needs rapidly</td>
<td></td>
</tr>
<tr>
<td>Having physical disabilities</td>
<td></td>
</tr>
<tr>
<td>Encouraging parents to help child grow</td>
<td></td>
</tr>
<tr>
<td>Training growth for further development for the child’s future</td>
<td></td>
</tr>
</tbody>
</table>

3.9.3.2 Focused coding

This process was followed by focused coding in which the most significant or frequent line by line codes were clustered together to account for larger sections of data (Charmaz, 2006). As Rennie and Brewer (1987) state, “all elements (e.g., single lines, sentences, or complete thoughts in text) of an initial set of data (e.g., archival information, interviewees’ accounts) are compared and conceptualised in terms of commonalities” (p. 11). This phase involved deciding on which codes made the most analytic sense. Codes in this phase were selected on the basis of their ability to categorise the data in a more penetrating and complete way.
(Charmaz, 2006). The final column in the document contained the more focused codes. Table 3.2 presents an example of focused coding from a participant.

Table 3.2 Example of focused coding

<table>
<thead>
<tr>
<th>Line by line coding</th>
<th>Transcription of Interview</th>
<th>Focused Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having positive experience</td>
<td>Ah yeah I’d have to say it is very positive, we were brought on line very quickly which was a huge help with regard to physiotherapy which was the initial service that we got and Sean was here within 8 weeks of his birth which was fantastic and the physiotherapist here at the time was fantastic I’ll never forget her because she dealt with development issues like that like getting over the whole shock of the experience in so far as we had no indication before he was born that Sean was going to be special needs. She dealt with his needs very quickly which were mainly physical development but she kind of encourages us to help his growth in certain ways with regards to his legs and tongue and all the things that kind of give or if we could train the growth that it would help down the road.</td>
<td>Positivity Immediate Early Intervention Coping with disclosure of disability Supportive staff Dealing with disability Meeting child’s needs Support – encouragement Growth – developmental, psychological, emotional etc. Child’s future in mind</td>
</tr>
<tr>
<td>Being helped quickly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being a huge help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing physiotherapy initially</td>
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<td></td>
</tr>
<tr>
<td>Training growth for further development for the child’s future</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.9.3.3 Axial Coding

Axial coding was then completed, by bringing focused codes together to clarify the nature of the categories and the relationship between different categories and subcategories. Data, fractured during initial coding, is reassembled to give coherency to the emerging analysis. Constant comparative methods (Glaser & Strauss, 1967) were employed at every stage of analysis to establish similarities and differences within and between different transcripts and to generate a more sophisticated understanding of the data. Having compiled the codes from the transcribed interviews, these codes were then compared and categories emerged. These categories were filtered back in order to validate the concepts until it emerged that a reliable category had emerged (Charmaz, 2006). The data was constantly compared until no new categories emerged. In this way, theoretical saturation was ensured. This refers to the point at
which gathering more data about a theoretical category reveals no new properties or any further insights about the emerging grounded theory (Charmaz, 2006). This occurred both within any one participant’s data and also across and between participants.

3.9.3.4 Selective Coding

The final phase in the analysis was the process of selective coding. This refers to a process whereby the theory is integrated and refined (Strauss & Corbin, 1990). At this stage of the proceedings a tentative pattern started to emerge. To this end several core categories were selected and systematically related to other categories thus validating the relationships between categories. A category is considered to be ‘core’ or central insofar as other categories can be integrated around it (Strauss & Corbin, 1990; 1998). According to Charmaz (1983) and Strauss and Corbin (1990) the core category is the central theme or story line of the data, around which all the other categories can be subsumed.

3.9.3.5 Memo-writing

Memo-writing constitutes a crucial method in grounded theory because it prompts the researcher to analyse the data and codes early in the research process. Detailed memo-writing during the entire analysis process required writing down thoughts and ideas, assumed associations and theoretical reflections related to each of the emerging categories. Theoretical sensitivity is also an important concept in grounded theory and reflects the researcher’s ability to use personal and professional experiences as well as methodological knowledge and thereby see data in new ways and think abstractly about data in the process of developing theory (Corbin & Strauss, 2008).

3.9.3.6 Theoretical Sampling

Strauss and Corbin (1990) connected specific theoretical sampling strategies to the three types of coding mentioned above. They suggest that open coding requires open sampling in which data are gathered to uncover as many relevant categories as possible. Open sampling can be done purposefully to gain the maximum amount of data needed to unearth potential categories and their dimensions; systematically, by moving from one person to another on a list to uncover subtle differences. Axial coding requires relational sampling, in which data are gathered to uncover and validate the relationships among categories that have been discovered. This type of sampling can also be done purposefully or systematically. Selective
coding calls for discriminate sampling, where data are gathered to verify the emerging theory and develop categories that have not been well saturated.

During all phases of coding, great emphasis was placed on using the participants’ own words and descriptions wherever possible. This was done for a few reasons. Firstly, it was a key means of keeping participants’ voices alive in the data. Secondly, a participant’s own description of a phenomenon or event often captures an essential quality that only becomes clear as the analysis progresses. Finally, it enhances rigour insofar as it reduced the danger of one’s own perceptions and preconceptions becoming the dominant influence on the data (Chiovitti & Piran, 2003). Using participants’ own language at all levels of coding can further ground theory construction and add to the credibility of findings (Strauss & Corbin, 1990).

3.10 Validation of Analysis

3.10.1 Trustworthiness

Silverman (2000) asserts that there is little point in completing research unless procedures are reliable and results valid. In order to enhance the rigour of the approach and the credibility of the data produced, (Lincoln & Guba, 1985) a number of strategies were employed.

3.10.2 Inter-coder Reliability

This refers to using a type of researcher triangulation by which multiple researchers are involved in the analytical process. This is an attempt to increase the validity and reliability of the study through the provision of a more complex and nuanced understanding of the possible interpretations of the objects of the research. During the stages of analysis a sample of each transcript was sent to a second coder who independently coded the data. The results of coding were then compared to ensure that both coders were in agreement as to what was emerging from the data. As for field note conventions and inter-coder reliability; Silverman (2000) highlights the importance of including nuances, pauses and overlaps in transcriptions and by doing so he asserts that inter-coder reliability is improved.

3.10.3 Reflexivity within Qualitative Research

It is recognised that interviews, focus groups and grounded theory can lend themselves to researcher bias. In individual interviews there are many ways by which 'errors' can be made by both the interviewer and the participant which may lead to 'bias' in the results. With interviewer bias, the interviewer may subconsciously give subtle clues with body language, or tone of voice, that subtly influence the subject into giving answers skewed
towards the interviewer’s own opinions, prejudices and values. However, the interviewer, in
the current study, aimed to minimise the likelihood of such bias arising. During the interview
process, the interviewer acknowledged her own influence on the direction of interviews
through detail-oriented elaboration and clarification probes. The researcher made continuous
decisions as when to employ these probes in order to encourage understanding of parents’
and team members’ experiences. The researcher also acknowledged her own areas of interest
likely determined the use of probing questions. In doing so, the researcher introduced her
own values and understanding into the emerging data.

The researcher made every effort to set aside any preconceived assumptions to
discover what was most important to participants. The researcher was also mindful of her
own experiences and beliefs, which have inevitably had some influence throughout the data
collection and indirectly shaped its outcomes. During all steps of the research process, the
effects of the researchers were assessed. There were regular meetings between the researcher
and supervisor, during which they discussed data and emerging themes, and were able to
reflect on how her background might impact on their interpretation of data.

During the focus group interviews, the researcher acted as a moderator whereby
collecting the data may have a major impact on the quality of the data. For example, the
moderator’s facial expressions, body language, tone, manner of dress and style of language
may have introduced bias. In addition, the moderator’s age, social status, race and gender
may have produced bias. Although some of these influences are unavoidable, every effort
was made to control some of the physical influences, such that the moderator attempted to
remain neutral in dress, tone and body language.

Throughout the focus group discussions, the moderator was aware that there were
many potential opportunities for bias to occur. For example, some participants may have felt
that they could not give their honest opinions due to the psychological pressure on them
arising from their concern as to what other members of the group may think. Some may have
been tempted to give opinions that they felt would be respected by the group. The presence of
one or two 'dominant' participants may have repressed the opinions of others. Some may not
have felt confident about expressing an opinion. The interviewer, however, observed and
monitored the way in which the participants reacted and interacted in the group.

One consideration taken into account was the way in which participants viewed the
researcher. This may impact on responses, for example, participants were aware the
researcher was not working within the Early Intervention service and this knowledge may
have led participants to respond in a more open way. Through careful planning and management many difficulties arising were overcome and the most value from both individual interviews and group discussions was obtained.

3.10.4 Awareness of Researcher Effects

The grounded theory method of data analysis encourages the researcher to set aside any preconceived assumptions and discover what is most important to participants. In keeping with qualitative tradition, the research attempted to suspend her biases, assumptions and judgements in order to facilitate parents’ and team members’ free expressions of their own experiences. The researcher had an awareness of their own influence on the research. Constructivist arguments were noted, whereby the researchers’ interpretation and construction of the data through the filter of their own experience and understanding of the area of study were emphasised (Grbich, 2007). During all steps of the research process, the effect of the researcher was assessed. Adequate accounts of these effects are presented in the study, as the frame of discussions of limitations and strengths of the study, and transferability of findings.

Although the researcher acknowledged that her preconceptions influenced data analysis, she aimed to remain as true to the data as possible by choosing participants words to code data. In addition, data was coded by a second researcher and is open to reinterpretation. Data generated through social interaction between the researcher and participant, inevitably led the researcher to influence emerging data as the personal-self becomes inseparable from the researcher-self.

Many qualitative researchers argue that reliability and validity remain within the realm of the positivist or qualitative tradition and thus are less of a concern for the qualitative researcher (Marshall & Rosman, 1989 cited in Silverman, 2000). It is incumbent upon qualitative researchers, however, to include these methods to justify engaging in research. Polit and Hunglar (1999) stated that qualitative data is very intensive activity that requires insight, ingenuity, creativity, conceptual sensitivity and hard work. Data analysis was not an easy process, it was time consuming and the researcher also had to consider the trustworthiness of data. Trustworthiness was an essential component of qualitative research. One strategy that was used to maximise the trustworthiness of the findings was to undertake bracketing which contributed to trustworthiness by helping the researcher ensure that their beliefs did not influence the collection of the data and its analysis. Bracketing was a process of suspending personal beliefs so that the researcher entered the world of the research.
participant. In this way biased results were avoided and a reliable description of the participants’ lived experiences were provided.

Reliability was enhanced in the current study by involving more than one researcher in the analysis process. The themes, codes and categories identified by each researcher were compared and differences discussed. Furthermore, Silverman (2000) suggest that a study’s validity is enhanced when the researcher actively searches for evidence that contradicts as well as confirms explanations being developed, which was also completed in the study.
Chapter Four: Results

4.1 Chapter Introduction

In this chapter, the results of the grounded theory analysis will be presented. The chapter will begin with an overview of how the data will be presented. The findings of the study will then be presented in three broad sections. Finally, the chapter will end with a summary of the findings.

4.2 Overview of Data Presentation

The results are presented in three sections, reflecting the three main research questions:

1. Section one describes themes regarding parents’ experiences of the multidisciplinary approach in operation in the Early Intervention services.

2. Section two outlines the main themes regarding parents’ experiences of the transdisciplinary approach in operation in the Early Intervention services.

3. Section three outlines the experiences of the transdisciplinary approach identified by team members in the Early Intervention services.

4.3 Contextualisation of the Findings

In section one and two, the aim of the research was to focus on, and explore, parents’ lived experiences of the multi- and transdisciplinary approach in Early Intervention services. However, before considering the kind of approaches or services parents wanted, a number of issues arose which were very important for families. As such the parents spoke about issues that were more pertinent to them before they could consider what they wanted from the service. These factors are reflected clearly in the findings and the emerging themes which transcend the initial scope of the study. In section three, the aim of the research was to focus on team members’ experiences of operating the approaches in practice in the Early Intervention services.

4.4 Section 1. Parents’ Experiences of the Multidisciplinary Approach

This section will outline the findings relating to parents’ lived experiences of the multidisciplinary approach in practice. The research revealed five core themes each containing a number of sub-themes. The themes are as follows: (1) Coming to Terms with Child’s Disability, (2) Coping Strategies, (3) Experiences of the Multidisciplinary Approach
(MDA), (4) Operating as a Multidisciplinary Team and (5) Shifting (from one model to another). The themes are presented in Table 4.1 and described further in the following section.

Table 4.1 *Core themes and sub-themes for experiences of the multidisciplinary approach*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub Themes</th>
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<td>1 Coming to terms with child’s disability</td>
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<td>• Dealing with disclosure process</td>
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<td>• Establishing a sense of normality</td>
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<td>2 Coping strategies</td>
<td>• Information</td>
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<td></td>
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<td></td>
<td>• Sharing experiences</td>
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<td>3 Experiences of MDA</td>
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<tr>
<td></td>
<td>• <em>Child-centred approach</em></td>
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<td>• <em>Readily accessible &amp; available</em></td>
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<tr>
<td></td>
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<td>• <em>Gaps</em></td>
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<td>4 Operating as a Multidisciplinary Team</td>
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<td>• Individualisation</td>
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<td>5 Shifting (from one model to another)</td>
<td>• Mixed Feelings</td>
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4.5 Theme 1: Coming to Terms with Disability

The themes which centre upon coming to terms with their child’s disability encompass the continuing efforts of parents involved in searching for Early Intervention services for their child to promote the best developmental outcomes possible, the manner in which the family deal with the disclosure process and their ability to establish a sense of normality in their lives. These themes reflect parents’ awareness of the importance of effective Early Intervention approaches at early stages of their child’s disability.

4.5.1 Searching for Early Intervention

In 2004, when the traditional multidisciplinary approach of Early Intervention was in practice, some parents were given their choice of service they wanted for their child. Parents spoke about their wide selection of services available to choose from at that time.

P3: In 2004 it was parental choice was the order of the day.

There were mixed feelings expressed by parents when they had full responsibility for the selection of the Early Intervention service, with little or no guidance.

P3: There was pluses and minuses to the parental choice thing because you really…we didn’t especially for first time child with special needs you haven’t a clue I didn’t know what he was going to need.

Parents showed a good knowledge and understanding of the potential benefits an Early Intervention approach could have for their child.

P3: It’s definitely made us aware that the earlier you intervene the better for the child.

P1: It is so critical…and if you can put it in those first 2 to 3 years it’ll pay huge dividends to how well they’ll walk, how sociable they’ll be.

When parents experienced challenges and/or disorganisation during the referral process, it tended to taper their views of the referral set-up to the Early Intervention service.

P7: It’s a disaster…they were just a joke like but there’s no thought-out approach to referring and that’s a big thing.

P3: The whole referrals and that CDC [Child Developmental Centre] is a disaster.
One parent of a child with an unknown diagnosis faced more challenges than others when looking for a referral to the Early Intervention service. Even aware that the child would not have been fully suited to intervention, she was still left her feeling disappointed.

\[ P2: \text{I found it disastrous...we fell between all stools so we didn't get referred...now she was quite ill in that she was on heart failure by 18 months so she needed a pacemaker so she wouldn't really have been up for much before that anyway.} \]

4.5.2 Dealing with Disclosure Process

Parents had many different experiences when learning about their child’s disability. Certain factors were shown to be crucial for parents when dealing with the disclosure process, such as, the time lapse between the suspicion of disability and the diagnosis and the stating of a certain diagnosis compared with an unknown diagnosis. Parents shared their individual experiences of how they learned about their child’s disability for the first time.

\[ P1: \text{His diagnosis was made about 3 months after he was born.} \]

\[ P2: \text{We didn’t know anything until she was 2 days and she was whipped off us like straight to open heart surgery.} \]

\[ P3: \text{We were in the unusual situation that we knew am while I was pregnant that he would have Down syndrome.} \]

Another factor that shaped parents’ attitudes of the disability was whether the disclosure by the professionals seemed sympathetic and understanding in their approach, particularly the level of guidance conveyed during this critical period.

\[ P5: \text{The geneticist in Dublin didn’t really give me any...kind of direct me in any way as to where I go from here...I didn’t really have a clue where to go from there. His words were “if you think your daughter is going to walk down the aisle or even make her Holy Communion, it’s not going to happen”.} \]

Parents of children with an unknown diagnosis tended to have more negative feelings towards the service than parents of children with a stated diagnosis.

\[ P2: \text{We don’t have a diagnosis which is even worse because we are so isolated we’ve nowhere to go like...We’re in limbo most of the time...I’ve nowhere to go so you can’t say “Where’s my group?”} \]
Parents’ reactions to the disclosure varied across families and were influenced by an immediate or a delayed response from the team in the Early Intervention service.

P1: Very good, I was very impressed that there were people sort of attending to us so early.

P3: I was having the horrors during pregnancy...we were ready to hit the ground running and hit an absolute dead stop...we were told someone would come to you in the hospital and talk to us about getting into the service; that didn’t happen.

Feelings of shock were common at the time of disclosure.

P5: I mean you could have dropped a bus on my head and I would have been less you know I was totally shocked.

4.5.3 Establishing a Sense of Normality

Changes to life styles and routines were necessary in order to adapt to and provide for the child’s care needs. Families had to readjust and be flexible in order to effectively respond to their child’s disability.

P3: You are there at home and you are trying to build in these things into normal day-to-day living normal and day-to-day routines whether it is from how he is sitting to how he is eating to you know the toilet to naming things.

Another mother spoke about the constant struggle and activity in her life.

P2: It’s hard to switch off when you have a child with special needs...you’re kind of pushing stuff all the time.

Parents wanted other people to accept their children for who they are, which facilitated a sense of normality in their lives, but other people endeavoured to enforce their models of normality on their children. Consequently, parent commented on this hardship.

P7: If you went to a normal baby group, like anytime I took Jack anywhere like that you always had the sly looks like the this and the that...I felt like saying “would you ever F**k off and mind your own business”.

P3: I don’t want to bring him out into a supermarket or somewhere and him misbehaving and people to go “Oh sure he’s got Down syndrome God love him” that’s not good enough I don’t want that shi*, I don’t want that.
Parents minimised their child’s disability if they were comparable to typically developing children of the similar age. This was certainly the case if their child had the ability to attend mainstream school; this embedded a greater sense of normality for the families.

_P1_: We were lucky in that regard because he was…I suppose compared to other children he is a bit more able.

_P6_: He is able to be in a mainstream setup as a result of all the intervention that has taken place.

Having successfully adapted to the changes in their lifestyle, parents felt a greater sense of normality in their lives.

_P3_: We have kind of come out of our bubble a little bit we have kind of realised that parenthood is more than just about medical intervention, and Early Intervention and you know it kind of just took over our life we are beginning to enjoy it.

4.6 Theme 2: Coping Strategies

Many different coping mechanisms were identified by the parents. Adequate information about the child’s disability seemed to be a very important determinant of how parents accepted the disability. The way in which professionals supported children with disabilities and their families had potential to enhance or to impede families’ ability to cope. For many parents the realisation that they were not alone and having the opportunity to share lived experiences with other parents was a crucial turning point in their lives. These strategies appear in the following results and examples.

4.6.1 Information

Parents emphasised the importance of getting adequate information and advice at the beginning. Parents found it valuable and helpful.

_P6_: Plenty of information would be a definite thing in the first place…it’s very important.

_P2_: You need advice. _P7_: Well you need guidance. _P3_: You need advice.

Some parents appeared to have better coping strategies in place. These parents admitted that they had been informed well by the team members about their child’s diagnosis and treatment.
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P9: You’re given guidance, you’re given information, you’re pointed in so many different, you know, in all these possible directions so, you know, little hints you pick up and they’ve all been of benefit to Jim.

Parents who made use of good coping strategies tended to have a better understanding, a realistic outlook of the child’s disability and acceptance of the situation.

P3: They don’t have you know a disability per say, they are just delayed in getting to holding themselves up, sitting up and walking and so on crawling and walking so you need someone to guide you and show you the right things to do.

P8: Mary will drive in the road and she won’t shut-up the whole way in and the minute you sit her inside with the speech therapist...wouldn’t even look up from the table you know...she just shuts down but that’s their nature.

One parent who struggled to understand the nature of their child’s disability showed greater difficulty with coping and had a pessimistic view of the disability.

P7: He is just so ploddingly slow...he’s going to be delayed anyway but it just seems like we are getting...literally its inches...he just basically doesn’t cooperate...and I find his speech is dreadful.

4.6.2 Support

The parents regarded the help and support from the services as an effective intervention for improving the wellbeing of both parents and children. In particular, some parents spoke about how they felt continuously supported by the team members in the Early Intervention service.

P1: They don’t let you fall by the way side which from my experience was fantastic...she would come once a month and as she saw that we were coping she would ask what our needs were she would come once every quarter.

P6: Without them we would have been lost...they were absolutely fantastic from day one.

P9: It was a great pillar to have there...it was excellent.

Parents reached out and sought support in different ways. One important form of support was having good contact with the team members. It was important to parents as they needed reassurance that they had a team to contact if they needed help.

P6: You could ring them anytime of the day or anytime you could ring them to say you had a problem.
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P5: No matter what I’d ring them and ask for advice on this or that and they’re always at the end of the phone and they’ll always take the time to listen to you or do anything they can to help.

In other cases, parents spoke about not having contact with the team members, leading them to feel isolated. For certain parents they consequently found it increasingly difficult to cope with their child’s disability.

P2: There’s no contact and you are sitting there watching Tom, Dick and Harry running around the place and you’re seeing them all speaking and I can hardly drive pass the school in Doon at the minute because I’m having heart palpitations about next year.

P7: I think I’ll have to go in and scream and shout and get somebody to come out and talk to me or for me to come in and talk to somebody…Nothing’s being offered.

4.6.3 Sharing Experiences

Group sessions were provided as part of the multidisciplinary approach, which provided supportive and safe group sessions for parents and children to actively participate together. Parents highlighted that the conversations and the exchange of experiences with other parents who had a child with a disability had been very rewarding.

P9: We learned from other parents of children…that baby group at the beginning, you’re exposed to other parents…you’d have chats with the parents as well…we were given a lovely environment.

P6: With those baby groups…we really did very well and other parents did very well from us and we did from them, just looking at each other and everything.

Some parents felt that parents who were in a similar situation had a greater understanding of what they were dealing with than others.

P5: You could talk to parents who were probably at the same stage or in and around and you knew that they understand where you are coming from.

P7: It felt like you weren’t alone well you know?

4.7 Theme 3: Experiences of the Multidisciplinary Approach

Parents were given the opportunity to describe the most and least favourable characteristics of the MDA in practice in the Early Intervention services. Parents reported experiences of the MDA are divided into positive client-focused values and obstacles to client-focused values.

4.7.1 Client-focused Values
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Having a child-centred approach in the delivery of services, together with parent empowerment, having readily accessible and available services, and home-visits were considered by parents as important indicators of quality in the MDA. The parents’ experiences of the MDA in the services are presented in the sections that follow.

4.7.1.1 Child-centred Approach

One important characteristic of the MDA was that it operated as a child-centred approach. Parents spoke about how the MDA provided their child with comprehensive care in all areas of development. Parents explained the ways in which the MDA was able to meet their child’s needs by having the team and parents working together while focusing on the child’s goals and targets.

P5: We’d all make goals from short-term to long-term goals…so we were all singing off the same sheet. We’d always be striving to reach something that we weren’t just dealing with everything day-to-day that there was goals at the end of it.

P6: They were always focusing on the strengths of the child and you know you could sit round there and try to get, you know, the most potential and the best of the child in that environment.

Team members on the multidisciplinary team used a variety of strategies to formulate and implement interventions for children. One parent commented on how their ability to liaise with the school helped with the child’s development.

P3: I think it is very important then that the Early Intervention services links in with the primary school pre the child going to class or school in September, so the school can learn the abilities of the child and also the needs of the child so they can put the correct resources in place to support the ongoing development of the child.

For some parents, the Early Intervention service’s preschool was available to their child in preparation for mainstream school. Parents felt that attending preschool and playgroups in the MDA benefited their child.

P6: What was nice about it was that it gave Frank a classroom environment here…it’s got tables and chairs and he got used to going over to get this work and sit down in the morning, hang his coat up…little routines that stand to him now that he’s in mainstream school…he loves going to school now.

P3: The nursing team here with the Montessori teachers and the whole setup downstairs with the structure and the routine has really put in place a very good
grounding for Andrew going into you know 500 people in a mainstream school, 20 in a class, 1 teacher and an SNA from time to time and so that’s a huge strength.

4.7.1.2 Parent Empowerment

Parents felt empowered when they learned to help their child, this enabled the parents to become actively engaged with the child’s programme. Parents sought to be involved in and participating with interventions in place for their child.

_P5: I was very much involved in the session so I would know exactly the way they were doing, say with the physio the way she was doing the exercise and the proper way of doing them._

The service facilitated continuous inclusive for parents which bolstered their self-confidence when learning how to put interventions into action.

_P3: That would be the strength of the initial aspects from our experience of this service was that the parents were involved in every step of the way and we learned._

The MDA offered advice to parents which helped them to attribute positive changes to their own strengths over longer periods.

_P5: The best piece of advice they gave me was you can’t make a child do something, you have to create the environment to encourage them to do it and for the last six years this has made sense._

4.7.1.3 Readily Accessible & Available

The presence of appropriate approaches which were readily available to parents was an important determinant of quality. This highlighted what parents wanted from an Early Intervention service. Parents spoke about their experiences of being offered plenty services within the MDA.

_P1: I am astounded and I was amazed at all the stuff being brought to us you know we didn’t even seek it out._

The importance of having an available team was mentioned.

_P5: If it kind of wasn’t for the Early Intervention services…she would have just been left with her diagnosis and that was it._

Some parents spoke about the integrated and coordinated interventions which were delivered to children during Early Intervention preschool time.
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P6: In the playschool they would be taken out of class and he would still get his physio and his occupational therapist and his speech therapist. He still had all of those things even though, you know, they weren’t coming to the house, he still had them in school time.

P5: She got all her services for the week and it was a little bit easier than making 3 appointments.

4.7.1.4 Home-visits

Home-based visits were a significant attribute of the MDA. They were regarded as hugely beneficial to many of the parents. Positive outcomes for the parents were reported when interventions took place in a home-based setting and were supervised by the team members.

P6: She came to the house so we were in our home environment… it was great, it was fantastic.

P3: I can’t recommend strongly enough the Early Intervention delivery in the home.

Several parents commented on how the team offered practical advice and addressed issues, such as emotional demands, during home-visits.

P9: If a parent had a few children at home and a child with disability it’s hard for a parent to get down to a service whereas if you had a home-visit it was fantastic, you know? If somebody is coming to your house… and you’re much more relaxed in your own house as well.

P5: At the beginning I didn’t want to go out. I didn’t want people looking at me. I didn’t want to have to face people’s questions and what, and this is yours and then looking at him and then going you know... I felt because it was new to me... how do you tell people... how do we you know what are we going to say. I’m sick of explaining the way he looks.

One parent described the team members as having a role in educating families within the learning culture of the home-visit.

P3: Therapist coming out to the house helping parents to do things the right way because you could be doing stuff and you could be giving them a curve in their spine or a twitch in their eye or God knows what but you’re trying to do the best.

Within the MDA, having structured activities provided a framework for the delivery of home-based services. The use of toys and demonstrations by the team members were useful in enabling families to learn.
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\[P1\]: She would come and bring activities to the house, very similar to these puzzles and books and things...they would bring extra things and it’s just maybe practical things that you wouldn’t have thought about like pegging, clothes pegs around a tuber ware container small things like that.

\[P3\]: She would come out and do the physical therapy so you really got going from the get-go on all of the hand-eye coordination stuff, getting them into the position, getting them ready for holding their head up...that basically was home-visits.

### 4.7.2 Obstacles to Client-focused Values

For the most part, parents’ negative experiences were in relation to inconsistencies and practical issues in the service. These experiences are presented in the sections that follow.

#### 4.7.2.1 Gaps

Some parents felt that there were insufficient services delivered by the MDA and found that getting enough services was often challenging. Parents felt that the inconsistency and gaps in the service would play a negative role in their child’s development.

\[P2\]: You can count in one hand literally now...I found we have we have gone private for everything we have a private physio we have a private speech lady that we see every week. We’re in limbo most of the time so we’re kind of and that’s how we operate so...I may as well be living on the moon.

One parent felt that the MDA was neither well-coordinated nor made an effort to meet her child’s developmental goals.

\[P2\]: I want her to walk independently I want her to speak...they’re huge goals in Fiona’s life but they want to kind of plod her along just to kind of, “Oh we’ll do a bit of physio you know?” The end goal is not to get her walking the end goal is to get her on a walker...am speech they want to put in PECS and fair enough she needs PECS but they don’t want to work on her speech do you know what I mean?

One parent commented on the poor time management of the service. Parents were increasingly frustrated about the amount of time the team spent on paper work, which created gaps in the child receiving interventions.

\[P7\]: It seems to me that the HSE are full of...kind of a lot pencil pushers and a lot of filing and a lot of paper work, and that personable thing is gone, it’s all about reception, files, eh a lot paperwork.

#### 4.7.2.2 Integrating Interventions

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When the delivery of therapies was integrated into the Early Intervention preschool schedule, parents noticed their involvement with the team decrease. Although this was more convenient for families, some parents spoke about the way information sharing decreased.

\[P3\]: The support therapies of OT and speech and physio or physical therapy all happened behind closed doors whereas prior to that we were involved so you really didn’t know what was being delivered, when and how frequently.

\[P7\]: The issue we have with that is that we didn’t know what they are getting in terms of the additional therapies because you weren’t there until you maybe sat down with one or two of the therapists in the IDP or IEP.

### 4.7.2.3 Replacing Staff

Another constraint with the delivery of services in the MDA was that when staff were absent or on leave, there were no replacements to cover their roles and responsibilities. This led to a lack of continuity in the service.

\[P3\]: Another thing that is a disaster in this service...there were definite huge gaps in Andrew’s development when the nurses went on maternity leave.

\[P7\]: The problem is, it’s not even the inconsistency, the problem is…P8: They don’t have them replaced…P3: They don’t replace them and you might if you’re lucky see a physiotherapist.

### 4.7.2.4 Isolation

A parent who did not get adequate assistance with decision-making for schooling struggled to cope. She spoke about the isolation and added-stress this caused.

\[P7\]: Nobody is saying to me look “Jack is going to be 6 next April school in September” sit down with me, what do you need to do? What do you need us to do? Do you want us to go and talk to Catherine McAulay, do you want us to talk here, sit down and say and give me feedback…I mean now because I’m doing all the ringing around of schools and I’m losing sleep over this because I’m thinking am I doing the right thing as a parent?

Some of the implicit expectations that some parents had, and the lack of fulfilment of these expectations led to increased isolation and frustration.

\[P2\]: We were on our own doing nothing like we had no support…I was half psychotic at that stage…I had absolute nowhere to go to and no feeding team, nobody, paediatricians nobody.

\[P7\]: Nobody looks after parents at all in any sort of a service…they don’t look after you as new mothers.
Chapter Four: Results

4.8 Theme 4: Operating as a Multidisciplinary Team

4.8.1 Relationships

Parents felt content when they had developed quality relationships within the Early Intervention service. Parents felt a great sense of inclusion and community with the team members of the intervention service and this was valued greatly.

\[ P9: \text{You had the best of both worlds. You had almost a friendship with them, you know? That you could see and there was a great bond built up with us as parents and the child.} \]

\[ P5: \text{You’d know by them, that they actually really gave a shit about Ciara.} \]

The parents enjoyed the personal side to the team-based aspect of the model. Parents felt like they were part of the team.

\[ P1: \text{I knew them personally and they knew me personally.} \]

\[ P5: \text{What I liked about it as well it was personable you went into the service and someone met you at the door and said “Hi” and you have a cup of coffee and you felt like you were part of something.} \]

Parents valued the presence and assistance of the team members in the delivery of services. Parents highlighted the important characteristics of the multidisciplinary team members.

\[ P8: \text{I think the centre of the place was the staff members.} \]

\[ P8: \text{She is an absolute star she is…every member of staff should model themselves on her, shouldn’t they? P3: Absolutely she’s so proactive P8: She’s absolutely fabulous but she’s out with her pregnancy again.} \]

4.8.2 Guidance

Parents spoke about their early experiences of working with the multidisciplinary team. One parent mentioned how she found the team approach stressful in the beginning.

\[ P1: \text{I was trying to cope with the situation of my first baby you know I suppose not being 100% and I did I found it a bit stressful initially all these people coming at me wanting to do all these things but that was I suppose it was fine it was just me who had to try and cope with the setup.} \]

Parents identified the ways in which they were given guidance and support by the team. In some cases working with the team was initially challenging but later they were able to see the benefits of the team’s guidance.
Chapter Four: Results

P5: They were fantastic where they knew, one way of putting it was they sorted my head out and they got me in to a way of thinking...they were really a backbone for me.

P6: I think you need somebody from the outside to come in and help you because sometimes you might not extend your child to the limit they can actually reach, because you are emotionally involved.

Parents found the joint team-working aspect of the approach was very helpful, particularly with regards to the assessment process.

P6: They were all sitting down for the assessment...we had a board and they wrote down what would his needs be.

P9: Us and Jim and a group of people with us as well, you know, so it was very good now...for us it was very important...those kinds of groups...they were always very honest assessments.

4.8.3 Promoting Optimal Development

Many parents identified how the team in the MDA helped their children achieve good outcomes in the different developmental areas, such as, cognitive, sensori-motor, communication and language and social-emotional. A father explained that his daughter had better understanding.

P2: I suppose expressively she’s not able to get her stuff out but like the other side of it language she understands everything.

Parents spoke of how the team helped the child’s sensori-motor development by motivating the children to walk.

P5: I definitely don’t think, if I hadn’t got in contact with the Early Intervention I’m 100% positive she wouldn’t be walking or talking now.

A mother described how progression in communication helped to fill a void at home.

P3: It was just so invaluable in helping the whole communication vacuum to be filled because he was doing a little bit of this and we then started putting Lámh signs to it and he was using that and then he started to articulate the words.

Parent gave examples of how their children had progressed in the ability to engage socially.

P6: His social skills are fantastic.
Chapter Four: Results

P9: Our experience is an experience with a lovely, sociable child who’s healthy.

Several parents’ expressed their satisfaction with the multidisciplinary team. Parents acknowledged the efforts made by the team.

P5: I couldn’t praise them enough I really don’t think Claire would be at the stage she is at today if it wasn’t for the team that she has had like for the last 6 years…I really don’t think she’d be half the child she is today without them.

4.8.4 Individualisation

As part of the MDA, individual team members would meet with the families and complete their own discipline specific interventions at different times. Most parents were satisfied with the discipline specific one-to-one interventions put into practice. Parents recalled how the multidisciplinary team members individually worked with the child.

P6: Separate teachers would teach him…the physio would give us a programme to do from week to week so to do this and to do that exercise and the same with the home teacher.

P4: We had physio intervention and then the speech therapist would also work with him.

One father preferred one-to-one sessions for his son over group interventions which were also an option in the service.

P9: For us the group session didn’t work because it was, there was too many distractions for Jim…he needed the one-on-one.

4.9 Theme 5: Shifting (from one model to another)

4.9.1 Mixed feelings

Although negative experiences were expressed by some parents, others did not experience any major difficulties or problems during their time in the service.

P9: Over all those years, I would find it very hard to find negatives in our experience.

P4: I’ve got on good now; got on great…I’ve never had a problem with them or anything like that.

4.9.2 MDA versus TDA

One parent had two children with disabilities attending the ECI service and had experience of both approaches in practice. The parent mentioned the lack of access to services currently.
Chapter Four: Results

P8: With the new model [transdisciplinary] now there is no comparison at all, we’ve been here once or twice…it’s fine for us because we’re ahead of here but for new parents coming in that meet anyone else you know they must think “geez we’re the only ones”…I can see what was there and what is there now because of the 2 girls…if I started where I am now with Jane sure I would know nobody I would have no place to come to I would be coming in here once a month, not knowing is this right or wrong or am I doing the right thing?

Group interventions were no longer available as part of the MDA. The parent spoke about the experience of the group interventions that took place in MDA. The parent felt group interventions facilitated building relationships with other parents.

P8: What is…was brilliant about that service that ye don’t know now but with Jane now in the second one…is we got to know the all these people [parents]…and we’ve friends out of it and Pamela has friends out of it.

The parent went on to explain her experience of the loss of group interventions.

P8: We haven’t met anyone only the therapists we’ve met no parents, there’s been no group there’s been no introduction and I’ve asked about it and it’s not there and it doesn’t exist anymore. That’s an awful loss.

P3: Awful loss. P7: It is yeah it is a big loss.

Changeover from the multidisciplinary approach to the transdisciplinary approach did not sit well with parents who were happy with the delivery of existing services at the time.

P3: Well one of the major difficulties was in the first 4 or 6 months into the service back in 2004, the CDC tried to withdraw it… they were changing the model…and we were hearing all kinds of rumours of how disjointed this new model was going to be, this play-based model that they’d be going in for an hour for 6 weeks and then you wouldn’t see them again for a year and all this kind of stuff.

One parent who entered into the service during the changeover to the TDA spoke about her experience of the service that she received.

P2: It is diluted, there’s nobody watching you, you go into physio there’s no programmes given and it’s only because we go private we get our programmes and we do what they tell us at home, it’s not because the crowd here are telling us.

Other parents who opted to remain in the MDA were happy with their decision.

P3: Yes and certainly don’t regret it, even though there are gaps but it’s certainly a dam size better than what new referrals are getting…from what we hear.
4.9.3 Recommendations

Recommendations from parents for the delivery of approaches in the future of Early Interventions services were gathered. One parent emphasised the importance of obtaining consistency and continuity in the delivery of approaches.

P3: It’s the consistency and the continuity of delivery so a continuum of delivery, very important in the early years, recommend strongly enough, the Early Intervention delivery in the home…coming out to the house helping parents to do things the right way.

Another parent expressed the desire to receive home-visits from the team and to be involved in the child’s interventions.

P7: Certainly the first 3 years of life that home-visits, practical direction and guidance in the home…then after that it is the preschool setting but what they have to change in the preschool setting for kids of the future is to involve the parents more.

One parent highlighted the importance of maintaining parents’ participation and they also wanted the service to provide a detailed checklist for parents to examine their child’s developmental areas.

P3: Make sure the parents know daily what it is the child has achieved and what it is in terms of homework for the next day or the next week. A checklist, this is something I have said a dozen times recently because I have been frustrated because I’ve learnt about things that I should have known about 3 years ago.

Some parents spoke about what they really wanted for their child. One father highlighted the importance of investing in the child in the early stages.

P8: You want them out and about and have their little job and their little life yeah and if they can do that they’re not going to be a burden on society whereas the system are not they’re not fully prepared so they’re going to be a burden so down the road while it might cost a few pound down the road it will pay dividends hugely it will pay off tremendously.

Taking into account the parents’ suggestions and experiences, there seemed to be common ground in what parents wanted for their children in the future.

P7: I want them to be integrated and enjoy the best of their potential.

P2: Reach their potential I think that’s what any of us or any parent wants.
Chapter Four: Results

Coming to terms with disability:
- Searching for Early Intervention
- Dealing with disclosure process
- Establishing a sense of normality

Coping Strategies:
- Information
- Support
- Sharing experiences

Experiences of the Multidisciplinary Approach

Client-focused Values:
- Child-centred
- Parent empowerment
- Readily accessible & available
- Home-visits

Obstacles to Client-focused Values:
- Gaps
- Integrating interventions
- Replacing staff
- Isolation

Operating as a Multidisciplinary Team:
- Guidance
- Promoting optimal development
- Relationships
- Individualisation

Shifting (from one model to another):
- Mixed Feelings
- MDA versus TDA
- Recommendations

Meeting Expectations

Figure 4.1 Tentative Model Depicting Parents’ Experiences of the Multidisciplinary Approach
4.10 Section 2. Experiences of the Transdisciplinary Approach

This section will outline the findings relating to parents’ lived experiences of the TDA in practice. The research revealed six core themes, each containing a number of sub-themes. The themes are as follows: (1) Coming to Terms with Child’s Disability, (2) Coping Strategies, (3) Experiences of the Transdisciplinary Approach (TDA), (4) Operating as a Transdisciplinary Team, (5) Experiences of Key Worker System and (6) Facing Challenges. The themes are presented in Table 4.2 and described in the following section.

Table 4.2 Core themes and sub-themes for experiences of the transdisciplinary approach

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4.11 Theme 1: Coming to terms with disability

The themes which centre upon coming to terms with the child’s disability encompass the continuing efforts of parents involved in searching for Early Intervention services for their child, the manner in which the family deal with the disclosure process and the ability to establish a sense of normality in their lives. These themes reflect parents’ awareness of the importance of effective Early Intervention approaches at early stages of their child’s disability.

4.11.1 Searching for Early Intervention

Parents shared both their positive and negative experiences of the referral process. These early experiences of contacting the Early Intervention service tapered parents’ views of the service in which they sought interventions. Immediate access to the service was favoured by the parents.

P8: I’d have to say it is very positive, we were brought on line very quickly which was a huge help…they came to me before I kind of came to them which was fantastic.

P5: We have been very lucky in that we had very good structure in place from the word go.

However, gaining access to the service appeared to be challenging for some parents. In certain cases, there was a delay or struggle in getting a referral. One parent spoke about a mix-up with the referral letter, which caused a greater delay in her daughter’s referral.

P1: The referral was suppose to be sent here, it got lost in the mail so I had to then go through my local GP…so it was something that should have taken no more than 3 months took until March [8 months].

A father spoke about having to pester a local politician, in order to get a referral for his son.

P2: It ended up with me having to go up to Willie O’ Dea’s office and sit there until Willie O’ Dea actually got pissed off with me and then we actually got the phonecall at 10.30pm one night saying to bring Andy over to the service…Oh I kicked and screamed.

A mother explained how she was forced to take action against the service to obtain the appropriate help required for her child.
Chapter Four: Results

P3: I went through the Disabilities Act 2005, where by law your child by the age of 4 has to be seen by these professionals so I went down that route so they were all very quick to react then.

When parents had good knowledge and understanding of the potential benefits Early Intervention would have for their child’s development, they were more anxious to commence the intervention process immediately.

P6: It’s always better to catch something earlier better than later I always felt grateful that Fred was diagnosed so early...a year between the age of 0 and 5 is a massive massive difference...the earlier the intervention is given the more powerful it is.

P7: I knew that if it was autism that the sooner we found out the better for him because Early Intervention like is the big thing that you hear everywhere and it was a big media topic at the time.

4.11.2 Dealing with Disclosure Process

There were many different experiences shared by parents about the disclosure process and parents explained the ways they dealt with the disclosure of their child’s disability. Parents spoke about discovering their child’s disability for the first time.

P8: There was query initially but obviously it was diagnosed very quickly.

P9: It’s very hard to hear...it’s is hard to think there is something wrong.

Parental reactions to the disclosure varied across families and were influenced by an immediate or a delayed response from the service. Parents were more positive when there was an immediate response.

P8: Jack was here within 8 weeks of his birth which was fantastic.

A delayed diagnosis proved to be more difficult for parents.

P7: It took around 18 months before we finally got a diagnosis which was awful.

The ability to deal with disclosure was influenced by the manner in which the information was delivered. Parents shared their negative experiences of the disclosure process when little or no information was given with the diagnosis.

P9: I went in thinking that he’d be okay, and this one I’ve never seen her since and I don’t want to see her...first thing she said to me “you’re not stupid, he’ll need special needs going to school”...and they wouldn’t tell me what it was or why.
Chapter Four: Results

P10: The day Derek was diagnosed the psychologist told me I was on my own and I had to drive 20 miles out the road...I cried the whole way out...I don’t know how I got home...I just cried the whole way...I don’t think I should have been told on my own, they should have had a social worker out to us telling us...they never told us what we were entitled to, never told us what to apply to for, nothing.

Some parents found it more challenging than others to deal with their child’s disability.

P2: Sometimes I look at him and God I wish he would do this or throw a tantrum or he would want to do this.

P4: I actually think there should be a counsellor here as well...because you would have a lot of issues around it.

4.11.3 Establishing a Sense of Normality
Changes to lifestyles and routines were necessary in order to adapt to and provide for the child’s care needs. Families had to re-adjust and be flexible in order to come to terms with the child’s disability. Parents spoke about how they achieved this.

P2: I find with a lot of things it was a lot easier to bring him up than it was the other two because he doesn’t expect as much.

P3: He is slower at a lot of things but he is a very enjoyable child and we all love him to bits, we’ve all adjusted well and we are all mad about him.

Having successfully adapted to the changes in their lifestyle, parents felt a greater sense of normality in their lives.

P8: He is one of four...you can’t let them or Down syndrome take over your life.

4.12 Theme 2: Coping Strategies
Many different coping mechanisms were identified by the parents. Adequate information about the child’s disability seemed to be an important determinant of coping. The way parents and services represented the child’s disability was another predictor of parents’ ability to cope. Another coping strategy used was the support provided by professionals to the children and their families, which had the potential to help or hinder families’ ability to cope. These strategies appear in the following results and examples.

4.12.1 Information
Parents highlighted the importance of getting valuable information and guidance from the professionals.

P8: They were guiding you along the way you obviously wanted to do as much as you could...if I wasn’t informed or given structured guidance you wouldn’t know where you were going.

P4: They are used to children on the autism spectrum so we are taking everything that they say to heart you know and dealing with it.

4.12.2 Representation of Child’s Disability

The child’s disability was presented by parents as more severe when they had greater difficulty coping with the disability.

P7: Autism was number 5 on the list and to me that was the worst thing that could possibly be wrong with him but I didn’t know that much about it at the time either but I had a vague idea.

P10: It never entered our heads that he had a disability...but like autism autism and that’s all I could hear autism, autism.

When the parents received negative reports about their child’s disability from the professionals, parents expressed a greater sense of struggle and less of an ability to cope.

P9: They gave him an awful report now, oh it was heartbreaking to get, I cried and cried and cried because I thought he was doing so well...I’ll never forget it because he was doing so well and he was starting to talk and I got this report and I’d say I cried for a full day after it.

P2: They don’t seem to realise that they send you this report and then you feel like everything you’ve done personally for your child has been a waste of time and that you are the person that is doing everything wrong.

One mother made a suggestion about how children should be assessed in the service, which she felt would give an accurate representation of their ability.

P3: To assess a child, with our acute conditions you can’t come along and be somebody that pops up for 15 minutes every six months...it has to be somebody who is there continuously with him who knows what he does on a day-to-day in other words who knows his routine you know who knows that if he is throwing a fit for a reason...and they can explain why he is doing it...if he is having a brilliant day...if he is doing whatever he does you know that there is a reason behind because this person has seen him do it and knows his whole work-out.
4.12.3 Support
The parents regarded the help and support from the service an effective coping mechanism, which improved the wellbeing of both parents and children. Some parents spoke about the continuous support by the team members.

P4: The Early Intervention services were adamant that they would support us fully... they keep you motivated as well because you can get a little bit complacent when he is doing well you kind of sit back a little bit but they keep you encouraged to keep going.

P5: The service provide us with support...the people calling are all very friendly, they are encouraging, they give you a lift if you're down, quite a few of them have a cup of tea or coffee when they are working.

Some parents did not rely solely on the delivery of support from the ECI service and in some cases when no support was given, the parents sought help from other services.

P9: I was getting nothing, he was nonverbal, he was getting worse he was going in to his own little world and I was getting nothing...I went into DOCHAS one day and they gave me a link worker.

P3: I have the support of Down Syndrome Limerick who are fantastic.

For parents who did not receive adequate support from the service, there was a sense of disbelief in the services and they felt a greater sense of responsibility for their child’s development outcomes.

P2: When our kids were diagnosed and we were given all this information that this was going to happen we felt great we felt there was somebody there to support us but now we feel like you’re talking crap, there’s nobody there to support us and everything we have to do we have to do by ourselves.

4.13 Theme 3: Experiences of the Transdisciplinary Approach
Parents were given the opportunity to describe the most and least favourable characteristics of the transdisciplinary approach in practice in the Early Intervention service. Parents reported experiences of the TDA are divided into positive and negative experiences.

4.13.1 Client-focused Values
The parents’ positive experiences of the TDA are presented in the section that follows.
Chapter Four: Results

One important characteristic of the TDA was that it operated as a family-centred approach. Parents explained how the TDA was able to meet their child’s needs by having the team and parents work together while focusing on the child’s goals and targets.

P8: They are constantly creating goals and aims that we are trying to work towards so that is a big help you know as I said, they are doing that they are focusing your attention to what is coming down the road. I find that the biggest, of the single biggest assistance because they are marking your card for you all the time.

The TDA met children’s needs by focusing on relevant goals from the start.

P6: He got so much attention he got so much intervention from such a young age you know that I would just shudder to think about what he’d be like if he didn’t get it like now he has a mild learning disability but he was just supported so well along the way.

4.13.1.2 Parent Empowerment

Empowerment of the parents was expressed in that parents were enabled to use their abilities. Parents felt empowered when involved in and participating with the interventions in place for their child.

P6: I did feel they listened to me and they did ask me questions about my perspective and from what I thought and from what I saw and things like that and they did take note of those things as well so it was very helpful.

The service allowed parents to be included and take control which bolstered confidence in parents to put interventions into action correctly.

P8: They had told me what I had needed to be doing because obviously I didn’t know from an early stage…they keep you posted in relation to what is next, what’s coming up, what’s coming down the road you know…they would always give you exercises.

4.13.1.3 Quantity & Quality Interventions

For some families, the frequency of services was sufficient to meet their child’s needs.

P6: They never let me down…I never felt that they were doing something that I disagreed with I never felt to instinctively say my child needed this and that he wasn’t getting it.

Positive experiences regarding the levels of continuity of interventions were expressed.

P4: The speech therapist is good here you know, she set us up in the PECs and we do a lot of work at home as well so we are getting the continuation of it.
Chapter Four: Results

P5: We would often have a new programme to follow, exercises every month or every two months or whatever…what is good is that they are continuous, there is a pattern there.

Regularity was an important indicator of both the quality and quantity of the service. It ensured that children were seen consistently and appointments were arranged frequently.

P5: It has been very positive...on average the speech and language therapists comes on average probably every 2 months...it was much more regularly, she was coming generally every 3 or 4 weeks at the beginning.

4.13.1.4 Flexibility
Flexibility in the structure allowed assessments, interventions and sequences of events to be changed, depending on the needs of the individual child being evaluated. The transdisciplinary team used play-based assessments, which were adapted to the children’s individual needs and provided relevant information for interventions. Some parents commented on their effectiveness.

P6: There was play groups that he was invited to different groups to come along and play with other children but it was done in a structured environment...I feel he benefitted from them.

P4: You have to entice the child with special needs, you have to encourage him and make it fun, more fun than the typical child...very happy with it...it was done in a play sort of environment because he was only a baby.

4.13.2 Obstacles to Client-focused Values
For the most part, negative experiences of the TDA were in relation to the service itself. The negative experiences spoken about by the parents were related to practical issues including fighting for services, time wasting in the process, and having poor accessibility to and/or availability of the services. The parents’ negative experiences of the TDA are presented in the section that follows.

4.13.2.1 Fighting for Services
On entering the service, some parents were promised that there would be a variety of services available to them; however this was often not followed through.

P9: They said they’ll give me this and blah, blah, blah “we’ll get on to you and start the help” and of course me being me thought this is great now at least they’ll start helping him and I kept ringing, kept ringing them saying ”I wonder did I miss your phone call”?

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Parents talked about the difficulties caused by continually fighting for appropriate services.

P1: It is the hardest thing is fighting for the services you need for your child there are so many kids out there that need the services that everybody is in the same boat that they are fighting.

P2: It’s embarrassing we as parents have to go out and do so much…they make it harder for us, it’s hard enough being told your child has a disability, but to fight for everything then is another thing…nothing comes easy after that, it gets harder.

Feelings of frustration and stress arose for parents who constantly fought for appointments for their child.

P6: A year went by and that was a year now of her tearing her hair out ringing people and pushing for appointments and trying to find out…eventually she was assessed and got her diagnosis…she does find it she is always pushing, pushing, pushing for stuff.

A mother expressed her desperation and need for access to services.

P9: I begged them for speech therapy…I even taped him and bought it in, they were saying he just doesn’t have enough words…and he wasn’t ready for it…sure how do they know he’s not ready when they’ve never seen him?

4.13.2.2 Time Wasting

Time delays were another negative experience encountered by some parents in the service. Parents commented on the delays when accessing services for their child.

P3: It’s been hit and miss all the way along…I feel there’s no continuity with anything, I’m just not happy, there’s no feedback, no continuity.

P9: There’s no continuity there at all…it’s like they pick the names from a hat it’s like we’ll give them that and that.

The cancellation of sessions and the inconsistency of appointments were reported as significant cause of concern for families.

P10: We are not one bit happy with the service they were to come out from here before the holidays and that was cancelled and stopped and cancelled.

P3: It goes on for 6 to 8 weeks and that’s it then until you hear from them or until you’re banging the doors down saying “what’s happening what’s going on?”
Other parents were disappointed with the delivery of interventions and identified the gaps that remained in the teams’ practices. Parents felt that the time spent in “team meetings” was not time well-spent on their child.

\[\text{P3: They (team) spend the day having a group meeting and the child sitting at home...they're doing sweet f-all for him we are all at home breaking our back...they don't know him because they don’t see him.}\]

\[\text{P2: That used to annoy the crap out of me when you'd ring up about something and they'd say “Yes we are all having a meeting next Monday about that, you will be brought up in the meeting”.}\]

4.13.2.3 Limited Access & Availability

Parents who experienced difficulties in accessing services were forced to take control and they had to provide programmes to teach their child. Parents spoke on how they struggled to avail of sufficient services.

\[\text{P3: I am providing myself from research I do on the computer from Down syndrome I'm giving her work to concentrate on for him. In the past she has not done up a programme for the SNA yet to say he needs this that or the other, that’s not done yet.}\]

\[\text{P2: I teach my son sign language from a programme called ‘Something Special’ on CBBs at 10.20am in the morning...I learn things from it and I’m teaching him.}\]

Parents felt a greater amount of pressure and expense when they were forced to uphold the quality of interventions themselves for their children. In many cases, parents were obliged to supplement interventions with private sessions.

\[\text{P2: We don’t need to be going on the internet and getting all the information...to be going down to actually hire a personal fucking trainer to teach me to do physiotherapy with my son.}\]

\[\text{P3: Down syndrome bought someone in from Cork who we pay now which is expensive...it’s very expensive, it’s €80 an hour every week.}\]

\[\text{P10: I shouldn’t have to go private for things but I have to I just have to for him because he needs it now, it’s not 12 months down the road it’s now he needs it.}\]

Lack of services was another concern expressed by parents.

\[\text{P3: Very little of the services on offer very little...I’m lucky if I get anything...so I’d be very disheartened...I can count on both hands the amount of physiotherapy he has gotten...they’re throwing you bits...crumbs.}\]
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**P9:** I can count in my hands the amount of times I’ve been.

One parent felt that his child was not getting adequate services because they were being discriminated against due to their disability.

**P2:** You have kids in this country that are really actually taking up a small percentage of kids...who are getting eh substandard services because of the way that they are and...anything that’s going to happen with these kids is because the parents are going to put everything and the parents have got to change their lives in dramatic ways to get what their kid needs.

### 4.14 Theme 4: Operating as a Transdisciplinary Team

The transdisciplinary approach was operated by some of the Early Intervention teams. It was implemented by a team consisting of the parents, psychologists, occupational therapists, speech language therapists, early intervention specialists, social workers and physiotherapists. The main themes surrounding the transdisciplinary team were the guidance given by the team, the teams’ ability to promote optimal development and the benefits of operating a holistic approach, together with its’ goal of bridging gaps in the delivery of services. The only challenge of the team approach that was highlighted was that parents felt at times it could be invasive.

#### 4.14.1 Guidance

Most of the parents spoke about the importance of guidance they received. Guidance was seen primarily as receiving support when making decisions regarding school choices. The teams acted as a liaison with schools and implemented interventions for children in order to integrate them into the school setting.

**P7:** The Early Intervention girl...she arranged to call out to the school to meet with his teacher and SNA to discuss any problems that they had and to actually show them how to use visual schedules for him and how to set tasks for him and what different approaches to use.

Parents commented on teams’ support in accessing special needs assistance and explained how this helped with the child’s development.

**P4:** From day one then they said they’d get us a special preschool assistant for preschool, that was August and he was starting preschool in September...he got preschool assistant straight away for 3 days.
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P10: When he started playschool they got me a preschool assistant with him…I had nothing to do with that, they organised that they told me the psychologist came out and she wanted to do a few things.

4.14.2 Promoting Optimal Development

Many parents identified how the working of the team in the TDA helped their children achieve good outcomes in the different developmental areas such as cognitive, sensori-motor, communication and language and social-emotional. One mother gave an example of how her child has improved cognitively and spoke about his improvements in his ability to pay attention.

P4: Before at home out of 20 times I called him he might look once now I’d say the opposite, once in the 20 he wouldn’t look at you.

A parent spoke of how the team helped the child’s sensori-motor development by focusing on his postural background from the start.

P8: From the word go we got to work with the way that he sleeps with his legs so he doesn’t end up with frogs legs…they are preventing something or at least guiding the way along the way.

Parents described how progression in areas of communication had resolved frustration.

P4: They were very good they started the PECs that has solved a lot of frustration at home…he is beginning to make sounds with it as well, he is going “mmm mmm” you know so that was a big help as well.

P5: Yesterday she began to imitate the word “key” and she began to imitate the word “car” and in her situation that is a big breakthrough, a big breakthrough.

Another parent spoke about how her child had progressed in his/her ability to engage socially.

P6: He has gotten to 5 now he is walking, talking, he is hearing, he is playing, he is social he has had help for his social skills but for the most part he needs very little support.

4.14.3 Holistic Approach

One theme that emerged was that the transdisciplinary service operated in a holistic manner. The team shared roles across disciplinary boundaries to enhance communication, interaction and maximised cooperation among the team members. One father discussed the benefits of having a transdisciplinary service in operation.
P5: The cohesion of the service it does not seem to be splintered, if we have a difficulty in relation to physiotherapy, or occupational therapy or speech and language or if we need clarification, instead of having to ring several different people…we either ring the direct Early Intervention services or we ring our own link worker and we get an immediate clarification of what the latest is.

Parents emphasised the benefits of the TDA, which included it operating holistically and having good communication.

P6: When you think about everything, every aspect that might have to do with a child you are talking about walking, talking, hearing, seeing, listening, speaking…it could mean that you are going to be going to a physiotherapist, a rehabilitation therapist, an occupational therapist, a speech and language therapist and a play specialist…you could imagine how often you have to do that with a very small child…so that aspect of it was the absolute best.

P8: Yeah I think that is actually quite good because as I say when you do have the different disciplines interacting you have a chance like that that like the physio fed in to the speech therapy and they coordinate with each other.

Enhanced and streamlined communication was considered to be a key benefit for the family.

P1: It’s great I believe everybody should talk to everybody else and everybody needs to know okay well she is good at this…oh firm believer…there’s no point in somebody doing something that is totally against what the OT is teaching her, the child would just get confused.

Confusion was reduced for parents as there was less repetition of information from different service providers and they knew who to contact when issues arose.

P5: The notion of the team operating together as a unit is a notion that we like very much, it certainly simplified our lives in terms of contacting some member of the team because it is a centralised team.

P4: I do find the team approach is excellent really because anything that ever happens kind of the whole team know about it.

Parents commented on the practical set-up of the transdisciplinary team and felt it was productive to have the whole team collaborating together.

P7: The team would have been there in the one room, I found that good.

P5: Having that team working together, they all operate together from the same centre here…that is a great thing.
4.14.4 Bridging Gaps

When the TDA was in operation, parents only needed to build one key relationship and often only had to attend one professional to obtain all necessary services.

P6: Do you know the way it was a multilayered physiotherapist? So not only was she the physiotherapist but she could also keep an eye on other things as well, so that meant then I didn’t have to go to 3 or 4 appointments...I found that very beneficial, it was obviously then if you have other children as well you know it just has an impact on everyone’s life when your child has any sort of diagnosis so I found that to be its biggest strength.

In saying that, one mother’s experience of having a team-based assessment was described as “daunting”. She expressed her concern regarding the set-up of the approach.

P10: I remember the psychologist was just firing questions at us...that was daunting for us to have them all just there but having said that it was only the psychologist firing questions but you could imagine all just sitting there, the poor child...there was a pile [of professionals] inside in the room.

Parents explained the values and benefits of having a cohesive and collaborative team working together across disciplines, sharing roles. This approach minimised any gaps in the delivery of services to the family.

P6: I found them invaluable, definitely invaluable...you don’t have to go to so many appointments...if you have more than one child you are talking about dropping children to school, picking up children from school and then you are trying to do the absolute best for the child...so that transdisciplinary might mean you might only have to go to 2 appointments that in itself I think it is fantastic...children get sick of it like being pulled at and probed at as we all would like so that way then they get to bond a bit and they get to know the person.

4.14.5 Challenges

Two mothers expressed their frustration when they found some team members judged their child based on written reports or from inadequate assessments.

P8: We had one meeting like that I didn’t find it very constructive to be honest but that was because of the people that were there didn’t know the child at all and were asking questions about him...so I was a bit disappointed at that. I find it a little bit frustration listening to people who don’t know the child. Like people who work with him are absolutely fantastic but then there are people who don’t know him and work from paper.

P3: I would prefer if they wouldn’t judge any child, my child as in what happened on a 15 minute observation and then write up this terrible report...that was given to the
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SNA…so negative I actually rang and said “you cannot judge my son, you don’t see him for 6 months, by walking in saying “blah blah blah he’s bad at this”…the child with a disability cannot be assessed in a 15 minute time-frame.

4.15 Theme 5: Experiences of Key Worker System

The key worker system appeared as a key theme and an essential part of transdisciplinary team approach. Parents who were designated a key worker felt that key workers provided a valuable service for families and had positive impacts on many families’ lives. The main roles and benefits of the key worker were highlighted.

4.15.1 Supportive Open Relationship

Many participants indicated that they developed a vital relationship with their key worker. Parents described the role of the key worker as a supportive one. They approached the key worker for practical help with any problems related to the child.

P4: I would consider my key worker my family support. The main strength well definitely a key worker to the family, family support is a big thing like because we don’t know what we’re at like I’m taking everything that they say here as gospel.

P6: You have this person that you can latch on to.

Parents emphasised the importance of having a good quality relationship with the key worker.

P7: We had a quiet close relationship.

P5: When you are the parents of a special needs child the last thing you need is to be dealing with awkward people so the human level to have nice people coming to your door is very, very important indeed and that side has been very, very positive as well so that is kind of where that is at.

4.15.2 Communication

The overriding theme was being able to contact the key worker and having a named person at the end of a phone should they need to speak to someone. There was confidence in the knowledge that the key worker was contactable should the need arise.

P4: Absolutely brilliant…I can ring at anytime…if you have an issue you can ring him or if you ran in to difficulty with something I’m doing with Peter I can ring him.

P7: If we had any problems or concerns about anything to contact the link worker even if the concern wasn’t what she would deal with she would point us in the right direction…at least there was like one particular person who dealt with any concerns that we had.
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4.15.3 Role Release

The key worker teaches and works across disciplinary boundaries to implement coordinated services. Parents described their experiences the key worker enacting role release on the team.

P4: He is just a mixture of everything really...he is looking at the speech therapy side, occupational therapy without being in those professions you know?

P5: Our understanding of her role is that she basically over-sees the different programmes...the speech and language...the physio and occupational therapy that she over sees them in terms of making sure that they all happening, she intervenes if something goes wrong.

One parent who did not have a key worker expressed her need and mentioned the value of having one for guidance.

P3: You should have somebody there to tell you exactly, one person to tell you “look here this is what we’re going to do” and work out a programme.

4.15.4 Family-centred

Family-centred practice involved working with families as active participants in the Early Intervention programme. Parent spoke about their participation in the programmes at home.

P6: I was given stuff to do at home.

P5: We’ve a written programme for her exercises which shows you exactly what position to put her in, what exercises to do with her and so on.

The focus was on the family’s role in decision making about their child. The key worker was the vital link in responding to family priorities and empowering parents.

P4: Our key worker literally comes in and takes down to the floor or wherever the child is and follows him around the house...and then he was letting us do it and he’d say maybe if we try it this way without saying don’t do it that way but you’d kind of know you shouldn’t or should have done it that way he is giving you ideas all the time.

P8: Apart from the fact that it is very convenient for me but and he makes a big effort to know the other children in the family and he knows the set up and surround...he really knows Jack...I find he is very in touch with the child.

4.16 Theme 6: Facing Challenges
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There is a sense that the Early Intervention service could be more efficient and effective when dealing with challenges facing them. Some parents identified what they felt were constraints within the service.

4.16.1 Limitations of Service

The cancellation of appointments was a big concern and cause of frustration for parents attending the service.

P2: You get letters saying that they're going to do group therapy or group meetings and everything else...then the day before you get a phonecall saying it's been cancelled because so many people have pulled out of it.

Parents spoke about the inconvenience cancelled appointments have caused them in the past.

P10: I am living ¾ of an hour out...I could get a phone call just as I am leaving to say it is cancelled. I have more appointments cancelled than anything.

P2: Twice where we turned up for something and we were told “sorry did you not get a phonecall? It was actually cancelled”.

Parents still wanted appointments to be scheduled, regardless of the number of people who could attend the group sessions.

P3: Just because other people have decided no we don’t want to do that, that’s fine but we have got kids who do want to do that and who we need for them to do that so whether it’s 3 parents sitting with 3 kids in a room or 20 parents sitting with 20 kids in a room. That is one thing that is a big problem here with the service.

Another challenge the service was faced was providing replacements when team members were absent, such as being on sick leave or maternity leave.

P10: If that person was out, there was nobody there to replace them...the lady was out sick quite a lot and never replaced, like they don’t seem to have any back up that if somebody is out sick.

Another issue facing parents was trying to access a medical card for their child.

P3: I have to buy everything...`cause I don’t have a medical card. I think he’d be entitled because God forbid when we’re not around if anything happens, he be able to go to his doctor or have his medical card.

P2: I don’t understand...why are you even asking do they need a medical card? They should be automatic.
4.16.2 Recommendations

Parents made various recommendations of what they wish to see in future services. The first recommendation was related to obtaining more funding from the government to supply appropriate services.

*P1:* The main recommendation would be for the government to supply the funding to actually help...what’s the other alternative?...set up homes with special needs which nobody wants...it would be cheaper to have another team to cope with all the children than something else.

Parents also wanted more consistency and regularity with appointments.

*P7:* More consistency to the appointments but that is just the way the system is...it’s nobody here...there isn’t the staff you know it’s just the way the system is.

Three practical suggestions were made by parents to be incorporated in future services, which included having an introductory meeting, meeting all team members regardless of needs and having a yearly meeting updating the child’s plan.

*P8:* An introductory overall thing might not be a bad idea...because you have a chance to adjust and get your head around the whole thing... an introductory meeting, this is the service, this is the Enable Ireland, this is what we try and provide, this is what we are short at the moment, this is what we have.

*P4:* It probably would have been good to see every team members even if you didn’t need them because how would I know he needs to see a physio when he doesn’t look physically like there is anything wrong with him he is able to do most things you know?

*P6:* It wouldn’t be any harm to have a meeting in or around the child’s birthday to have a meeting to say this is what he plan is, this is what you should be doing, this is what you should be aiming for.

Two suggestions were made whereby the service should maintain the standard of services currently being provided.

*P5:* Our big hope would be that the service would continue not just for ourselves here but for other families who have the service as well and added to that because of is the fear of the current economic climate controversies and that there might be an effort to cut it back.
In addition, one parent wanted to keep the transdisciplinary approach and build on it for future services.

*P8: Transdisciplinary is a fantastic thing that is really fantastic thing they should keep that they should build on that.*
Figure 4.2 Tentative Model Depicting Parents’ Experiences of the Transdisciplinary Approach
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Parent’s experiences of the TDA and TDA are displayed in Figure 4.3 below. It gives a clear outline of the characteristics of each approach as facilitated in the Early Intervention services. The TDA facilitated a flexible, family-centred and holistic practice which introduced a key worker system to address families’ needs. Parents felt frustrated with time delays and limited access and availability of services. The MDA operated a child-centred practice, which facilitated one-to-one sessions and delivered home-visits. Parents complained about gaps in the delivery of services and the idea of a new integrated approach. Overlapping values of the two approaches included parent empowerment, guidance and promoting optimal development for the child.

Figure 4.3 Tentative Model Depicting Experiences of the Transdisciplinary Approach & Multidisciplinary Approach
4.17 Section 3. Team Members’ Experiences

This section will outline the findings relating to team members’ experiences of working together with both the multi- and transdisciplinary approach. The research revealed six core themes each containing a number of sub-themes. The themes are as follows: (1) Experiences of the TDA, (2) Experiences of Transdisciplinary Team Working, (3) Experiences of Key Worker System and (4) Selecting a Model. The themes are presented in Table 4.3 and described in the following section.

Table 4.3 Core themes and sub-themes for teams’ experiences of the transdisciplinary approach

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4.18 Theme 1: Experiences of the Transdisciplinary Approach

Team members were given the opportunity to describe the most and least favourable characteristics of the TDA in practice in the Early Intervention services. Team members reported experiences of the TDA are divided into positive and negative experiences.

4.18.1 Client-focused Values

4.18.1.1 Holistic Approach

When using the TDA, team members stated that they viewed the child in a more integrative and holistic manner. They emphasised the importance of getting input from the entire team to enable a holistic view.

_EIS1:_ I’m looking at the whole…the holistic development of the child so I need to have input from all the disciplines.

_EIS3:_ We looked at the child in a more holistic way and we wrote up the report together so it wasn’t that we were all experts in every area of development but we could just tease out and look at the different areas and where a child might be struggling and all have input into it.

The Early Intervention specialist gave a practical example of how the TDA facilitated an integrative view of the child.

_EIS1:_ It might be that the child has got behavioural problems and that is why it is affecting their speech or it might be the sensory issues and it’s very complex for children am that is why we have come onto this team so we can leak out the areas that the child has got difficult with, rather than just being a simple “oh they got speech and language problem”, this child might have loads of issues affecting the speech side of it.

The Early Intervention specialist spoke about how, as a result of TDA, she has a broader overview of a child’s development.

_EIS2:_ I’ve definitely opened up to it’s not just education, its speech and language…definitely you put a couple of hats on now when you look at a child now you do look at every area.

4.18.1.2 Family-centred

The TDA enabled a family-centred practice, whereby the team worked with the family to support them in their participation with the programmes.
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P1: It is more of a one-stop shop...a lot of our families especially if they have social welfare issues have every man and his dog in their lives and at least with our model you know they get a report that is one report that reflects that team and not just the physiotherapist and then there is a SLT report and then there is a psychologist report and it is all reflected in the one.

One way of how the team felt they had facilitated a family centred approach was by including all of the child’s relationships network was considered in the development and implementation of intervention programmes.

PT1: We meet with parents but also meet with other service providers...granny and granddad, or might be child minders or preschool and preschool assistants...the idea would be that that whatever programmes is put into place is carried out in a 24 hour way so the same programme is being carried out in all settings that are appropriate for the child so again that should be more effective because you know everyone who is involved with the child and has an understanding of what their goals are, what their programme is and what their responsibilities are within that.

The TDA facilitated easier access for families to enter the Early Intervention service. The approach appeared to be more sensitive and convenient for families’ needs.

PT1: We offer a much more cohesive, manageable service to service users and their families. I think that is a huge strength it is much more coordinated, it is much more timely am and just easier for them to access and I think that is much better.

4.18.1.3 Parent Empowerment

The TDA enabled the team to empower parents in their ability to participate and engage in the child’s programme. The team felt that they had empowered parents when there was a joint effort from the team and parents.

SLT1: Empowering them to think of targets rather than them seeing it just as us to give the targets...increase that joint approach.

The TDA stresses the importance of providing services to families that will empower adults in their roles as parents.

EIS2: Transdisciplinary based was about empowering the parents and saying that they had their children 24/7. We would have home-based and preschool-based programmes so that anybody and everybody involved in the child’s life was involved in their development so that’s a good aspect...what we need to do more of is empowering the parents.
Team members spoke about their increased confidence in their ability to empower parents as a result of the TDA in operation.

\[SW1:\text{ I find it very helpful to work with parents and people that I actually have experiences of seeing the work undertaken so I can explain to them a bit better what they can expect for their children and you know when they have queries about certain therapies and so on.}\]

### 4.18.1.4 Best Practice

The Early Intervention specialist spoke about the excitement of the set-up of the TDA. The service was implementing a “best practice” approach to coordinate and integrate service methods.

\[EIS2:\text{ In 2005 when the transdisciplinary play-based assessment model (TPBA) was rolled out, it was a very exciting time for Early Intervention because we were for the first time really we were looking at best practice by international standards for Early Intervention.}\]

The team spoke about how the TDA assisted the child in reaching optimal development. One example which illustrated this was when the team focused on the child’s functioning and prepared realistic and desirable goals.

\[PT1:\text{ It is easier to work on kind of functional goals, everyday realistic goals for the family eh when you are working because if you have let’s say the goal is for example that the child can sit at the table to eat his dinner rather than the physio kind of going off working at core strength or whatever that you have every aspect looking at that one goal so you know the child is getting kind of a global look at that one task that is just one specific area so I mean I think the children and the families benefit from it.}\]

The sharing of information and skills across disciplinary boundaries characterised the transdisciplinary team.

\[SLT1:\text{ You can create a better IDP, an individual development plan for that child when you’re looking at the child holistically and seeing what needs to be done first and foremost who’s involved functional goals definitely rather than it just being coming in and doing some looking and listening work that’s not linked into anything.}\]

### 4.18.2 Barriers to Teams’ Values

#### 4.18.2.1 Time Consumption

Poor time management with the delivery of services proved to be a major challenge to the team in delivering the best quality service.
**EIS1:** Teamwork takes extra time... you like have to plan together because you know if I am going to see a child I can quickly make my plans in my head and fit it in but now as a team I need to... plan with someone else and I need to debrief with someone else and that takes time you have to set time aside to do that.

Working together and making joint decisions tended to be more time consuming than managing an individual caseload within a specific discipline.

**OT1:** There is this certain time element... that could be in theory seen as paper work time or could be seen as clinical time that goes into teaming that goes into that general office discussion around finding the best solution to cases with children so whether that be prioritising which intervention is going to be the most important at any one time or whether it’s decided who needs or using the clinical room at any particular time so there is a process of negotiation that goes on around clinical environmental am process issues that that requires time.

Team members struggled with the balance between their individual discipline roles together with their team-based roles.

**OT1:** Caseload management is a big problem... you've got eh conflicting roles you’ve got the team part of your role you’ve got team assessment am you may want to do individual assessments then we all have a number of unidisciplinary roles but we also have that teaming part of our role as well and it is kind of am a management of all of that... so it is constantly you are balancing and prioritising am your own caseload versus the team caseload and that is kind of a challenge, you don’t have as much control over your workload.

The issue with time has led certain teams to revert back to working in a multidisciplinary manner in order to meet the demands of the waiting lists.

**SW1:** Time is a big factor... we’ve doubled the numbers attending the service with less resources, which is I think telling, so obviously the time-consuming the model on one side and then trying to facilitate children so they’re not waiting on waiting lists for so many months, which has led to the development of more MDT work.

**F:** The MDT kind of helps ye get through the caseloads?

**EIS2:** Yes... **PT2:** Much quicker.

### 4.18.2.2 Lack of Support

The transdisciplinary team spoke about the lack of support received from higher management. The social worker felt that higher management fought against the approach.
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SW1: You got a sense that upper management kind of partly worked against it because I think from a management point of view there is a lot of time and resources involved. The lack of support wasn’t from direct management but up higher in the ranks where it is seen as a luxury to have 3 or 4 clinicians for the whole day to facilitate one child in an assessment so I think some people didn’t get their heads around it to say it kind of very casual and I think there was lot of pro and cons up in higher management so there was a lot of undermining and then as a clinician you were kind of torn in between.

The failure to keep the TDA in operation appeared to be caused by the pressures and demands directed from management at higher levels.

SW1: When we did operate much more to the transdisciplinary model there was about the feeling about the clinicians against management.

SLT2: It sounds like it isn’t really our problem it’s like way, way up.

The team felt dictated by higher management and the team did not received sufficient support in the installation of the TDA at the time.

EIS3: Real dictatorship at the time really it was and you know…I suppose they just expected it to work with little or no support and wanted you know to get through all the waiting list, that there should be nobody waiting out there for anything, so you know it was just disastrous really going back looking at it.

4.18.2.3 Getting Parents on Board

The team found it difficult to convince parents that these integrative group-based interventions would be most beneficial for their children.

EIS3: We had a struggle convincing parents that it was a form of therapy where you know they always believed in the therapist and the child at the table sitting and it was a big shift for all our parents and even for ourselves I suppose for it to work.

Team members had to cope with parents demanding to have a more individualised based approach.

PT1: You’ve got the mere fact that there are some parents that won’t buy into this integrated programme.

OT1: They’ll say but I haven’t seen a SLT I know there’s one on the team why haven’t I seen her? Even though they don’t need it they kinda think well sure have a look at him and see if does he need SLT you know so you have that too.
When the team were successful at getting parents on board to try transdisciplinary interventions, it resulted in positive feedback.

\textit{EIS2: Parents come in and say “actually I don’t want to be involved in the group I want one-to-one with the speech and language therapist only” and you convince them to come and give it a try, try the group intervention and a lot of the time, not all the time, but a lot of the time the parents say after a 6 or 8 week block of intervention “I see where you were coming from, I understand now that it is more beneficial to have peers in with my child they learn from the peers”.

4.19 Theme 2: Experiences of Team-Working

The team members spoke about their experiences of working together as part of a team. Some team members had experiences of both the MDA and the TDA which was included in their accounts. Positive and negative characteristics of team-working are described below.

4.19.1 Enhancers to Team Functioning

4.19.1.1 Learning Curve

One positive characteristic of the transdisciplinary team was that team members built on each other’s knowledge and strengths to benefit the team, the child and the family. The team commented on their learning developing.

\textit{SLT1: I think what I have learnt from working with a team is certainly learning each other roles and seeing where we overlap and just making decisions that aren’t just you know yourself you are making decisions joint which I think is really good and that’s where I benefit from the support...it has been a big learning curve.}

\textit{EIS1: I see children more clearly because of the team like if you see a child writing thinking oh he is doing fine but now I see look at his shoulder positioning look at that back you know now ‘cause of transdisciplinary work I look for things in more detail.}

Staff development and learning occurred at different levels, including sharing general information and sharing of roles.

\textit{SW1: I learned as well very much hands-on about what is about physiotherapy? What is occupational therapy? So much so that obviously certain skills you actually develop for yourself to know.}

\textit{EIS2: It was a learning process throughout…we learned so much about each other.}

Some of the team members commented on the difficulty that they would be faced with if they had to revert back to an individual discipline practice.
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SW2: I feel like I couldn’t go back kind of, I do enjoy the team-work and the notch above the team-work, you know this kind of the transdisciplinary, so I’d feel like I would be very limited going back in to a typical social work role which I am not planning in doing.

SLT2: It has totally enriched my work I do and even the fact that the team allows me to sit in and watch and before when I was with a child I would only be looking at speech and language and I might miss out in big other areas like a bigger picture.

4.19.1.2 Collaboration
The team members highlighted the importance of having everyone working together to make collaborative decisions about the child’s development.

P1: The most beneficial part about the job that I find is that I don’t make professional decisions in an isolated way.

SLT2: The kids all have such complex needs…getting physio once a week in isolation isn’t going to help them in the bigger picture, but getting input from all of us or even if it’s just one session every two weeks or if it’s just an hour where 3 clinicians all contribute I think it makes that aspect of the TDA really really good and the TDA…you need input from all areas not just your own field and even knowing what others are doing helps mould my plan of action so I think that’s really good.

Team members acknowledged the TDA as being more effective in terms of planning and goal development.

EIS1: When we plan together we actually define actually better what’s really going on focusing on own goals it’s engagement and then once you get engagement suddenly the language just flows that you could be working on speech when actually the whole problem was engagement and we sussed that out as a team so I think that is where it has helped me.

The team spoke about the benefits of receiving input from all team perspectives, which lead to better decision-making and greater levels of support within the team.

P1: I think we have the ideal set-up here by whereby we can do the full functional analysis and test it within our team you know we can test that function of this child’s behaviours are because of communication issues, now the person on the team who I can test that with and follow that theory through you know and am whereas if I was operating in an isolated way the time delay, the lack of on the spot support we would never getting around to doing it you know?
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One team member whose team were no longer practicing in a transdisciplinary manner spoke about her preference of this approach.

SW1: I really enjoyed the transdisciplinary work and it enriched my practice very much...We literally sat there with 3 or 4 people around one computer and we had discussions around our observations and one of us was typing so it was very much, we were in one room working on this, the write up of the transdisciplinary play-based assessments.

4.19.1.3 Assessments

One team who have maintained the TDA spoke about how they had mastered the use of transdisciplinary assessments within the approach and its effectiveness.

EIS1: One thing we have all gotten good at is the transdisciplinary assessment and I think that has been the strength...sometimes you might say “that is purely a behavioural issue” and “oh no it isn’t, there is some sensory regulation that is impacting on that” and “how can posture impact on your behaviour?” “Wow, what a great question” and you know those things are wrestled out in the assessment.

SLT2: I do more group work, TDAs, I think I actually prefer it because you can only do so much as one clinician but if you share the work, like I find it has just captured so many more children and it’s more productive and parents are happier, see all parents want individual therapy but you can’t do that especially when there’s only one person on a caseload.

The use of transdisciplinary play-based assessments by the team managed to minimise stress and demands on parents and children.

EIS2: Play-based assessment, it can obviously be very stressful for parents to come in for assessments and I think feedback that we got over time...is that it’s play-based so it is fun for the child and not huge demands being placed on the child so the child isn’t stressed, the parents isn’t stressed because the child is upset and that it is more relaxed environment.

The intervention team who no longer practice the TDA in its entirety selected the assessment aspect of it to integrate this into their MDA.

EIS: We’ve carried on with some transdisciplinary play-based assessments with our colleagues and we’ve carried on with the group intervention...it’s not true transdisciplinary but we’ve taken aspects of it to work in a multidisciplinary approach.

4.19.2 Obstacles to Team Functioning

4.19.2.1 Interventions
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Transdisciplinary interventions proved to be a difficult aspect of the approach to be implemented effectively in teams.

_EIS1_: To my knowledge none of the teams have really gotten good at the intervention side of transdisciplinary we are still at that side uni- or multidisciplinary and that the inter- or transdisciplinary groups just haven’t really worked out.

Team members expressed confusion over what intervention strategies should be in place at different times.

_SLT1_: We need more care pathways you know I don’t think we sorted that out...sometimes you do want to do your individual blocks of SLT or OT am and then sometimes it is more of a generic group-based or play-based am for the intervention I just don’t think we don’t yet have that sorted.

The occupational therapists commented on how the use of group interventions for children with mixed and complex developmental needs was not an effective use of therapy time.

_OT1_: To have a range of age and disability within one group and therapy being provided by a lead therapist to me is not a good use of therapy time, am and we did try and we actually evaluated at least an 8 week block with a mixed group children and their parents and the outcomes that we have had or eh the feedback we have had from parents from something like our fun and networks group has been much more positive where there is homogenous group of children where it is targeted, structured, there’s a finite of time am and again it is more outcome based and much more specific goals I still feel instinctively that’s is a better model of intervention in group.

Another issue was the increasing amount of time spent on assessment procedures, which was resulting in less time spent on the interventions.

_PT2_: Our intervention time is getting smaller and smaller and...the time we spend on assessment is huge because every second or third kid is coming through assessment of needs [AON] again.

4.19.2.2 Pitfalls on a Team

The teams spoke about the pitfalls of working on a team. Some of the most difficult challenges are ones that are often outside of the control of the team. These included working in a unidisciplinary manner, neutral personalities, sharing of power and accepting and sharing other professionals’ expertise. One danger which was highlighted was when team members become too focused on their own discipline.
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EIS1: I think a danger on the team is that you could end up being solo for a unidiscipline anyway you could carve it out, you could work anyway and just do your own thing but what is working on this team is that people are genuinely interested in what each other thinks.

The psychologist highlighted that a key issue was the sharing power with team members on a team.

P1: The key issue is that there has to be a sharing of power...because you get people who are inexperienced who actually have a hell of lot to offer who don’t have their say...in terms of the work that is done and so I think to do that you must have other things with regards being a team member, having trust, getting to know each other, accepting criticism.

Certain philosophical differences may have caused conflict on a team. If team members did not adapt their actions to reflect the family goals, the programs would be dominated by the teams’ interpretations of the child’s individual needs. The psychologist gave an account of how their team have adapted to these differences.

P1: We have and still do have some philosophical...say OT1 might feel that the course of action should be this based on whatever...and I might feeling different I have more of a behaviourist approach or whatever you know and I guess I originally have problems with that but it is a matter of...the end product to the parents and the child and has to be agreed to, has to be negotiated. We might have had a hell of a row about it...I see that is not as criticism but I see it as a real integral power of being a team.

4.19.2.3 Turnover of Staff

One of the major difficulties the team were faced with was the turnover of staff members. As a result of the length of the waiting lists, the team were forced to revert back to multidisciplinary practices so no time was allocated to train new staff on transdisciplinary practices.

EIS2: The high turnover of staff and...because our caseloads were so high that we couldn’t give the time as well to orientate our colleagues and then is it really up to us as colleagues to orientate you know new staff coming on board so that was the difficulty because we lost a lot along the way in terms of nobody helping or assisting colleagues coming on board.

EIS3: Because there was such wait lists it was what they were so use to doing was the multi and to do their own am assessments... so it was to target them rather than wait for them to be trained up on the trans [disciplinary] side of things so we kind of went that way because of staff changes.
With high demands on the team, team members did not have the time or resources to train new staff members on the TDA and consequently lost more staff.

SW1: Because of the demands being placed on clinicians many clinicians left, there was a high turnover of people because of the high demands because you can imagine if you are in that intensity of work but you don’t get the proper supports you burn out very quickly.

4.20 Theme 3: Experiences of the Key Worker System

The team members who operated a TDA in the ECI service gave their views on the key worker system. Both positive and negative aspects of the key worker system were highlighted and recommendations for future practices were included below.

4.20.1 Coordination

The team reported that one of the major roles of the key worker was that they provided a single point of contact for children and their families.

P1: With the key worker approach there is one person that they can liaise through who liaises with them instead of you know every man and his dog and I think that is beneficial to the families. You are getting that information kind of that continuous information gathering all the time from everybody.

Another role highlighted by the team was that the key worker provided a level of coordination for families and the team which identified and addressed needs.

SLT1: As key worker you’d be as the coordinator thinking well it is more play-based at the moment so well EIS is the best one involved and I could link in a little bit with the speech therapy head. I think sort of being a key worker to see who is relevant at the time you know which member needs to be involved at the time.

OTI: They kind of coordinate the service. For example, if a child needs physiotherapy they’ll maybe say to the physio “I think you know maybe could you see this child please?” and maybe you would be aware of the programme that is in the file.

In addition, the psychologist reported that the key worker had a key role in observing the child’s behaviours.

P1: I see that we have a major role in observing as a key worker and...you know professionally we have the knowledge to observe like I observed that there was something definitely wrong with a child’s crawling pattern and then I saw my role as a
congruent of that information, gather some information maybe go to the physio and reflect what I saw am and I am a congruent for that to be followed through.

One of the main factors that worked against the implementation of the key worker services was that team members were not clear on their role of lead therapist.

EIS1: The real idea of key working which is you know if I am the key worker I present the whole package to the child but yet we don’t we are not really good at letting that go because we are not comfortable in delivering all the different disciplines together so the key worker role has been a source of problems in implementing.

4.20.2 Role Release

Central to the transdisciplinary approach was the role release, which was described by different team members as sharing certain roles and responsibilities across team members.

EIS2: Role release is that when we would go into transdisciplinary play-based assessment, you would have 3 clinicians maybe and the 3 of you looked at all areas of development together, it wasn’t physio[therapist] looking at just gross and fine.

This enhanced the skill base of the team in addition to providing more holistic service delivery.

EIS3: For those who were able to role-release and those who were very comfortable, it just made your team very solid and you’d have that great…I suppose…it’s not companionship but it’s like…EIS2: Trust.

One of the disadvantages of role release mentioned was it caused a feeling of threat for teams. Team members discussed the importance of role release.

EIS2: The role release was the biggest…what would I call it? challenge…threat to certain practitioners and it required a confidence in your own role to be able to work in this manner and we did…there was teaming difficulties to begin with but once there was group of people that wanted to work in a new dynamic way which had found to be again best practice, it worked well.

Role release was an issue on the team, particularly when there was misunderstanding of the concepts. Team members rejected the idea of role sharing.

EIS1: Role sharing in transdisciplinary has been a bone of contention where a lot of the transdisciplinary model has eh been controversial in this region, and ironically although everybody in name sort of fights the role sharing concept like for me to take on some of the speech role or for OT to take on some of the psychology role eh we both say “Oh we can’t do that we can’t mix roles I’m not trained to carry on a speech role”.

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However, in practice they implemented it within the team.

*EIS1: In spite of that we end up role sharing...we all sort of share roles anyway so it’s kind of funny how we reject it in theory but practice it anyway.*

4.21. Theme 4: Selecting a Model

4.21.1 Distinctions between MDA & TDA

The team recalled the key differences between the MDA and the TDA. A greater level of connection among the transdisciplinary team was described.

*EIS1: What I understand distinguishes multi from trans is that I might go out and assess a child and come back to the team and talk whereas with trans we are actually assessing the child together we are actually planning for the child together...I find...where a powerful experience happens if I’m working with SLT and SLT does something that connects to something else the psychologist was saying that really lifts the family up to a new level.*

The teams expressed their preference for the TDA over the MDA. They recognised that the TDA was better at addressing the children’s complex needs in areas of development.

*SW1: Many children that come to us may not be up for a more standardised approach or assessment they may not be able because of their difficulties and that is why the transdisciplinary play-based assessment suits better their developmental needs rather than having a formalised assessment where they wouldn’t reach any kind of type of standard.*

The TDA provided a more comprehensive and collaborative service, in comparison to the MDA which was reported as fragmented and disjointed.

*SLT2: It has to be client-centred and I couldn’t imagine a team, or treating a child like this not, a child like this coming to someone who’s not on a team but that’s why the team was set-up to have a team that when it is purely multidisciplinary just defeats the purpose of having a team for Early Intervention.*

*SLT1: I don’t think it is as comprehensive therapy [MDA] to a child though, because a child could get I dunno 12 sessions of speech therapy but their biggest problem might be physio and they might not have got any physio if we don’t collaborate on it.*

The MDA tended to decrease the numbers on waiting lists, yet the team did not report this as best practice. The Health Service management had forced the team to revert back to multidisciplinary practices which they felt overlooked the fundamentals of the Early Intervention, where children's development was viewed as integrated and interactive.
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SLT2: It’s still contradictory, I know like the speech therapist in the community they’ll work in isolation, they’ll just work on speech because a lot of the children will only have one area of need so I think the government wanting all these big numbers to be chopped down and not have big waiting list but they’re not looking at the children at all or their families.

4.21.2 Training Needs
The Early Intervention service providers were not provided with adequate induction or regular ongoing training for the team. Only one of the teams reported having initial training.

EIS2: We got extensive training in terms of transdisciplinary. Toni Linder who has devised the model of TDA, gave us training specifically to the teams of the mid-west.

The team members felt that the difficulties with the TDA could be overcome by provision of training and support.

PT2: I think far more training could be an answer for all my questions basically, if someone says a, b, c, d this is how we do it, this covers this, they should be in a position to.

4.21.3 Integrating MDA with TDA
The team that no longer operated as a purely transdisciplinary service spoke about the difficulties they had experienced when trying to maintain the TDA.

EIS2: It was very rushed in initially…expectations very high very quickly…we were all trying to find our feet in this new model…very quickly there was huge expectations from higher management you know numbers, how many children are you seeing? How many are going through your books? It was all about numbers…then it didn’t take into consideration that this team was new, that there was staff changes there it was all about well why aren’t you seeing so many numbers? and why aren’t you seeing this and this?

As a consequence of these difficulties, the TDA phased out in the Early Intervention service and the team reverted back to operating the MDA. They talked about the way they currently operated as a service.

SLT2: Nobody said the transdisciplinary model was being taken over by the MDT it was just kind of phased out and when I started here it was like all these whispers of the “don’t do TDA and do MDT” but no one said it, passive aggressive obviously.

EIS2: It kind of just phased out you know without anybody…nobody has said “you are not transdisciplinary you’re working multi now”, nobody says it but in terms of when new colleagues come in like that they’re not sure how we are working so we’re really working almost interdisciplinary-multidisciplinary, we’re not near trans (disciplinary)
only that we are using aspects of it, we because I suppose there was a number of us that had done trans so we tried to carry that through but we haven’t been supported in that.

As a result of this confusion on the team, the team members highlighted that there would be mixed response from parents experiences regarding the quality of the service.

SW1: The parents that are longer with us are very much at home with us. Some parents were unlucky and came when there were only 2 people on the team and right now I see those parents would find it hard, they don’t know anything about what is transdisciplinary really and I think they would have fallen in between difficult times and I think we have a two-tier system going certain parents are very well established with us and are very happy and I think others would have seen the more kind of coming from one you know isolated appointment and may be not here for awhile so it is a bit…I would say it is very varied.

The other team reported ways in which they have adapted their own versions of the approaches to suit their team in the provision of the Early Intervention services.

OT1: It is hard to nail you know our whole practice down to one specific way of doing it you know? A lot of it is on child based or you know on a case-to-case basis, what suits the family.

EIS1: We have never really fully implemented the transdisciplinary process it depends on whose model like. We were suppose to implement Toni Linder’s model am but none of the teams I think have actually really tested out the transdisciplinary model purely it has always been accepting certain pieces of it and rejecting others or rejecting it flat out or whichever it… it is going to be hard to say because what’s carried our team here has it been the transdisciplinary elements we have borrowed or has it been the traditional work ethics of the disciplines that has carried this.

Some team members spoke about how they would like to see the TDA developing in the future for Early Intervention services.

SW1: I’d be very much interested in further developing the transdisciplinary model rather than going backwards as I would call it. International guidelines and standards would be you know there is research backing up that transdisciplinary if it is done efficiently it can be very beneficial so it is a bit obviously highly frustrating for clinicians.

EIS2: It was definitely best practiced and love to go back to it but you know management I suppose they are not on the ground they’re not seeing what the difficulties are really you know?
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Figure 4.4 Tentative Model Depicting Teams’ Experiences of the Transdisciplinary Approach
In Figure 4.5 experiences of the TDA from parents and team members perspectives are highlighted. It gives a clear outline of the characteristics of the approaches delivered in the Early Intervention services. Overlapping values of the TDA included a family-centred practice, facilitating parent empowerment and a holistic delivery of service. Role release was highlighted as a key characteristic of the key worker system. Time was emphasised by both groups as an issue in the TDA.

Figure 4.5 Model of Parents & Team Members’ Experiences of the Transdisciplinary Approach
4.22 Chapter Conclusion

This chapter described the emerging themes from data analysis. Firstly, parents’ experiences of coming to terms with and coping with their child’s disability were examined. It then focused on parents’ experiences of the different approaches, multidisciplinary and transdisciplinary, that were in practice in the Early Intervention Service. It then also examined team members’ experiences of working with the two approaches, progressing to look at their experiences of services and how they responded to changeover of models. The following chapter will discuss parents’ and team members’ experiences of the two approaches in operation in ECI services in Ireland in light of previously reviewed international research in the area. The emerging themes from the present chapter will be analysed, compared to and elaborate on findings from similar studies.
Chapter Five: Discussion

5.1 Chapter Introduction

The chapter aims to present and discuss the findings of the current study. Following this, based on the research findings, recommendations for service development and provision will be presented. Finally, the strengths and areas of development for future research will be discussed.

5.2 Overview of Discussion

The current research examined parents’ and team members’ lived experiences of the multidisciplinary and transdisciplinary approaches in operation in ECI services. The use of a qualitative methodology provided a powerful means by which to capture in-depth experiences associated with the approaches. In this chapter, themes arising from grounded theory analysis of interview material with parents and team members will be discussed in light of previously reviewed research.

As previously articulated, in recent years, ECI services have adopted a multidisciplinary or transdisciplinary approach of practice. There has been limited research carried out examining parents’ and/or team members’ experiences of the approaches in ECI. One would, therefore, not expect to find a grounded theory model developed of parents’ or team members’ experiences in this area. In light of this, the models presented in Figure 4.1, Figure 4.2 and Figure 4.3 are tentative and not all encompassing models. They are based on evidence gathered for the present study. Other factors, not investigated in the current study and which would likely impact on the model, include the severity of the child’s disability, child’s developmental outcomes and team cohesiveness. Examining these issues was beyond the scope of the present research.

The thematic headings that emerged from the analysis will be continued in this chapter, while the interlinking nature of themes will also be discussed. The study has highlighted several perceived strengths and obstacles in ECI services as reported by families who are in receipt of services and team members who deliver services. The discussion will commence with parents coming to terms and coping with their child’s disability, progress to discussing positive and negative experiences of the approaches and culminate with the team members’ experiences of working with the approaches.
5.3 Summary of Parents’ Experiences

Parents interviewed for the current study tended to recite experiences regarding the quality of the services and whether the child’s needs were met or not. Before considering the kind of service or service approach parents wanted, a number of issues surfaced which were very important for families. As such, parents spoke about issues that were more pertinent before considering what they wanted or needed from a service.

5.3.1 Coming to Terms & Coping with Disability

Firstly parents described the process of coming to terms with the child’s disability, which included searching for an appropriate ECI service, dealing with the disclosure process and establishing a sense of normality. In the present study, parents’ ability to come to terms with the disability was, notably, determined by positive and/or negative early experiences, from the assessment and referral process to gaining access to services.

Gaining immediate access to a service was favoured by parents in the study. Similar to this finding, Bailey et al. (2004) and Cederman (2006a; 2006b) found accessing ECI services was a positive experience. Some inconsistencies and challenges, however, remain in ongoing subjective experiences of other parents attending the service. For example, parents spoke about delays and challenges faced with in the initial referral process. This finding, however, is supported by research which showed that there has been a significant increase in the number of referrals to early services providing help to people with disabilities (National Federation of Voluntary Bodies, 2006). In 2006, there were 1,110 children in receipt of early services, with the referral rate growing and established waitlists for services in excess of 519 children and some of these children had to wait for over a year for assessment (National Federation of Voluntary Bodies, 2006). Current levels of resources are not sufficient to meet the additional demand for services. Therefore, securing quick and easy access to an early intervention service is an important factor to consider for future referral system set-ups.

The finding that experiences of the disclosure process were crucial in determining how parents dealt with the disability was supported in the literature (Nursey et al., 1991; Quine & Rutter, 1994; Baird et al., 2000; Davies et al., 2003; Graungaard & Skov, 2006). Certain factors such as the shock of disclosure, whether the disability was stated or unknown and the sensitivity of professionals’ dealing with parents were found to be crucial in determining how parents coped with the disability. A number of parents recalled the sense of shock experienced after the disclosure. This is similar to Russell (2003) who stated that “at
the time of diagnosis of their child’s disability, parents can find their expectations of becoming a parent shattered” (p. 144).

In this study, parents’ satisfaction with the service tended to be greater when a definite diagnosis was given. This is in line with previous research, which examined parent’s reactions to having a child with special needs (Quine & Pahl, 1987; Howlin & Moore, 1997). Some parents were, however, faced with a vague and tentative diagnosis which, in some cases, resulted in the child falling between the cracks of services. Johnson and Rosenthal (2009) reported how children often fall through the cracks between primary health care providers and providers of Early Intervention. Research has consistently shown that satisfaction is low and more than 50% of the mothers were dissatisfied with the disclosure of the diagnosis (Quine & Pahl, 1987; Sloper & Turner, 1993; Quine & Rutter, 1994; Pearson et al., 1999).

The manner in which the professional informed parents of the child’s disability was found to play a crucial role shaping parents’ experiences. Research supported the finding that news of a child having a developmental disability is often the most frightening information that parents receive (Beckman & Beckman Beckman-Boyes, 1993). In addition, parents reported the insensitivity of the professionals in certain cases. This finding is important, as Irish guidelines on informing parents of their child’s disability have stressed the importance of informational, supportive guidance and clear professional signposting of ECI services to parents (National Federation of Voluntary Bodies, 2006). In addition, best practice guidelines for informing parents of their child’s disability in Ireland are at present being prepared by the National Federation of Voluntary Bodies. These findings provide insight into the importance of delivering the disclosure in a sensitive manner, as well as providing families with ongoing support and follow-up, particularly where a diagnosis is not available. In addition, professionals in this field must be informed of their duty of care and responsibility to ensure best practice for families.

Reactions to the disclosure were found to vary among parents in this study and were determined by immediate or delayed responses from the service. A lack of support following the disclosure was reported, such as a delayed waiting period between the disclosure and access to services. This issue has been highlighted in previous literature. If best practice guidelines were in place then lack of information and lack of immediate support for families could be avoided (National ASD Plan for Children [NAPC], 2003; Langford et al., 2007). The finding that coming to terms with their child’s disability required ongoing changes to
family life was supported also in the literature (Turnbull & Turnbull, 1990; Waggoner & Wilgosh, 1990; Marvin & Pianta, 1996).

Coping strategies identified in this study included receiving information about the child’s disability, professional support, sharing lived experiences with other parents and representing the disability. Research has shown that coping strategies are important to the well-being of parents caring for a disabled child (Beresford, 1994; Taanila et al., 2002). It is important to note that coping is not necessarily a conscious process, despite the use of the word ‘strategy’. In the literature, the most common way parents have dealt with disability was to arm themselves with information, thereby increasing knowledge and understanding (Graungaard & Skov, 2006). Parents in the present study were no different and this has been consistently found to have a positive effect as a coping strategy (Beresford, 1994; Pain, 1999; Taanila et al., 2002). However, some parents highlighted a lack of information and support following the diagnosis. Similar results were reported in other investigations, as parents continue to report that their need for information was not well met (von Essen & Sjödén, 1995; King et al., 1996; Langford et al., 2007). This implies that better informational support systems must be set up in future practices to provide parents with knowledge and education to help understand their child’s development. This includes the availability of practical information such as resources available like wheelchairs.

In this study, the support provided by the team helped parents cope with and come to terms with their child’s disability. Support provided by the Early Intervention team was needed and judged by parents as most helpful and beneficial (Tocci et al., 1997; Thompson, 1998; Dunst, 2000; Foran & Sweeney, 2010). Parents also expressed the supportive value of sharing experiences with other parents who were faced with similar challenges. Research confirmed that talking to other families in the same situation was very helpful (Tocci et al., 1997). As a result of accessing the ECI service, opportunities to develop relationships with other parents are increased (Anderson et al., 2006). From gathering parents’ experiences it appeared there was an almost tangible step between the ability to cope with the disability and being able to decide on the type of service needed. It seemed parents need to come to terms with and accept the disability before they could process which type of help their child needs.

This study found that not receiving adequate support from the team left parents facing greater challenges when dealing with the disability. Parents were then forced to seek support from alternative services, such as Enable Ireland and the Jack & Jill Children’s Foundation. This finding had not previously been reported in the literature. The result that parents experienced feeling hopeless and helpless on receipt of negative reports written by the team
was confirmed by previous research. Paige-Smith and Rix (2006) found that parents believed that the child's achievements reflected how much the parent had done for him or her. This is striking as other research indicated that parents found that a written report helped them to recall and think over the assessment findings and see the progress their child had made (McConachie, 1986). Other research, however, has concluded that there is a great deal of variability in how parents view child reports (Simeonsson et al., 1995). These findings highlight the responsibility of the early intervention team to deliver reports to the parents in a more positive light and to provide regular supportive contact with the parents’ regarding the child’s developmental progression. It is assumed that when a child is seen to make progress and when professional techniques and knowledge are shared with parents, parents have greater confidence in their own abilities to work with the child and the early intervention service itself.

5.3.2 Parents’ Experiences of MDA

5.3.2.1 Client-focused Values

Positive experiences of the MDA reported by parents in this study included the delivery of a child-centred practice, parent empowerment, having accessible and available services and receiving home-visits. Some benefits reported were a reflection of the delivery of Early Intervention service as a whole, rather than specific characteristics of the MDA. It was found that the team had facilitated a child-centred approach, which parents reported led to greater improvements in their development. Past research highlighted that a combination of child-focused services with parent directed interventions, is most apt in preventing developmental problems over time (Ramey et al., 1992; Shonkoff et al., 1992; Heinicke, 1995; Mahoney et al., 1998; Ramey et al., 2000). Most recent research, however, suggested that a family-centred approach needs to be developed (Rosen et al., 2009).

In this study, parents who felt involved in the child’s programme reported feeling more empowered and confident in effectively and efficiently implementing interventions for their child. Research confirmed this finding that parents are increasingly recognized by practitioners as partners in the delivery of child-focused services (Bruder & Dunst, 2000). Vanderhoff (2004) found that empowering parents is critical to the Early Intervention process, as parents ultimately are the ones who facilitate the child's progress.

One of the key positive characteristics of the MDA was that the team developed and implemented programmes for the family to apply in the home setting. Home-visits were reported to be hugely beneficial for the child and family, in terms of convenience and
application of best-practice methods. Other research supported the benefits of working with children in their natural environments, such as the home (Individuals with Disabilities Education Act [IDEA], 1990; Hanft & Pilkington, 2000; Brorson, 2005; Pierce et al., 2009). Easy access to and availability of the ECI team was also important to parents in this study. Tocci et al. (1997) found that help needed to be readily available and accessible to parents. These positive elements of the service and service model must be integrated into the development of future services. These characteristics could inform guidelines to coordinate the programmes and services necessary for children and their families.

5.3.2.2 Obstacles to Client-focused Values

Obstacles to the MDA reported by parents included gaps in the delivery of services, integration of interventions which reduced participation levels, replacing staff and isolation. The literature has highlighted challenges involved in delivering an intervention service to meet the needs of children with disabilities and their families (Wolery & Bailey, 2002; Odom et al., 2004; Guralnick, 2005b; Kelleher et al., 2006). Of note in the current study, and not reported in previous studies, was that parents felt the inconsistency of the delivery of therapies would have a negative impact on the child’s development and exacerbate the child’s disability. In addition, a gap between parental expectations and available resources resulted in adversarial situations, such as caused by cancellation of appointments. The finding that parents believed the team time wasted by attending team meetings and filling out paper work was significant. Similar to this finding, Carter et al. (2003) and Ashton (2008) reported that multidisciplinary teams were seen as time consuming.

Parents reported that their participation and involvement reduced significantly when therapies were integrated during ECI preschool time. Not witnessing nor knowing what or how interventions were being put into action was found to be a problem for some parents. This finding has not been reported in the literature previously. Research has, however, emphasised the importance of involving parents as a key to the success of Early Intervention programmes (White et al., 1992).

Isolation was experienced by parents who did not get ample guidance from the team and felt increasingly frustrated with managing aspects of the disability alone, such as, decision making for education system. A few parents felt neglected by the team in the sense that they had been left alone and were not given support. All attention was focused on helping the child with disability whereas parents were not given the help needed to cope with stress, anxiety and frustration. This finding was supported by Cederman (2006a) who
reported that feelings of despair were reported when parents own needs were not met. In addition, Ebersohn et al. (2007) emphasised that in health services the focus needs to be not only on the client who needs guidance, but on the family affected by and affecting the situation. The negative experiences of the service offer insight into building a better and more equipped approach and service in the future. To overcome such limitations, early intervention services must play a proactive role in supporting parents of children with disabilities to minimise gaps in the delivery of services and ensure staff are replaced in times of absence.

5.3.2.3 Operating as a Multidisciplinary Team

The finding that a supportive relationship between the parent and team members was greatly valued when supervision and friendship was offered simultaneously was confirmed in the literature. Friendliness and guidance by the team were greatly appreciated by parents. Research on Early Intervention practices reflected the importance of relationships between practitioners and parents (Turnbull et al., 2000; Edelman, 2004; Shaw et al., 2008).

The finding that a joint assessment approach, completed together with the family, child and team, was not a defining characteristic of a MDA; rather it was a significant aspect of the TDA. It was, therefore, noted that the ECI service had, itself, taken characteristics from the TDA and implemented these into the practice of the current service. This finding is significant in that this mixed method of practice had not previously been reported in Early Intervention literature. Research has, however, found that without joint communication and collaboration, there is a greater risk of fragmentation or duplication of services, as well as unmet family needs (Edelman, 2004).

One aspect of the MDA that was highlighted as valuable in this study was the practice of one-to-one, individual interventions. Although some parents in this study expressed a preference for this one-to-one intervention for their child, research has implied that children with disabilities have difficulty employing skills they have acquired in an isolated setting to more typical activities and environments. Therefore, isolated instruction to remediate specific skill deficits has little value for the child (Downing & Bailey, 1990).

5.3.2.4 Shifting (from one model to another)

In 2005, when a transformation from MDA to the newer TDA was proposed, mixed feelings and concerns were expressed by parents. It was found that parents formed negative opinions about the TDA based on anecdotal evidence. Certain parents in this study had fought against the changeover and opted to remain with the MDA. Research has, however, suggested that
parents must be assured that services are not being lost but rather integrated more meaningfully into their child’s programme (Downing & Bailey, 1990). Supporting this finding, Shaw et al. (2008) found that, despite the push at policy level to adopt transdisciplinary teams, the transformation to teamwork of this nature is slow. As far as is known, no study has examined parents’ experiences of the transformation from a multidisciplinary to a transdisciplinary approach.

5.3.3 Parents’ Experiences of TDA

5.3.3.1 Client-focused Values

Positive experiences of the TDA included a family-centred approach, parent empowerment, good quality and quantity of interventions and flexibility in the model. The finding that a family-centred approach was employed in the TDA was supportive of previous research. The literature has detailed that families play a critical part of the transdisciplinary team and are involved in setting goals and making decisions for themselves and their child (Bailey et al., 1998; Guralnick, 1998; Bruder, 2000; Judge, 2002). It was also shown that the increased level of parent participation in federal Early Intervention legislation has contributed to this shift from child-centred to family-centred Early Intervention services (Wehman, 1998).

This present study found that parents were empowered when actively involved in the child’s programme. Parents played an active role in programme participation and provided information concerning their child’s strengths and needs. The present finding was similar to research by Carpenter (1997) where professionals were encouraged to relinquish some of their domination of Early Intervention programmes and invest the power in parents who can control their own situation, their own lives and the lives of their children. Past research has emphasised the importance of people’s ability to feel that they are in control of the situation (Seligman, 1996).

The finding that the TDA was flexible in its approach, such as in its use of play-based assessments, was supported by previous research as Greco et al. (2005) found that the approach will differ for different families and at different times in a family’s life. The finding that parents sought regular and frequent services for their child was also supported by the literature. Other studies confirmed that parents believed that more therapy is better (Hinojosa, 1990; McWilliam, 1996). For parents in this study, it was noted that continuity of services was a key factor in determining the quality of the service. Past research has also shown that parents value coordination and continuity of services (Rosenbaum et al., 1998). These positive experiences of the TDA must be maintained in future early intervention settings to
ensure best-practice methods in the delivery of services. In addition, the favoured characteristics of the approach such as parent empowerment, provision of good quality and quantity of interventions and flexibility must be integrated and developed further in models that are implemented into practices in ECI services.

5.3.3.2 Obstacles to Client-focused Values

Obstacles reported by parents tended to reflect the service as a whole, rather than specific characteristics of the TDA. These included fighting for more services, time delays and accessibility and availability of the team and services. In this study, feelings of frustration, stress and desperation were elevated when parents struggled to access services for their child. Similar to this finding, Zaretsky (2007) reported that fragmented service delivery led to frustration for families. The literature also described that typically, parents of children with disabilities experienced greater stress and a larger number of challenges (Quine & Paul, 1985; Valentine et al., 1998; Roach et al., 1999).

Another major difficulty parents mentioned in this study was the time delay in accessing services or the time lapse whilst waiting for follow-up appointments. Past critiques of the TDA reported that one of the drawbacks of the approach was that it required a considerable time commitment (Benner, 1992; Nagle, 2007). According to Benner, professionals are required to attend team meetings, participate in pre-assessment planning, observe or facilitate the assessment and attend the final meeting to gather results and formulate recommendations.

The finding that services were not easily accessible or readily available was expected due to lengthy waiting lists and inadequate care through the ECI service. Many parents felt obliged to access private therapy for their children. In some cases, parents spoke about quitting their jobs and taking out substantial loans to facilitate adequate care for their child. This highlighted the inadequacy of service provision in Ireland. Naturally, parents feel obliged to source the best possible care for their children, even if it means paying for it, thus increasing financial strain and guilt if they do not have the means to pay for services. To date, no known study has examined parents’ perspectives on their need to supplement ECI services with private therapy. Obstacles reported by parents must be addressed and new ways of working must be developed to overcome such limitations mentioned. It is therefore recommended that early childhood intervention is delivered collaboratively and a joint approach for services is necessary to implement transdisciplinary assessment and intervention.
5.3.4 Operating as a Transdisciplinary Team

The key characteristics of the team in this study included guidance, ability to promote optimal development, operate a holistic approach and bridge gaps in the delivery of services. The finding that the level of guidance offered by the team was critical for parents in making a decision regarding the child’s development was supportive of previous research. Research confirmed that one of the main roles of the team members was to provide guidance to parents (Foley, 1990; King et al., 2009).

In this study, parents attributed progression of development areas to the help and support from the team. Parents recognised that the team operated in a holistic manner, which enhanced cohesiveness and communication among the team. Literature supported this finding as the TDA was reported as a more integrated and holistic approach to assessment and intervention (Patchell & Treloar, 1997; Zaretsky, 2007; King et al., 2009). It has also been found to reduce fragmentation in services and the likelihood of conflicting reports and to enhance communication and coordination with families (Walls & O’Connor, 2004; Carpenter, 2005; Davies, 2007).

The finding that the integration of services was critical to ensure the best outcome for children was confirmed in previous research. Parents reported that the TDA was less intrusive and reduced the number of individual appointments they were to attend with their child. Research has shown that families reported transdisciplinary teams are more powerful (Stayton & Bruder, 1999), less intrusive (Lisa et al., 2001) and that families participated more successfully in programmes (McBride & Brotherson, 1997) as compared with multidisciplinary teams. The finding in this study that some parents expressed concern for the level of invasiveness of the approach contrasted with the findings of Lisa et al. (2001).

The finding that some professionals on the team made critical judgements about the child, when having little or no previous contact with the child, tended to be problematic for a few parents. This has not yet been identified in the literature. One study, however, found that the number of people on a team often hits double figures, and extensive turnover from year to year can be problematic if it is not managed well (Giangreco et al., 1999). In saying that, services are offered with positive intentions and are meant to help children with disabilities, yet common professional approaches to “helping” can inadvertently have the opposite effects than those that were intended (Giangreco, 2000).

5.3.5 Experiences of Key Worker System
In this study, key workers were found to provide a valuable service to families and had many positive impacts on family life. Supportive open relationships, communication, role release and a family-centred approach were provided by the key worker system in this study. The finding that a relationship developed with the key worker was invaluable was confirmed by previous research. Liabo et al. (2001) reviewed Glendinning’s (1986) study and concluded that good relationships between key workers and parents are reported by parents as an important factor and of great value in themselves in the success of a programme. Similarly, Limbrick (2007) stated that the role of a key worker is to develop a helping relationship, to offer emotional support, to be available when needed and seek further help for families.

An increase in the level of communication between parents and the key worker was also reported. This is a positive finding, as Greco et al.’s (2005) review of the key worker system found that good communication among the key worker and family was critical. In addition, research found that listening and communication skills were essential for a key worker working with a family-centred approach (Kilgo et al., 2003; Scope, 2004).

The finding that parents described role release as one of the main responsibilities of the key worker had not been previously reported in the literature. Role release has not been defined as a key characteristic of the key worker. It was noted, however, that existing key worker services vary in how they are implemented and how the role of the key worker is defined and interpreted (Townsley et al., 2004; Mullins, 2008). Davies (2007) found that key working within a TDA was more effective due to the role release support. In this study, key workers also provided guidance and liaised with schools, which reduced stress and frustration for parents, as dealing with the education system was a major issue for parents. Research found that when supported by the key worker, parents reported that their child began to learn and liked going to school (Hume et al., 2008).

In this study, parents reported that a family-centred approach was employed in the TDA. This was a consistent theme in all of the research into key working (Carpenter, 1997; Barton & Clarke, 2006; Davies, 2007; Mullins, 2008). Research highlighted that the key worker helped parents set goals and coordinated and monitored the implementation of the plan of care (Mukherjee et al., 1999; King et al., 2009). Not all parents interviewed found their key worker useful. Research also supported this finding, as Greco et al. (2005) found that parents were dissatisfied with the service where the key workers were not coordinating care appropriately. In addition, parents in this study who were not assigned a key worker expressed a need to have one in future services. This was not surprising, considering that the idea of a key worker is a relatively recent addition to policy and legislative documents in
Ireland (Mullins, 2008). The National Health Strategy proposed that a holistic approach should be taken to plan and deliver care, which should include the appointment of key workers in the context of care planning, in particular for children with disabilities (DoHC, 2001). This finding is significant in that the inclusion of a key worker in the ECI service would be valuable to families in providing a supportive relationship, enhancing communication and facilitating a family-centred approach. This needs to be considered when setting out guidelines for practice and service development.

5.3.6 Conclusion of Parents’ Experiences

Given the findings of parents’ experiences of the multidisciplinary and transdisciplinary approach in this study, it is evident that parents did not take a direct stance on which model should be implemented in future Early Intervention services. In saying that, from reviewing the results of the current study, it is clear that parents expressed a desire for a model which reflected that of a transdisciplinary one. Parents wanted a “one-stop shop” to meet all their family needs, from the early referral process to later interventions. Receiving one comprehensive report was favoured and parents also wanted to be involved throughout the child’s development. In addition, the minimisation of attending several appointments was attractive and interaction and collaboration among team members was encouraged by parents. Finally, having a key worker as a secure point of contact was reassuring and supportive for all families. These characteristics reflect the notion of a transdisciplinary approach to be employed in future services.

5.4 Summary of Team Members’ Experiences

The team members interviewed for the purposes of this study shared their experiences of working on the transdisciplinary model. In some cases, certain team members had experience of working with both the MDA and the TDA. These experiences are encapsulated in the following sections.

5.4.1 Client-focused Values

The main benefits of working together on a team were highlighted. Firstly, it was found that team members worked in a more holistic practice, by expanding their own role and learning from the team. Previously Zaretsky (2007) found that within the transdisciplinary team
model, team members learned how to collaboratively share information, terminology and methods directly with one another.

The finding that the TDA offered a family-centred approach and professionals enjoyed better relationships with families was supportive of previous research. Effective ECI teams functioned optimally by adopting a family-centred approach, such as involving family participation in the process (Bruder, 1991; Filer & Mahoney, 1996). The TDA was also found to facilitate empowerment, by engaging parents at all stages of the programme in this study. This finding was similar to research which showed that the inclusion of parental voice, which is often marginalized or excluded, prompted new directions for the teams and increased parental engagement which was critical to the success of the model’s implementation (Tuchman, 1996).

The TDA was regarded as “best practice” by the team in delivering Early Intervention services in the current study. The TDA facilitated easier ways to work on functional and realistic goals for the child and family, better IDPs were developed, information was shared and role release created greater links on the team. These findings are in line with previous studies indicating that this model provides the best service to families by integrating the principles of co-ordination and family-centred service to a greater extent than other models (Tuchman, 1996; Carpenter, 2005; Davies, 2007; Coulthard & Hollo, 2009). From identifying the positive aspects of the TDA, it is recommended that ECI services administer early childhood intervention collaboratively and develop a joint approach for strategy, policy and support for the services to encourage all staff to embrace transdisciplinary assessment and intervention and support role release.

5.4.2 Barriers to Teams’ Values
Disadvantages of working on a transdisciplinary team as reported in this study included time consumption, lack of managerial support and difficulty getting parents on board with the new approach. The finding that transdisciplinary teamwork in Early Intervention was more time consuming than individual assessments and interventions was highlighted. Juggling individual professional roles together with team work roles was found to be a major challenge. This differed from findings by King et al. (2009) who reported that transdisciplinary team work takes less time. In addition, Myers et al. (1996) found that transdisciplinary assessments were more time efficient than multidisciplinary assessments and reported reasons why multidisciplinary evaluations took longer to complete. Having said that, King et al. (2009) noted that an appreciable amount of time was required for teams to
plan, practice and critique their work together, and to be able to deliver efficient and cost-effective services. The current study found that as a result of the issue with time, one team were forced to revert back to the MDA to manage the increasing number of referrals on the waiting list. This finding has not previously been reported in the literature.

A lack of support from higher management was found to increase demands and burden of the workload on the team members in this study. This finding was supported by Maher et al.’s (1998) results, which found that practitioners required peer support to be effective in a transdisciplinary role. The research suggested that managers must create an environment in which there is openness to learning and opportunity for team members to learn from one another and discuss shared intervention strategies (Davies, 2007).

The difficulties of working on a transdisciplinary team may be overcome through adequate support, training, education and understanding of the approach. The findings provide insight into the potential struggles and demands the teams are faced with on a regular basis. They are also helpful in informing further developments to the delivery of future services.

### 5.5 Experiences of Team-Working

#### 5.5.1 Enhancers to Team Functioning

The finding that sharing information among the team strengthened their professional abilities was confirmed by previous research which found that team members share information to remove the boundaries of each discipline and professionals gain skills in other practice areas (Locke & Mirenda, 1992; Reilly, 2001; Beukelman & Mirenda, 2005; Thylefors et al., 2005). The need for collaborative teamwork was supported by previous research where effective relationships were recognized as a benefit of a TDA (McGonigel et al., 1991; Hatton et al., 2002; Beukelman & Mirenda, 2005). Other benefits of collaborative teamwork have also been reported (Thylefors et al., 2005; Popich et al., 2006). Research showed that the process of collaboration has evolved over the years from unidisciplinary teams to transdisciplinary teams (Ferreira, 2004).

The finding that transdisciplinary assessments were continuously employed and were reported to enhance the assessment procedure was supportive of previous findings. Myers et al. (1996) found that transdisciplinary assessments were more efficient than standardised multidisciplinary assessments. In addition, one of the key components of a transdisciplinary model was integrating families and empowering parents in the process of assessment (Briggs, cited in Ferreira, 2004).
5.5.2 Obstacles to Team Functioning

The team members reported that transdisciplinary interventions were one of the most difficult aspects of the approach to implement effectively. There was a sense of confusion among the team on how to implement transdisciplinary interventions. The finding that a group-based intervention was not always appropriate to meet children with multiple disabilities needs had not previously been reported in the literature.

Another challenge reported by the team was the possibility of working in a unidisciplinary manner on a team. Research reported that historically, the practice of many health professionals has been characterised by unidisciplinary thinking, and individualistic and sometimes competitive behaviours have emphasised the roles and boundaries of each discipline (Robertson, 2002).

The present finding that team members experienced an imbalance on the team and greater burden and demands caused by the turnover of team members is different to previous studies. This study found that there was not enough time to train new team members on the facilitation of the TDA. Research found that transdisciplinary working was a useful method of working particularly when there is a shortage of therapists as team members were able to role release enabling less disciplines and staff to be involved with a family at the one time (Davies, 2007). In addition, Robertson (2002) found that team membership changed over time as new members are recruited and a process of learning to the team is necessary.

The findings are crucial in terms of those factors contributing to best early intervention practices. Through recognising the strengths and weaknesses of services and the approaches it may potentially assist in supporting parents and in the assessment and intervention processes.

5.5.3 Experiences of Key Worker System

The finding that team members were positive about the roles of the key worker for families and for themselves was confirmed in previous studies. Cederman (2006) reported that key workers helped plan what comes next for the child in terms of their provision, education and care and provided information on resources. In this study, key workers did not report further difficulty on their ability to manage their workload. Greco et al. (2006) found, on the contrary, that staff reported key working required extra time and effort, and lack of time to perform this role was a constraint. The transdisciplinary model is based on free-flowing
communication and the transfer of knowledge and skills across disciplinary boundaries (Cartmill et al., 2010).

The finding that role release was central to the responsibility of a key worker was supported. The team described it as crossing disciplinary boundaries which resulted in delivering a more holistic and comprehensive approach for the child. The team, however, also expressed concern in relation to the role sharing aspect of the TDA. This characteristic was widely reviewed in the literature, (Woodruff & McGonigel, 1988; Mayhew et al., 1999; Gargiulo & Kilgo, 2000) and concluded that role release was unique to the transdisciplinary team model within the context of the family. Sharing the expertise of all team members, including the family, provides a well-rounded approach without fragmenting services by specialty or domain (Dinnebel et al., 1999). Other research reported that role release was a challenging and controversial aspect for staff. Professional, personal and interpersonal challenges occur for service providers (Davies, 2007). These include the loss of professional identity, liability implications through lack of sufficient supervision (Ryan-Vincek et al., 1995) and inadequate sharing of knowledge and roles due to the experience of threat (Polmanteer, 1998; Sheldon & Rush, 2001; Warner, 2001).

The finding that one model of service delivery was not appropriate for all situations was striking. In certain cases, teams were not practicing in a truly defined transdisciplinary manner as confusion existed with regards to definitions and characteristics of the approach. One major difficulty was the uncertain role that team members assumed for themselves in the TDA. In the traditional model, roles are defined by job descriptions and responsibilities are designated to each team member. Whereas, in the TDA, roles and responsibilities are somewhat blurred, which causes confusion and misunderstanding.

In addition, the finding that, at times, the TDA was not the best fit with family or child needs was supported by recent research. King et al. (2009) found that the family may prefer separate services from individuals with disciplinary expertise or the family and child may have so many complex needs that it is not possible for one person to meet them all.

5.5.4 Conclusion of Teams’ Experiences

In conclusion, it was noted that in the ideal set-up where resources, support and staff were available and accessible, a transdisciplinary model of practice was favoured by the Early Intervention teams. In saying that, confusion around transdisciplinary roles and responsibilities needed to be minimised and barriers to practice were to be limited. This led to both teams’ expressing a greater desire and more positive attitude to work in a more
comprehensive and collaborative transdisciplinary manner. Key characteristics included a holistic approach and family-centred practice, team development and the key worker system. From reviewing the tentative models, implications of the models have been highlighted in relation to the early intervention services which are highly significant for children with disabilities.

5.6 Recommendations for future services
To date, there is a lack of research evaluating the effectiveness of Early Intervention services. In particular, little research has explicitly explored the models used in these services, such as the MDA and TDA. The present study, however, was informed by both parents and team members lived experiences of these approaches. The grounded theory models (see Figure 4.1, Figure 4.2, Figure 4.3) that were developed contain components from both of these different approaches.

In this study parents were encouraged to suggest recommendations for the purpose of future Early Intervention services, regarding the proficient delivery of services. These recommendations included:

- To facilitate a “one stop shop” approach to referral to eliminate the situation whereby parents of children with disabilities have to find out the appropriate service for their child. This would ensure that children do not fall through the gaps in service provision.
- To enhance and improve the consistency and continuity in the delivery of assessments and interventions for families.
- To reapply home-visits into the delivery of practices as this would facilitate parents’ desire and need for participation and inclusion throughout the process.
- Practical ideas included:
  - to receive an introductory meeting on entry to the ECI service,
  - to get a checklist to highlight areas of child’s development at potential risk (e.g., a child with Down’s syndrome may need orthotics),
  - to organise an annual review meeting and
  - to increase funding for resources.

5.7 Strengths and Areas of Development for Future Research
The current study had a number of strengths and areas of development for future research which will be outlined.

A major strength of this study was that it captured parents’ as well as team members’ experiences of the approaches applied within an Early Intervention service in an Irish context. This is the first study of this kind carried out in Ireland. Findings showed that the inclusion of parents’ voices, which is often marginalized or excluded, prompted new directions and increased parental engagement which was critical to the success of the model’s implementation (Tuchman, 1996). Bailey (2001) suggested that services must give parents every opportunity to be involved in planning and working with professionals, and be organized such that families feel competent to learn and to become advocates for their child. It was important to include parents’ experiences of the models in place in Early Intervention services to promote their growth and development and to continually expand involvement of family members. In addition to parents, it was important to include Early Intervention teams’ experiences in the study, as effective teamwork is a characteristic of good quality delivery of service (Sandall et al., 2000; Cederman, 2006).

It is vital to build and sustain successful Early Intervention teams as this maximises the chances that a child with special needs will reach their potential. As Miller and Stayton (2005) noted, transdisciplinary team-based services are now recommended as it allows professionals from different disciplines to work together with a key-worker and the family (Orelove & Sobsey, 1996). The transdisciplinary approach includes the parents as team-members and views the whole child’s development as integrated. Having highlighted parents’ and team members’ positive and negative experiences, it is hoped that this research will inform further Early Intervention services of the different models available. This research is informative to parents when selecting the best service for their child; it is also valuable to Early Intervention professionals and highlights the need to carefully consider the models.

Another strength of the qualitative approach adopted in this study was that such an approach provided richness and depth to the data through insights from parents and team members and generated findings from their self-reported experiences. The complexity and uniqueness of their experiences could not have been so comprehensively captured using a quantitative approach.

Given the experiences that have been accumulated by parents in the ECI service, several areas have been identified that may improve future investigations into the delivery of services for Early Intervention programmes. These included:
Chapter Five: Discussion

- To gather experiences from more ECI services, as this research took place in very specific contexts; two Early Intervention services for children with a disability under six years, which provides a non-designated key worker service in Ireland. It cannot be assumed that the findings equate with the experiences of caregivers accessing ECI in other contexts, such as those catering for children with disability accessing ECI via a mainstream crèche or pre-school. The small, purposive sample of 19 parents and 10 team members means that the findings may not be generalisable and are only representative of these participants’ experiences. It was also noted that these findings cannot be generalised to other teams, or team members working in Early Intervention services.

- In relation to the approaches in practice, to evaluate the significance of specific characteristics of both the MDA and TDA, in terms of assessment and intervention (e.g., one-to-one versus play-based assessments).

- A validation study of the approaches should be carried out to investigate and compare developmental gains of children’s participating in either the MDA or TDA as this may add to the reliability of significant differences found in either model.

- To examine whether team members’ and parents’ experiences change with the transformation of models and developmental improvements persist short or long-term.

- To investigate and use measures in both models that target wellness and mental health gain rather than the traditional deficit oriented measures that are used to measure states of unhappiness. Such measures may include: The Strengths and Difficulties Questionnaire (Goodman, 2001); Subjective Well-Being (Diener, 1994); The Children’s Hope Scale (Snyder et al., 1997); The Coping Responses Inventory (Moos, 1993) and other such positively oriented measures.

Suggestions in relation to the overseeing intervention team included:

- To identify and evaluate the positive and negative characteristics in relation to either model. These should be collated as there is a need for the development of a core curriculum for practices in ECI services. This has also recently been suggested by Coulthard and Hollo’s (2009) review of Trends in Early Childhood Intervention.

- Due to the limited time and resources available to the study, it was not possible to include mixed methodologies. This would have, however, identified the significant effectiveness of certain aspects of the models. Quantitative data from the team members could add corroboration and further illuminate the findings obtained here.
This would also allow ECI programmes to generate and operate best practice services.
Chapter Six: Conclusion

6.1 Summary of Main Findings

The study employed a qualitative methodology with parents of children with a disability who are clients of an Early Intervention Service and with team members of an Early Intervention team, to explore views of the models in practice. While there have been similar studies conducted, this is the first known study that has been conducted in Ireland to obtain the views of both parents of children with a disability and team members working with children with a disability regarding how the multidisciplinary and transdisciplinary models work in the Early Intervention services.

Parents’ reported their experiences of the MDA and the TDA and in some cases, experiences were a reflection on the delivery of service rather than specific characteristics of the approach. For the MDA, these included:

- Positive experiences such as
  - The delivery of a child-centred practice
  - Parent empowerment
  - Having accessible and available services
  - Receiving home-visits.

- Negative experiences such as
  - The gaps in the delivery of services
  - Integration of interventions which reduced participation levels
  - Replacement of staff
  - Isolation.

The inconsistency of the delivery of therapies was believed to have a negative impact on the child’s development and exacerbate the child’s disability. The favoured joint assessment approach was not a defining characteristic of a MDA. Certain characteristics of the TDA had been implemented amidst the MDA. One-to-one individual interventions were favoured by some parents. Transformation from a MDA to a TDA provoked apprehension for parents.

Similarly, parents reported experiences of the TDA. These included:

- Positive experiences such as
  - Family-centred approach
  - Parent empowerment
  - Good quality and quantity of interventions
  - Flexibility in the model.
• Negative experiences such as
  o Fighting for more services
  o Time delays
  o Limited access and availability of the team and services.

Key features of the team included guidance, ability to promote optimal development, operate a holistic approach and bridge gaps in the delivery of services. Key workers provided a valuable service and had many positive impacts on family life, including supportive open relationships, communication, role release and a family-centred approach.

Positive findings of team members’ experiences of the TDA included a holistic practice, a family-centred approach and better relationships with families. Best practice was delivered as it facilitated easier ways to work on functional and realistic goals for the child and family, better IDPs were developed, information was shared and role release created greater links on the team. In addition, team members were positive about the roles of the key worker. In addition, constraints were identified in relation to time consumption, a lack of managerial support and difficulty getting parents on board with the new approach. Positive findings of team members’ experiences of teamwork included sharing information, strengthened professional abilities, collaborative team working and transdisciplinary assessments enhancing the assessment procedure. Barriers were also identified in relation to the difficulty of implementing transdisciplinary interventions, the risk of working in a unidisciplinary manner on the team and the burden and demands by the turnover of team members.

6.2 Recommendations
Several recommendations arising from the findings of the research were made in relation to service delivery by the teams working collaboratively in Early Intervention services. These included:

• Having interviewed parents and learning about their difficult experiences of the disclosure process it is recommended to disclose a diagnosis to caregivers in a private setting. In addition, many parents spoke about being isolated after receiving a diagnosis, therefore it is suggested to offer on-going support and a follow-up meeting with the professional disclosing the diagnosis. In line with this, Carson (1995) advised that for best practice guidelines parents receiving any disclosures about their child of
a sensitive nature be told together in a private and comfortable place without any interruptions.

- In many cases, there was a shortage of information regarding support groups, resources and financial support available for parents. It is recommended that strategies are developed to ensure parents gain access to relevant support groups, are aware and mindful of the available resources and information on applying for financial support to assist in the child’s development.

- As regards the team members working on the early intervention team, many shared their experiences of training for their profession. Many team members spoke about the lack of training in relation to team-work and in particular having little to no training on ways to work in a multi- or transdisciplinary manner. From this, it is suggested to offer, in pre-service and in-service training, a number of relevant modules that focus on promoting team work and the different ways of working on a multi and transdisciplinary team approach.

- From researching the literature, it was evident that there was no undergraduate course that provides grounding in Early Intervention care services. Another recommendation, therefore, would be to develop a course that focuses on the importance of co-ordination and integration in teamwork. In addition, to establish a post-graduate diploma course that supports professionals from different disciplines to learn the additional skills they require to become skilled team-members, as well as Early Intervention Specialists.

- Research recommended an organized programme of ongoing training for early childhood staff to facilitate the acquisition and practice of skills for developing partnerships with families (Bruder, 2000; Wall & O’ Connor, 2004). This would potentially promote child-directed, goal-focused and challenging teaching practice. It could build a professional’s competence in working alongside early intervention teams. Future research could evaluate the ways in which team members implement and use the skills and techniques learned from the training programmes. In addition, having completed the various training, research could examine whether a change existed in relationship quality of parents and team members across time.

- From listening to the teams’ experiences there appears to have been no training to develop skills when working on a multidisciplinary or transdisciplinary team. Thus, there is a need to develop and implement a series of continuing professional
development modules for professionals actively working on an ECI team. This may enable them to teach parents how to cope with the stress associated with raising a child with disabilities, as inconsistent coping strategies were reported in this study. The basic premise of the model is that by increasing coping skills, parents can reduce their own stress and can become effective mediators in participating in their child’s programme. The training programme should also focus on increasing happiness in parents and develop strengths for parents. Future research is warranted to investigate the coping strategies parents implement to deal with stressors. In addition, it is important to look at parents’ mental health and well-being when coping with the stressors experienced when having a child with a disability.

- Having interviewed ECI teams, it is recommended that each ECI team should be given an option of adopting either a multidisciplinary or transdisciplinary approach. It was found that, in some cases, where a certain model was enforced upon the team it led to added pressure all round and the delivery of services was, in fact, counterproductive. Team members confessed about the struggles they had been faced with when a model was implemented where they had little support, no training and tried to manage a growing wait-list. Hence, by introducing and offering an ECI team the option of either model, it enabled the team to work within their means and empowers them to take control and implement best-practice services.

- A clear and structure of guidelines, detailing professionals’ duties, responsibilities and goals should be developed and distributed among ECI services. This may eliminate confusion that professionals’ spoke about regarding their roles on the team, particular regarding role release.

- Research suggests that the TDA is more effective in addressing children’s needs and in the delivery of services (King et al., 2009). However, results of this study showed that, in practice, the TDA can in fact create further tension and conflict within a team. For example, many of the team members spoke about the difficulty of getting parents to attend group-based interventions. In addition, a few parents spoke about the intrusiveness and invasiveness they had experienced on the TDA. It is therefore suggested that in some cases, where necessary, separate services from individual professionals could be offered.

- However, it is important to acknowledge that the child may have many complex needs therefore it would not be possible for one person to meet them all (King et al., 2009).
In this case, the team should assess the individual needs of the child and hence exhaust their options and come to a mutual agreement on which model should be employed to best meet the child’s needs.

- From the literature a transdisciplinary team approach is widely accepted as the best practice approach in ECI services (Kilgo et al., 2003; Carpenter, 2005; Davies, 2006; Department of Education and Early Childhood Development, 2008). In addition, it is seen as a cost effective way of delivery of services and is a very useful method of working, particularly when there is a shortage of therapists. Each year a transdisciplinary team costs approximately between €750,000 and €1,000,000 when more senior and experienced team members are required (National Federation of Voluntary Bodies, 2006). With the ever-shrinking resources available in the current economic climate, the TDA may be the only way forward if services are to continue to give families skills that will benefit children’s needs. Costs were not evaluated in the current study and from this it is recommended that future research should be undertaken to investigate the cost-effectiveness of the MDA and the TDA. This may potentially guide which model would be implemented in an ECI service.

6.3 Implications for Services

In Ireland there have been a number of changes in health, education, social and disability policy and legislation, which have affected the delivery and provision of ECI services for children with disabilities and their families. Despite these changes, there is still confusion as to which model to implement in the delivery of services.

In view of the many positive findings concurrent with previous studies in the literature, it would appear that the transdisciplinary approach and the key worker system are worthwhile and valuable to provide to families and team members caring for children with a disability. However, some aspects of both approaches should be considered further. Agreed standards should be introduced to the Early Intervention team so as to reduce the constraints identified in this study. The protocol could address issues, such as, what happens when the a team member leaves, goes on maternity leave, on holidays, on sick leave or works part time. It could also address how the team select which model of practice to implement within the service depending on the family’s needs. Standards could address issues such as clearly defining how the multidisciplinary and transdisciplinary approaches should be practiced and their distinct features as well as the role of the key worker and the job description with time allocated for the role.
6.4 Conclusion

The findings suggest that the journey of Early Childhood Intervention is fraught with questions and challenges for both parents and team members.

Despite broad satisfaction with ECI services, some inconsistencies remain with the models of Early Intervention services. The effect of policy and legislative changes may not necessarily lead to any significant improvements in terms of receiving ECI services. Existing and future economic challenges may lead to further changes in service delivery with a reduction in available resources to families and caregivers, therefore it is imperative to evaluate and decide on the most effective and efficient model in ECI.

This study adds to results drawn from the other research and contributes to the development of quality standards in services by highlighting the positives and obstacles in the models used in ECI service in Ireland. These findings will be informative to parents when selecting the best service for their child. It is also valuable to ECI teams as it highlights the areas that need to be carefully considered within each model. The methodology adopted in this study to explore parents’ and team members’ perceptions has made it possible to draw from their experiences a number of good practice factors, which guide the manner by which ECI services could develop in the future. The following themes were obtained which are considered good practice factors include a family-centred approach, parent involvement, accessible and available services, home-visits, good relationships, support and collaborative teamwork.

6.5 Reflection

As part of my Research Masters, I interviewed parents and team members about the models in Early Intervention Services. In this thesis, I explored their experiences and in turn, I concluded the thesis by suggesting a transdisciplinary approach was the best model of practice. Having met with parents for interviews and analyzing the data, it was evident that parents did not have a clear understanding of which model they wanted or needed for their child. Parent had, however, openly stated many valuable characteristics of the models in practice including a family-centred and holistic approach, but they did not outwardly state which model they preferred. By analyzing the data using a grounded theory approach, I was able to identify that these characteristics were, for the most part, representative of a transdisciplinary approach.
As a qualitative researcher, I was immersed in a large quantity of data and maintained a close connection with the data being analysed at all times. A great deal of time was invested in this aspect of data analysis. It was from this, I was saddened to hear about the horrible lack of resources, constant struggle and continuous fight to avail of the best services that parents were faced with when searching for appropriate services for their child. It was both difficult and frustrating for me to hear the same kind of challenges and difficulties for most parents. I was delighted to hear when family life had improved and in particular, when children made developmental gains. I was also privileged that parents were happy to be involved in this piece of research as I had given them the opportunity to communicate their opinions and they felt that they were being listened to for the first time.

Hearing about the teams’ burden of demands and constant pressure, from both the Health Service management and parents, provided me with new insights. The constant sense of strain was highlighted by the endless waiting lists, limited resources and lack of support from the services they worked within. With the hope of pursuing a career in this field, it gave me a greater understanding of the challenges teams are currently faced with in this area of work. It also gave me awareness about how people in this work must learn from experience and have the ability to transfer their knowledge and personally adapt.

Having undertaken this piece of research, I have a better insight of what parents and teams require from an Early Intervention service. From this, I have developed many valuable skills including reflective listening, good communication skills, the ability to generate theory from research data and the ability to evaluate services for children. I now have a deeper understanding of the topic area and I have better awareness of the issues that professionals, parents and children may face in Early Intervention Services.
References


Children in Hospital Ireland and the Irish Association for Hospital Play Specialists (2000). The Hospital Playlink. Dublin: Children in Hospital Ireland.


References


References


Hanson, M. J. and Lynch, E. W. (1995) *Early intervention: Implementing child and family services for infants and toddlers who are at risk or disabled* (2nd ed.). Austin, TX: PRO-ED.


Charlottesville, VA: University of Virginia, Children's Medical Center, Kluge Children's Rehabilitation Center.


Kelleher, E., McGough, A. and Ware, J. (2006) Early years provision for children from birth to six years with special needs in two geographical areas in Ireland. Centre for Early Childhood Development and Education.


Kitzinger, J. (1994) The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness, 16*, 103-121.


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References


References


References


References


References


References


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Appendix A: Parents’ Interview Schedule in a Multidisciplinary Approach

Opening Questions
How many children do you have and what ages are they and what schools do they go to?
What is it about your child/children that you enjoy the most?

Transition Questions
How long has your child been involved in this Early Intervention Service and how were you first referred to this intervention service?

Key Questions
Please tell me about your general experiences of using the early intervention service? E.g. how have you got along the professionals; has there been improvements in your child’s development, how often would you use the service?
From your experiences to date, what you would describe as the main strengths of the service?
What challenges or difficulties you have been faced with regarding the service and how you have dealt with this?
How satisfied are you with the assessment and intervention plans put into place for your child to reach their target goals?

Ending Questions
In what ways has this service enabled you to help your child to learn and develop? Can you give me an example?
Overall, how much of a difference has the early intervention service made to you and your child’s life since you were first referred?
Is there anything else about your time in the service that you would like to share with me before we finish up the discussion? Have I missed anything?
Appendix B: Parent Interview Schedule in Transdisciplinary Approach

**Opening Questions**

How many children do you have and what ages are they and what school do they attend?

What is it about your child/children that you enjoy the most?

**Transition Questions**

How long has your child been involved in this Early Intervention Service and how were you first referred to this intervention service?

**Key Questions**

Please tell me about your general experiences of using the early intervention service? E.g. how have you found the professionals; has there been improvements in your child’s development, how often would you use the service?

From your experiences to date, what you would describe as the main strengths of the service?

What challenges or difficulties you have been faced with regarding the service?

How satisfied are you with the assessment and intervention plans put into place for your child to reach their target goals?

What is your understanding of the role of the key worker in the service? E.g. what are their duties, jobs are they to be doing?

What aspect of your key worker service do you value MOST?

What aspect of your key worker service do you value LEAST?

In what ways does the key-worker enable you to help your child to learn and reach targeted goals?

**Ending Questions**

Overall, how much of a difference has the early intervention service made to you and your child’s life since you first entered?
Appendix C: Demographic Questionnaire for Parents

Evaluating Early Intervention Service: What Parents’ think?

We are asking parents to give us some background details on their family. This is so we can tell whether those who take part in our study are representative of parents in Ireland and whether there are differences in the views of parents from different backgrounds. Please complete the following questionnaire.

Please Note: This questionnaire is for research purposes only. You do not need to put your name on it and anything you write will be strictly confidential

1. Are you the child’s:
   - Birth Parent: Mother □ Father □
   - Foster Parent □
   - Adoptive Parent □
   - Grandparent □
   - Other □

2. What is your date of birth? ……………………

3. How many children do you have? ……………………

4. What age is your child in the Early Intervention Service? Years……Months……

5. What is the nature of child’s disability: ……………………………………………………………

6. How many years has your child been in the Early Intervention Service?
   - Less than 12 months □
   - 1 – 2 years □
   - 2 – 3 years □
   - 3 years + □

7. Martial Status.
   - Single □
   - Married □
   - Separated/Divorced □
8. What did your education include?

Intermediate/Group Certificate ☐ Bachelor’s Degree ☐
Leaving Certificate ☐ Higher Degree ☐
Diploma/City & Guilds ☐ No schooling ☐
Other, please specify…………………………..

9. What is your current employment status?

Homemaker ☐
Employee (Full-time) ☐
Employee (Part-time) ☐
Self-employed ☐
Not employed ☐
At College/ University, student ☐
Other, please specify ……………………………

If in paid employment, please give your job title:
_____________________________________________

IF YOU ARE LIVING WITH A SPOUSE/PARTNER

10. What did their education include?

Intermediate/Group Certificate ☐ Bachelor’s Degree ☐
Leaving Certificate ☐ Higher Degree ☐
Diploma/City & Guilds ☐ No schooling ☐
Other, please specify…………………………..

11. What is their current employment status?

Homemaker ☐
Appendix C

Employee (Full-time)  □
Employee (Part-time)  □
Self-employed  □
Not employed  □
At College/ University, student  □

Other, please specify  ……………………………

If in paid employment, please give their job title:
__________________________________________________________________________

Thank you for helping us with this study. Your participation is much appreciated.
Appendix D: Team Members Interview Schedule

**Opening Questions**

Please tell me your job title and what is your favourite part of the job?

**Transition Questions**

How long have you been working in the Early Intervention Service?

How did you first become involved with this intervention service?

**Key Questions**

Please tell me about your general experiences of working with others in EI services as part of a multi/trans disciplinary team?

From your experiences to date, what you would describe as the main strengths of the service?

What challenges or difficulties you have been faced with in the service and how you have dealt with these?

How did your professional training prepare you for working with the transdisciplinary model?

How has your professional role evolved by working in the transdisciplinary model?

How are you satisfied with the assessment and intervention methods put into practice for children in the service?

**Ending Questions**

Overall, how much of a difference has your work made to the lives of the children with disabilities in the early intervention service?

Is there anything else about your experiences in the service that you would like to share with me? Have I missed anything?
Appendix E: Demographic Questionnaire for Team Members

Evaluating Early Intervention Service: What Professionals think?

We are asking professionals to give us some background details on themselves. This is so we can tell whether those who take part in our study are representative of professionals in Ireland and whether there are differences in the views of professionals from different backgrounds. Please complete the following questionnaire.

**Please Note:** This questionnaire is for research purposes only. You do not need to put your name on it and anything you write will be strictly confidential.

1. What is your job title? .............................................

2. How many years have you worked in this profession?
   - Less than 12 months ☐
   - 1 – 2 years ☐
   - 2 – 4 years ☐
   - 4 years + ☐

3. How many years have you been working in Early Intervention Services?
   - Less than 12 months ☐
   - 1 – 2 years ☐
   - 2 – 3 years ☐
   - 3 years + ☐

4. How many years have you been working in this Early Intervention Service?
   - Less than 12 months ☐
   - 1 – 2 years ☐
   - 2 – 3 years ☐
   - 3 years + ☐

5. Prior to working on this service had you worked with the transdisciplinary model?
   If yes, for how long:
   - Less than 12 months ☐
   - 1 – 2 years ☐
   - 2 – 3 years ☐
   - 3 years + ☐
6. **What did your education include?**

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Option 1</th>
<th>Option 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intermediate/Group Certificate</td>
<td>☐</td>
<td>Bachelor’s Degree ☐</td>
</tr>
<tr>
<td>Leaving Certificate</td>
<td>☐</td>
<td>Higher Degree ☐</td>
</tr>
<tr>
<td>Diploma/City &amp; Guilds</td>
<td>☐</td>
<td>No schooling ☐</td>
</tr>
<tr>
<td>Other, please specify</td>
<td></td>
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Thank you for helping us with this study. Your participation is much appreciated.
Appendix F: Parent Recruitment Letter

UNIVERSITY of LIMERICK

July, 2009

Dear Parent/Guardian,

We are undertaking research evaluating the method by which the Early Intervention services in two regions carried out their work. This research is specifically interested in parents’ experiences of the service put into place for you and your child/children.

In order to complete this research, you are being invited to take part in a group discussion.

The interview will ask you about your experiences regarding:

- The service put into place for your children
- The effectiveness of the model regarding child outcomes
- Your ideas on the approaches of assessment and intervention
- Your thoughts on the strengths and weaknesses of the model

The group discussion will facilitate a general discussion with a group of parents who also have experience of how the service was delivered.

The purpose of collecting information is to determine the effectiveness of the existing methods of working. It will place emphasis on the best practice methods for early intervention.

We are inviting you to take part in this study. If you are happy to take part, we would appreciate if you could please sign the enclosed consent form and return it to your local Early Intervention Service to enable us to carry out our research. Please read the information leaflet before signing the consent form. **We would be grateful if you could return the consent form to the service centre by MONDAY the Xth of July.**

If you have any further queries about this study please do not hesitate to contact Ms. Noelle Fitzgerald by phone at 061 202741 or by email at noelle.fitzgerald@ul.ie

We hope that you will be happy to take part in this study. Thank you for your time.

Yours sincerely,

____________________
Noelle Fitzgerald    Dr Patrick Ryan
PhD Researcher       Director, Doctoral Programme in Clinical Psychology
Appendix G: Parent Information Sheet

**An Evaluation and a Comparison of the Models of Early Intervention**

**Introduction**

You are being invited to take part in a research study on evaluating the effectiveness of the service delivered in Early Intervention Services. Before you decide to take part in the project, there is more information below that will explain to you why the study is being done and what it will involve. If you agree to take part, we will ask you to sign a Consent Form. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this study when you feel that you understand what is being asked of you and you have had enough time to think about your decision.

Thank you for reading this.

**Who is carrying out the study?**

The study is being carried out by a team of researchers from the Department of Education and Professional Studies at the University of Limerick.

**What is the study about?**

The study seeks to explore the effectiveness of the early intervention services in Limerick and Tipperary. The study will examine two different models put into practice. It will examine the multidisciplinary method whereby interventions are undertaken on a one-to-one basis and it will also examine transdisciplinary method which focuses on play-based assessment and group-based interventions. This research will have a significant impact in terms of the best practice methods of early intervention at a local level.

**What will I have to do?**
Participants are asked to take part in a group discussion. This will involve a group of parents from the early intervention service answering some general questions on their experiences of the service.

**All information will be kept confidential and at no stage will you be identified in the findings that are reported.**

<table>
<thead>
<tr>
<th>What are the benefits to you in taking part?</th>
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We think you and your child will benefit indirectly and potentially directly from the research. The project will expand our knowledge on the strengths and weaknesses of the interventions put into practice for children. It can help to improve future assessments and interventions and the information you provide can help researchers and health professionals develop further and more effective methods to enhance the early intervention services.

<table>
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<tr>
<th>What are the potential risks of taking part?</th>
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It is not expected that this research will be difficult or upsetting for you. However, you always have the right to withdraw at any time from the study.

<table>
<thead>
<tr>
<th>What happens to the information?</th>
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</table>

The group discussion will be tape-recorded and the tapes will be transcribed verbatim with all identifying features removed. All information that is collected during the course of the research will be kept strictly confidential. The information collected in this research study will be stored in a way that protects your identity. Results from the study will be reported and will not identify you in any way.

<table>
<thead>
<tr>
<th>Who else is taking part?</th>
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</table>

The research team will be asking a total of 20 families from East Limerick and North Tipperary to participate in a group discussion. It is estimated that 10 parents will be in each group discussion.

<table>
<thead>
<tr>
<th>What happens at the end of the study?</th>
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</table>

The information gathered by the researcher may be presented at an academic conference or published in a journal. However, the information you provide us in this project will be kept confidential. This information will be kept in a secure location. No one else will see your responses.

<table>
<thead>
<tr>
<th>What happens if I change my mind during the study?</th>
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</thead>
</table>


It is your choice if you would like to take part in the study. If you decide to take part you will be asked to sign a consent form and will be given this information sheet to keep. You can withdraw your participation and consent at any time, even after the data has been collected. If this should arise any data pertaining to you will be removed.

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

The research team will be available for you to contact if you have any questions during your participation in the study.

Feedback will be sent to the Early Intervention service for those who require it at the end of the research study. At the end of the consent form, there is an additional section where you can provide your home address if you would like to receive information about the study results.

If you have any questions, please do not hesitate to contact the researcher, Ms. Noelle Fitzgerald (061 202741).

*If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ‘The Chairperson of the University of Limerick Research Ethics Committee, c/o Anne O’Dwyer, Graduate School, University of Limerick, Limerick. Tel: (061) 202672*
Appendix H: Consent Form

Please give this form to the Early Intervention Service before Thursday, July 30\textsuperscript{th}.

Please tick the required boxes below to indicate whether or not you agree to take part in the study and sign the form at the end.

I confirm that I have read the information sheet for the above study.
I am satisfied that I understand the information provided and have had enough time to consider the information.

I understand that all my information will remain confidential,
I will not be named in the study report and I can withdraw at any time from the study.

I am aware of what the study is about.

I agree to take part in the group discussion.

I _______________________________ consent to take part in this study.

Name           ___________________
Signature          ___________________
Date           ___________________

Contact Number: ……………………………….

Optional information about study findings
To receive a report about the results from the study, please provide your home address below:
Address:

……………………………………………………………………………………………………………………………