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UNDERSTANDING EARLY INTERVENTION SERVICES IN IRELAND: A CONCEPTUAL EVALUATION

A thesis submitted in fulfilment of the requirements for Doctor of Philosophy in Health Promotion

By

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June 2016
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<tr>
<td>DS</td>
<td>Down syndrome</td>
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<td>DSA</td>
<td>Developmental Systems Approach</td>
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<td>EI</td>
<td>Early Intervention</td>
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<tr>
<td>EPSEN</td>
<td>Education for Persons with Special Educational Needs Act</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
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<tr>
<td>ICF-CY</td>
<td>International Classification of Functioning – Children and Youth Version</td>
</tr>
<tr>
<td>ICON</td>
<td>Integrated Care One Network</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>LAC</td>
<td>Local Area Coordinator</td>
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<tr>
<td>MPOC</td>
<td>Measure of the Processes of Care</td>
</tr>
<tr>
<td>MPOC-SP</td>
<td>Measure of the Processes of Care for Service Providers</td>
</tr>
<tr>
<td>MPOC-NL</td>
<td>Measure of the Processes of Care Dutch Translation</td>
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<tr>
<td>NESC</td>
<td>National Economic and Social Council</td>
</tr>
<tr>
<td>NSPCC</td>
<td>National Society for Prevention of Cruelty to Children</td>
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<tr>
<td>SLCN</td>
<td>Speech, Language and Communication Needs</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>UNCRC</td>
<td>United Nations Convention on the Rights of the Child</td>
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<td>USA</td>
<td>United States of America</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy, is entirely my own work and has not been taken from the work of others and to the extent that such work has been cited and acknowledged within the text of my work.

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Abstract

In Ireland the provision of early intervention services for children with disabilities is changing. With the policy and legislative contexts driving this change, these services need to be informed by evidence and underpinned by conceptual constructs which are grounded in praxis within the Irish context. These constructs can support the implementation and evaluation of best practice EI services in Ireland. Underpinned by an interpretivist paradigm, this study used a qualitative case study design with a Grounded Theory methodology, and developed a substantive theory which is represented by a conceptual model. Data were collected from multiple perspectives within one early intervention disability service in Ireland. In total, 31 indepth interviews with young children with disabilities, parents and professionals were included and data were collected and interpreted in a coherent, systematic and rigorous way. The conceptual model acknowledges that synergistic interdependent relationships exist in the EI context. When considering outcomes to service delivery professionals need to consider how rewarding and enabling the service is to all involved in the relationship. Balancing interdependence within the complex relationships is crucial to support positive outcomes. Finding this balance requires an acknowledgement of the constructs within the relationship and conversations about process and outcomes for individual families. This balancing act is core to EI practice and regard must be given to the driving and restraining factors within each partnership. The goal of the partnership is one where the rewards exceed the costs. In order to meet this goal, attentive consideration needs to be given to the profile and influence of each individual within the relationship. The concept of the relationship trajectory is paramount and how the position of the individual on this trajectory influences their interaction, expectations and level of involvement needs to be considered. This study proposes considering the relationship stages as momentous in the development of early intervention relationships between partners.

Key words: Early intervention, disabilities, multiple perspectives, grounded theory, case study.
1. **Introduction**

1.1 **Purpose Statement**

In Ireland the benefits of prevention and early intervention (EI) programmes for children from socially disadvantaged families and communities, their parents, and projected societal outcomes are documented (Harvey, 2014). The benefits of EI for children with disabilities in Ireland are under researched. For children with disabilities and their families, access to effective EI services, within the first five years of life, is critical to the child’s development (Guralnick, 2011). The Government of Ireland (2014, p. 11) published a National Framework aiming ‘to promote a shift in policy toward earlier intervention and to ensure the provision of quality Early Years services and interventions, aimed at promoting best outcomes for children and disrupting the emergence of poor outcomes’. Currently no standardised evaluation of the quality of EI intervention exists in Ireland; hence research investigating the processes to support child and family outcomes is recommended (Carroll, Murphy, & Sixsmith, 2013). It is deemed best practice that EI programmes allocate resources and time to evaluation as an essential way of determining the quality of the services that they provide (Fallon, 2000). According to DiClemente, Salazar, and Crosby (2013, p. 25) theory ‘is at the core of effective public health approaches’. Hence, there is a need to develop a conceptual model of constructs, grounded in praxis in Ireland, to support the delivery of high quality EI disability services in the future. The development of this conceptual model will identify the process constructs to support the evaluation of EI services within the Irish context.

Supporting parent-child relationships within family-centred and coordinated services is currently presented as the best practice model for providing EI services to children and their families (Adams, Tapia, & The Council on Children with Disabilities, 2013). In Ireland, family-centred care is the driving service delivery approach within the health service (Health Service Executive, 2011). The guiding principles to inform all children’s and young people’s services in Ireland are children’s rights, family-oriented, equality, evidence informed and outcomes focused (Government of Ireland, 2014). In contrast to the principles of family-centred care, current guidelines and
standards do not include the input of families (Hayles, Harvey, Plummer, & Jones, 2015). Services need to be informed by evidence from the perspectives of all who use them.

The aim of this study was to gain an understanding of the processes that facilitate integrated EI services for families with children with disabilities from multiple perspectives in the Irish context. Because of the heterogeneity of EI service provision and the lack of research generally to support EI practice in Ireland, qualitative exploration was required. Yung (2010) recognises that interventions must work well for both the child and their family for the child to reach their potential. Collaboration and relationships underpin EI services (Bridle & Mann, 2000; Matthews & Rix, 2013). Therefore, the collaborative relationships between the professionals, young children and their families are the key to the success or failure of intervention in Ireland and require deeper exploration.

1.2 Early Intervention

The term EI generally refers to services provided to young children (birth to six years) at risk of or who have developmental disabilities or delays (Carroll et al., 2013) in the published paper in Appendix A. In Ireland 66,437 children have a disability (5.8% of the child population), with over 10,000 of these children requiring EI services (Department of Children and Youth Affairs, 2012). Designed to support family patterns of interaction that best promote children’s development, EI services have long-term benefits for children and their families (Guralnick, 2005). For children with disabilities and their families, access to effective EI services, within the first five years of life, is critical to the child’s development (Guralnick, 2011). The increase in research in the neurological, behavioral and social areas has affirmed beyond doubt the importance of early life experiences (Shonkoff & Phillips, 2000; Shonkoff, Richter, van der Gaag, & Bhutta, 2012). The transactional model of development stresses that the child and their contexts shape each other and that this complex interaction impacts on development (Sameroff, 2009). The contexts in which a child interacts, in particular the distal influences, such as the family, education and EI are important to consider. Providing family-
centred and coordinated EI services to children and their families are regarded as best practice (Adams et al., 2013). A family-centred model is represented well in international legislation reflecting the importance of early identification and collaborative working (Health Service Executive, 2011). The United Kingdom endorses giving every child the best start in life and enabling all children to reach their full potential as necessary policy objectives to reduce health inequalities (The Marmot Review, 2010). In September 2015, the United Nations (UN) General Assembly adopted new Sustainable Development Goals as part of the ‘Transforming our world: the 2030 Agenda for Sustainable Development’ (United Nations, 2015). The Sustainable Development Goals validate the work of early childhood professionals around the globe and set core actions for EI services around the world to achieve. The fourth Sustainable Development Goal is to ensure equitable and inclusive quality education to support early childhood development and to ensure lifelong learning. Target 4.2 states that by 2030 ‘all boys and girls will have access to quality early childhood development, care and pre primary education, so that they will be ready for primary education’ (United Nations, 2015, p. 19).

Guralnick (2001) defines early childhood intervention as a system designed to support family patterns of interaction that best promote child development. Guralnick (2001) promotes the use of the Developmental Systems Approach (DSA) for early childhood intervention in order to inform service provision and to support uniformity. In Ireland in particular, radical change is taking place in the provision of early services for children with special educational needs and disabilities (Government of Ireland, 2014). The Health Service Executive (HSE) is committed to ensuring that every child will receive timely, coordinated, high quality, family-centred services (Health Service Executive, 2011). The HSE currently aims to ‘provide integrated services that meet the highest standards’ for those using disability services (Health Service Executive, 2015, p. 8)

The development of best practice tools to help professionals to work with families within EI and prevention services is the vision (Government of Ireland, 2014). EI team services involve multiple professionals, parents and children with disabilities. There is an identified need in Ireland to organise
services so as to promote optimum child outcome and greater parental well-being (Government of Ireland, 2014; Health Service Executive, 2015). Although early childhood interventions have a common objective to provide family-centred and coordinated services (Adams et al., 2013), there is no international uniform model (Carroll et al., 2013) in the published paper in Appendix A. This is not surprising at one level within the context of diverse health systems but it highlights that there are no core components of EI service provision. These core components are necessary to support quality and evidence informed practice that can be evaluated. With the policy and legislative contexts driving change in EI disability service provision in Ireland, these services need to be supported by a consistent approach informed by an evidence base and underpinned by conceptual constructs within the Irish context.

1.3 Policy and Legislative Contexts

Underpinning the provision of child and family services in Ireland are the Irish Constitution and the United Nations Convention on the Rights of the Child (UNCRC, 1989), which was ratified by the Irish Government in 1992. The Education for Persons with Special Educational Needs Act (EPSEN), (Government of Ireland, 2004) and the Disability Act, (Government of Ireland, 2005) set out a rights based approach, giving access to legally enforceable rights to services, to assess the needs of children with disabilities and/or special educational needs for health and/or educational services. The National Disability Authority supports and believes strongly that a rights perspective is fundamental in the development of policy and practice for people with disabilities (National Disability Authority, 2004).

In 2004, the Irish Government launched the National Disability Strategy (Department of Justice and Equality, 2004) as a framework of positive action to support the participation of people with disabilities in Irish society. The National Disability Authority also advocates an understanding of disability based on the social model underpinned by the key values and principles of equality, participation and inclusion (National Disability Authority, 2004). The National Children’s Strategy incorporated these values and principles
emphasising that a child’s voice will be heard and that they will receive quality supports and services to reach their potential (Department of Health and Children, 2000). This Strategy reinforced the UN Convention on the Rights of the Child (UNCRC), specifically Articles 23 and 24, which focus on the right of children with disabilities to care, education and training and on the right to the access to services respectively (Office of the United Nations High Commissioner for Human Rights, 1989). In 2015, the first National Strategy to ensure that children will have a voice in decision-making was launched progressing the values and principles of participation and inclusion further (Department of Children and Youth Affairs, 2015). This Strategy supports the Irish Government’s commitment to listen to children and support them to express their views (Government of Ireland, 2014).

1.4 Practice Context
The context of EI services in Ireland is undergoing radical change guided by the Health Service Executive’s national programme ‘Progressing Disability Services for children and Young People’ in joint partnership with Non-Government Agencies, the Department of Health and Children and the Department of Education and Skills. There are variations in access to EI services in Ireland and access is dependent on referral and access criteria within particular geographical locations. EI teams exist providing comprehensive assessment with coordinated input from the various disciplines such as: Nurse, Occupational Therapist, Physiotherapist, Social Worker, Speech and Language Therapist, Paediatrician, Medical Doctor, Psychologist, Early Childhood Educator, Family Support Worker, Dietician and Administrator. Teams may be co-located or work across different locations A variety of models of team working, however there is no standardised model of practice for team-based assessment. All Health and Social Care Professionals have professional qualifications, from third level institutions, in their area of expertise. Interventions can include building family support, empowering the family, facilitating coping strategies, carrying out specific interventions, and/or teaching techniques and strategies. Based on geographical location and variations in priority/waiting list management criteria interventions may be
interdisciplinary or discipline specific. Some services provide a key worker to support families. Interventions can be home-based, pre-school based or clinic-based and may be one-to-one or group.

1.5 Researcher Perspective
The researcher is a Speech and Language Therapist by professional background and specialised in working with people with disabilities during her practice career. She is currently a lecturer in the Discipline of Speech and Language Therapy at the National University of Ireland, Galway. She worked in the Health Service Executive for nine years; working fulltime in an EI service for five years acting as both the Speech and Language Therapist and Team Leader on the EI team. The researcher was experienced in communicating with children with significant communication needs using Lamh (Augmentative Sign Language System for children with disabilities), communication boards and other systems of communication such as PECS (Picture Exchange Communication System) and observing children’s communication both verbally and non-verbally. The researcher is passionate about EI services and about children and their parents having a voice and being included on an EI team. The researcher holds the perspective that professionals collaborate with families to help a child reach their full potential. During the course of the research, the researcher also became a parent adding another lens through which the researcher carried out this research.

1.6 A Socio-ecological Perspective
For children with disabilities, their families and EI professionals the concept of disability has changed significantly over the second half of the 20th century. New ideas in biological science, psychology, and human services reframed thinking of disability. The recognition of the social model of disability (Oliver, 1981), the normalization principle (Wolfensberger, 1972), and the environmental influence on intelligence (Lewin, 1935) created new expectations and opportunities for children with disabilities and their families. The Ottawa Charter for Health Promotion (World Health Organization (WHO), 1986) acknowledged the influence of complex environments on health. The highest priority is for countries to ensure that every child has a
good start to life (Marmot, Allen, Bell, Bloomer, & Goldblatt, 2012). Family Systems Theory (Bowen, 1978) and Ecological Systems Theory (Bronfenbrenner, 1979) offered new ways of thinking about the family and the context of human development. Both theories have influenced treatment and opportunity for children with disabilities and their families in EI practice. Other theories, which became relevant during the study to EI practice in Ireland, were Social Exchange Theory (Homans, 1961) and Interdependence Theory (Thibaut & Kelley, 1959). How these theories supported the development of the conceptual model illuminated by this study will be discussed.

1.7 Participation in Early Intervention

The UNCRC established key principles in Articles 3, 12 and 13 to guide children’s participation: Article 3 states that the best interests of the child should be the primary consideration; Article 12 states that the child has a right to express an opinion; and Article 13 states that the child has a right to express his/her views (Office of the United Nations High Commissioner for Human Rights, 1989). Historically children were virtually excluded as active participants in the research process and were rarely asked to tell their own stories (Grover, 2004). The voices of children with disabilities have also been overlooked in research (Kelly, 2007). The inclusion of children in research about EI services is extremely important and an understanding that their involvement can be facilitated is required. Parents’ views are central to ensure children attending EI services are supported in reaching their full potential (Bailey et al., 2006; Bruder, 2010). The important role that families play has been validated through evidence-based research studies (Bruns & Fowler, 1999; Pang, 2010). The views of professionals are extremely important to support the development of quality EI services. Service providers play a central role identifying and meeting the needs of children and their families (Bailey et al., 2006; Bruder, 2010). Effective relationships among professionals have long been recognised as important to EI. Further qualitative research of EI services is indicated particularly to understand the process constructs that are important to EI practice in Ireland. This understanding will support the evaluative process to determine quality services. Research including young children with
disabilities views is warranted both internationally and in Ireland. As an important part of EI services, children’s views together with parents’ and professionals’ views, should be included in the building of a conceptual model to underpin Irish EI services.

1.8 Study Question, Research Aims and Objectives

The overarching research question that was pursued in this study was:

- What are the process constructs that underpin early intervention services in Ireland?

To assist in answering this research question, the following research aims and objectives were considered:

- **Study Aims**:
  1. To understand early intervention services from the stakeholders’ perspectives.
  2. To build a model of facilitating and hindering constructs to facilitate best practice and support integrated care for early intervention service provision in Ireland.

- **Research Objectives**
  1. To explore the stakeholders’ accounts of their experiences with their EI team.
  2. To identify and explore factors which facilitate and inhibit EI services from the stakeholders’ perspectives.
  3. To illuminate the processes within EI practice.
  4. To explore and evaluate the engagement of children with disabilities in the research process.
  5. To determine conceptual constructs which frame a potential best practice model for Ireland.

1.9 Outline of Chapters/Thesis Structure

This thesis is divided into five chapters. Chapter 2 reviews the literature and describes models underpinning EI development and practice, such as the
models of disability, models of EI practice and team working. Section 2.2. (The Development of Early Intervention Services in Ireland) relates to the published paper in Appendix A, which sets the context for the study and applies the Developmental Systems Approach (Guralnick, 2001) to the EI system in Ireland. This chapter also outlines theories that are relevant to the findings of the study, such as, Family Systems Theory (Bowen, 1978), Social Exchange Theories (Homans, 1961; Thibaut & Kelley, 1959; Rusbult, 1980), Relationship Development Models (Altman & Taylor, 1973; Knapp & Vangelisti, 2005) and the Family Life Cycle (Turnbull, 2000). Section 2.7.3 (Relationship Development Models) relates to the published paper in Appendix B. Section 2.8 (Child Participation in Early Intervention) relates to the published paper in Appendix C. The concept of participation of families and professionals is also explored.

Chapter 3 describes the study methodology; it highlights the philosophical underpinnings of interpretivism for the study design. It provides the rationale for using a case study design (Stake, 1995) in conjunction with the Grounded Theory approach as proposed by Strauss and Corbin (1998), as the methodological approach. The chapter further explains sampling procedures, the data collection methods, the process of data collection and analysis and how the researcher strengthened the rigour and trustworthiness of the findings in this qualitative study. Sections 3.5.1 (Methods for Child Participants) and 3.5.1.1 (Development of Tools for Child Participants) relate to the published paper in Appendix C.

Chapter 4 presents the findings from the study. The key findings are represented in three key figures. In Section 4.5, Figure 3 outlines a force field analysis of the data highlighting the Driving and Restraining factors, which were identified as influencing EI practice in the current study. In Section 4.7, Figure 4 presents the predominant influencing factor on the core category, that is, a developmental trajectory of relationship stages in EI. Sections 4.7.1 (A Trajectory of Relationship Development for Early Intervention) and Sections 4.7.1.1 to 4.7.1.5 relate to the published paper in Appendix B. In Section 4.9, Figure 5 displays the overall conceptual model, Synergistic Interdependent Relationships in Early Intervention, which emerged from the study. A detailed
presentation of the findings is provided in this chapter in relation to the figures.

Chapter 5 presents a general discussion of the findings. Section 5.2.1 (Conceptual Theory, Models and Constructs) relates to the published paper in Appendix B. Section 5.2.4 (Methodological) relates to the published paper in Appendix C. It also outlines the strengths and limitations of the research and provides an overview of the multi-faceted approach that was used to disseminate the findings to different stakeholders. The contribution of the study findings to the evidence base, policy and practice is discussed. The connection between the three published articles (Appendices A, B & C) is presented with reference to the study aims and conclusions are drawn. A chronology of the thesis is presented in Appendix D.
2. Literature Review

2.1 Introduction

The Irish context of EI is different to other countries and is evolving within the context of a changing health system. Irish services for children with a disability or developmental delay and their families were initiated and developed in an uncoordinated way and delivered by both statutory and non-governmental services. Religious orders and others, for example, groups of parents and/or professionals initiated some of these non-governmental agencies to address the needs of a specific group. Therefore, they developed defined and limited criteria for access to their services, to include the geographic area they serve and the nature of the disability. The concept of working in multi-disciplinary EI teams is relatively new. Furthermore, the practice of EI services involving families in the delivery of services is also different to expert led care.

The researcher acknowledges that the literature review was written during the course of the study. Initially, literature was accessed to formulate a research proposal as part of the ethics applications for the study. As Strauss and Corbin’s (1998) model of Grounded Theory informed the study, the researcher was aware that she came to the research situation with a level of awareness and knowledge of the research area based on her previous reading and experience as a speech and language therapist and researcher. Dunne (2011) argues that early and on-going literature review supports theoretical sensitivity. DiClemente et al. (2013) suggest that multiple theories are required to adequately address the complexities involved to understand behavior. Throughout the study, the researcher reviewed literature based on concepts that emerged during the research. These included the development of EI services in Ireland, factors underpinning these services, such as, models of disability; models of EI practice in particular, family-centred practice and models of team working. This chapter critically reviews these models and explores their impact on the development of EI practice. Relationships, both in healthcare and EI practice, are also explored with consideration given to models of relationship development. The concept of participation in EI of the family, that of the child and their parents, and of professionals is described.
with particular regard to their potential roles in the development of successful EI teams. Through the application of Strauss and Corbin’s (1998) Grounded Theory several theoretical models emerged, which in turn formed the theoretical underpinnings for the study. These theoretical models enhanced the researcher’s understanding of the complex phenomenon under study, an EI team (Green, 2000). The literature served as an additional source of data, and a means of theoretical sampling; it gave a context for the data and played an important role in validating the theory (Strauss & Corbin, 1998). Through constant comparison Social Exchange Theories and models of relationship development became important theories in the development of the conceptual model, which emerged from the data in this study.

The word model has a number of different meanings. For the purposes of this research study a model is defined as ‘a representation of a more complex reality used deliberately to throw light on a problem’ (Seedhouse, 1997, p. 43) and it’s development is guided by theory. Numerous theories, to support the development of the model, were identified during this study, which highlights the complexity of the EI context in Ireland. EI service provision has become more complex over the years and the number of children with complex needs has increased. This chapter places the relevant theories within the current context and concludes with a summary.

2.2 The Development of Early Intervention Services in Ireland

The value and benefits of EI have been recognised since the 1930’s (Shonkoff & Meisels, 1990). Guralnick (2001) defines early childhood intervention as a system designed to support family patterns of interaction that best promote child development. For Guralnick, the focus is placed upon parent-child transactions, family-orchestrated child experiences and on the help provided to parents in order to maximise their child’s health and safety. Blackman (2003, p. 2) considers that “the goal of early [childhood] intervention (EI) is to prevent or minimise the physical, cognitive, emotional, and resource limitations of young children with biological or environmental risk factors”. Blackman emphasises the role played by families as a success factor of the intervention.

In the United States of America (USA), EI is a statutory requirement since 1986. In Australia, the Disability Services Commission (2003) highlighted
a collaborative approach to therapy as best practice and approved the role of Local Area Coordinators (LAC) to assist with coordination of services. In the United Kingdom (UK), Early Support Programme (Department For Education and Skills and Department of Health, 2003), Team Around the Child (Limbrick, 2004) and Every Child Matters (Government of United Kingdom, 2003) inform services. In Ireland, both policy and legislative contexts are driving change in EI disability service provision. The Agenda for Children’s Services (Office of the Minister for Children and Youth Affairs, 2007) set out key goals of public policy in Ireland to promote a systems approach to meeting the needs of children with a focus on better outcomes for children and families. During the data collection phase of this study, in 2012, no EI policy existed to support uniformity of service provision and development (Carroll et al., 2013) in the published paper in Appendix A. Family-centred care was the driving service delivery approach within the health service context (Health Service Executive, 2011). All teams were guided by the six operational principles of the National Children’s Strategy (Department of Health and Children, 2000), which are: child-centred, family-oriented, equitable, inclusive, action oriented, and integrated. More recently, in 2014, the publication of the National Policy Framework for Children and Young People 2014-2020, ‘Better Outcomes Brighter Future’ (Government of Ireland, 2014) together with the Quality and Standards in Human Services in Ireland: Disability Services (National Economic and Social Council (NESC), 2012) underpin and guide the progression of EI services.

Children’s disability services in Ireland aim to provide geographically based services, which are timely and accessible for children with disabilities and their families and to provide a singular clear pathway for assessment and intervention, with health and education working in partnership, to support children to reach their full potential (Health Service Executive, 2011). In practice, there is tremendous variation in what comprises EI (Ramey & Ramey, 1998). In Ireland, services to young children with disabilities are delivered by both statutory and non-governmental agencies with wide variation and no national consistency in service provision (Carroll et al., 2013) in the published paper in Appendix A. Currently, the guiding principles to inform all children’s and young people’s services in Ireland are children’s rights, family-oriented,
equality and evidence informed and outcomes focused (Government of Ireland, 2014).

The National Framework (Government of Ireland, 2014) sets out six transformational goals aimed to achieve better outcomes. These goals include supporting parents, listening and involving children, ensuring quality services and strengthening transitions. The Framework indicates the Irish Government’s commitment to provide quality evidence informed intervention for children, to develop practice tools to assist professionals in working with families, to listen to children, to strengthen efforts to support children in expressing their views, to focus on effective transitions (Government of Ireland, 2014). The commitment to focus on respecting and listening to children is signified further with the publication of Ireland’s first ‘National Strategy on Children and Young People’s Participation in Decision-making’ to ensure that children have a say in decisions that affect their lives (Department of Children and Youth Affairs, 2015). Daly et al. (2015) state that Irish policy (Department of Health, 2012; Health Service Executive, 2012) supports the reframing of disability and service provision to support rights-based approaches to disability. The national programme, ‘Progressing Disability Service for Children and Young People’, commenced the implementation structures for disability services within a changing primary health care context (Health Service Executive, 2009). In 2013, the HSE published a framework reiterating that EI practice must be underpinned by a child and family centre philosophy and that professionals need to measure and document the outcomes and achievements of children and families.

The development of EI services in individual countries is guided by legislative acts. The USA passed amendments to The Individuals with Disabilities Education Act (IDEA) (US Department of Education, 2004) and the UK passed The Children and Family Act (Government of United Kingdom, 2014). In Ireland, the Education for Persons with Special Educational Needs (EPSEN) Act (Government of Ireland, 2004) provides the legislative framework for the provision of education for children with disabilities between 4 and 18 years of age. It is intended to ensure that persons with special educational needs can be educated where possible in an inclusive
environment. The current focus is to find every possible means by which a child with a disability can participate fully in mainstream education and in social and leisure activities. Issues of health and education policy for children and adults with disabilities were addressed in the Disability Act (Government of Ireland, 2005). The Disability Act (Government of Ireland, 2005) protects the rights of people with disabilities and provides for an assessment of their health and educational needs and ensures appropriate planning will be undertaken on their behalf. In 2007, Part 2 of the Disability Act (Government of Ireland, 2005) was implemented providing a statutory assessment system for children younger than 5 years. It provided the statutory right for children to have an independent assessment of needs within a specified time frame and a Service Statement outlining the services they require. An assessment officer who is employed by the Health Service Executive coordinates the process. The Disability Federation of Ireland (2010, p. 1) asserted that they are “deeply concerned that the operation of the Act is not nearly as effective as it could be”. Disability policy has progressed, and although it appears more coherent with a rights-based approach than education policy, some have considered it not as robust in this regard as it could be (De Wispelaere & Walsh, 2007). The further development of EI services needs to be supported by evidence within the Irish context.

2.3 Models and Theories of Disability Relevant to the Study

The impairment/disability binary was first proposed in the UK in the 1970s, where disability is distinguished from impairment as a social condition; a discriminatory social response to an atypical body (Depoy & Gilson, 2011). The social model of disability reformulates the relationship between individuals with impairments and society. According to Cole (2007, p. 70) the social model describes disability “as residing in the socio-structural barriers that disadvantage and exclude people with impairments”. The key assertion of the social model is that society should strive to change attitudinal and structural barriers that limit people from participating in society. The International Classification of Functioning Disability and Health (ICF) (World Health Organization, 2001) encompasses both medical and social models of service delivery. The ICF and the more recent version for children and youth, the
International Classification of Functioning, Disability and Health – Child and Youth Version (ICF-CY) (World Health Organization, 2007) classify health-related functioning in a holistic way taking account of bio psychosocial perspectives which contribute to overall well-being.

Bronfenbrenner’s (1979) Ecological Systems Theory underlies our understanding of the many factors influencing EI services (Odom, 2001), as well as how services are provided for families and children. Ecological Systems Theory offers a way of seeing development within the context of various mutually influencing systems. This view is supported by the Ottawa Charter, which emphasised that there are ‘inextricable links between people and their environment’ with ensuing effects on their health (World Health Organization, 1986, p. 2). Bronfenbrenner (2005) helps explain disability through four exterior nested systems in logical and linear terms. An ecological perspective on child development ‘is a holistic perspective which focuses on the ways in which children’s developmental needs, the capacity of their parents to respond appropriately to those needs and wider environmental factors interact with one another over time’ (National Society for the Prevention of Cruelty to Children (NSPCC), 2000, p. 41). Hence, the family is viewed as a system that is part of other social systems, for example, education and healthcare. Bronfenbrenner (1979, p. 9) stated that parent’s evaluations of their own capacity to function, as well as their view of the child, are related to such external factors as flexibility of job schedules, adequacy of childcare arrangements, the presence of support networks and quality of health and social services. Furthermore, the child is understood as developing within the context of multiple levels of social systems that interact and influence one another as shown in Figure 1. These levels include: 1. Microsystem level - The child’s most immediate social contexts have direct influence, 2. Mesosystem Level - Interactions between the child’s various microsystems, 3. Exosystem Level - The various community structures and services that indirectly effect the child’s development, and 4. Macrosystem level - The overarching cultural values, social attitudes, and ideologies that influence systems.
TRANSACTIONAL MODELS OF DEVELOPMENT

Transactional models of development (Sameroff & Chandler, 1975; Sameroff & Fiese, 2000) also emphasise that the active environment and the active child influence each other over time. Hence, the child and their environment play a role in determining the course of development.

2.4 Family-Centred Practice

In the 1990s the family-centred model emerged as a new model of practice and basis for relationships between families and professionals (Rosenbaum, King, Law, King, & Evans, 1998). However, Bruder (2010) acknowledged that the concept of family-centred practices emerged in the 1960’s to describe service delivery. The development of the family-centred model of practice has been influenced by the application of Bronfenbrenner’s (1979), Human Ecological Theory to child development. Lombard (2009) states that children with disabilities and their families need differentiated services compared to those received by other families, to meet their specific needs. These differentiated services should be flexible and based on an assessment of the whole family. Daly et al. (2015) highlighted that families living with disability appreciate multiple supports being available to them. Lombard (2009) identifies that the term ‘differentiated’ is widely used in education and within healthcare the term ‘differentiated services for disabled children’ should be used. Hence, services for families should be designed from the bottom up rather than from the top.

Figure 1: Bronfenbrenner (1979) Multiple Levels of Social Systems.
Ascertaining multiple perspectives of services will allow for the evolving practice to be informed by the people who use them.

The Department of Health and Children (2000) recognise that the family is the primary and most essential resource for the child with disability and developmental delay and that the service role is complementary and secondary to that of the family. The National Federation of Voluntary Bodies (2009) also recognise that ‘families are the primary nurturers, supporters and advocates throughout the life cycle of the citizen with a disability’ (p. 9). A.P. Turnbull et al. (2007) state that there is a void in the literature in relation to what supports and services should be offered to families in EI programmes. They suggest that clear conceptual models are needed to maximise rather than limit choices for families. The formation of a conceptual model can add an explanatory story of participants’ experiences (Avis, 2005).

Family-centred practice is a social model for health, education and social care services that expands the focus of intervention beyond the child’s level of functioning to view the child in the context of their family (Davies, 2007). Using a systems approach is compatible with a family-centred philosophy in EI when the target of intervention is the family system and not solely the child. Influencing factors on the developing child can be understood together. According to Dunst (1995) interpretation, family-centred practices regard the family as the centre of service delivery; family concerns, priorities, strengths and needs should be taken into account. Families should be served as a whole, meaning not only the needs of the child with developmental disability, but also that of each family member should be considered. Every family member should be informed about options and involved in service delivery and family cultural differences should be respected (Baird & Peterson, 1997; Bruder, 2000; Dunst, 2002).

Family-centred practice endorses a belief that parents know best what is needed for the family to live successfully with their child’s disability (Bailey et al., 2006). Promoting the family’s ability to make decisions about their needs and preferences through partnerships with professionals is central to family-centred practice (Bruder, 2010). According to Ecological Theory, the family is viewed as a whole unit, so a child cannot be isolated from his/her family or home environment, and the community, school, and societal environments are
seen as combined to impact a child’s development. Thus, the interaction between the family and service providers and teachers cannot be neglected, which in turn influence the development and application of family-centered practices. Family-centred services reflect an enabling model of helping, fostering the skills of families to care for their child with special needs (Dunst & Trivette, 1996). The aim of family-centred practice is to identify and enhance child and family strengths rather than focusing on weaknesses, and to promote competence rather than dependence on service providers (Andrews & Andrews, 1986). Family-centred practice was defined and developed by academics and policy-makers and its proposed benefits have been discussed in the literature for many years (Dunst, Trivette, & Hamby, 2007; Dunst, 2002; Rosenbaum et al., 1998). However, the perceptions of two of the major participants (families and health care professionals) in the implementation of family-centred services have been explored to only a limited extent (Iversen, Poulin Shimmel, Ciacera, & Meenakshi, 2003), while the perceptions of children as part of the family have been ignored. Identifying the factors that support and hinder practice from the multiple perspectives of all those involved in EI services will be of benefit to EI service development in Ireland.

Several terms have been used to portray intervention practices that are synonymous with the family-centred model. The most notable of these include family empowerment (Dunst, Trivette, & Deal, 1988), family-focused intervention (Bailey et al., 1986), and family-centred service, practice, or care (Bailey, Buysse, Edmondson, & Smith, 1992). The term ‘family-centred’ has become the most widely used and accepted of these labels (Dunst, 2002). Family-centredness is a philosophy of service delivery and an approach to service delivery (Powell & Dunlap, 2005). According to (Dunst et al., 2007), family-centred practices are relational and participatory. Relational relates to clinical skills, beliefs about families, strengths and capabilities. Participatory relates to individuality, flexibility, responsivity and informed choice. Carlhed (2003) acknowledges that the underlying assumption behind family-oriented services is Systems Theory and a number of concepts are used interchangeably for family-oriented services, for example, family-focused, family-centred services and family-driven interventions. Dunst, Johanson, Trivette, and Hamby (1991) following a multiple method and multi-source meta-analysis
describe a continuum of family-oriented services based on the degree of family empowerment and involvement: family-centred, family-focused, family-allied, and professional-centred, as shown in Figure 2.

Dunst (2002) advocates that true family-centredness involves professionals supporting the capability of parents to make informed decisions. However, Dunst (2002) recognised that there are levels of family-oriented services:

- Professional-centred, where professionals provide the interventions.
- Family-allied, where professionals prescribe treatment for families to conduct.
- Family-focused, where families choose level of involvement and interventions are monitored by professionals.
- Family-centred, where families make informed decisions.

For the purposes of this thesis, family-centred practice will be used to incorporate the terms family-oriented care, family-oriented practice, and family-centred care. Positive outcome research exists in support of family-centred care (King, King, & Rosenbaum, 2004). However, a deeper understanding of the processes involved to achieve these outcomes is required. Family-centred care is associated with positively reducing parental stress and increasing emotional wellbeing and satisfaction with services (King, King,
Rosenbaum, & Goffin, 1999; King, Law, King, & Rosenbaum, 1998; King, King, et al., 2004; King, Teplicky, King, & Rosenbaum, 2004; Law et al., 2003). When service delivery incorporates family-centred practices, family and children outcomes are improved (Dempsey & Keen, 2008; Dunst et al., 2007). Family-centred care positively improves a child’s psychosocial adjustment (S. King, King, et al., 2004). Although there is evidence to support family-centred care, how the principles of family-centred care translate to practice remains unclear (Wilkins et al., 2010). In Australia, King, Rosenbaum, and King (1997) found that differences in programme characteristics such as organisational structures, climate and philosophies impacted on scores in the validated questionnaire, the Measure of Processes of Care (MPOC-56). Bjorck-Akesson, Carlhed, and Granlund (1998) proposed a model differentiating between process and outcome dimensions in family-oriented services. Process dimensions are relationships, information-exchange, and involvement. Outcome dimensions are satisfaction, knowledge and perceived activity. Carlhed (2003), in a quantitative study, recruited 237 professionals from nine disciplines through convenience sampling. The professionals completed a self-rating measure of family-centred practice. The analysis focused on the process dimensions of relationships, information exchange and involvement only. Carlhed (2003) argues that, although relationships between parents and professionals serve to accomplish common goals, they are not enough. She found that family involvement reflects the way in which professionals create conditions for collaboration with parents and stresses the need for a strong participatory approach within the process of family-oriented services. The results may be influenced by the self-desirability of the sample (van de Mortel, 2008). No child or family perspectives were included in this study and according to Carlhed (2003) these perspectives are needed to understand true family-oriented services. Further research is required to investigate the processes facilitating and hindering family-centred care from multiple perspectives within the Irish context. We need to understand what is important from the multiple perspectives of those currently involved in EI. Gaining these perspectives will progress the delivery of optimum family-centred practices.
2.5 Models of Team Working

Depoy and Gilson (2011) noted that within models of teamwork there is an assumption that the combination of mutually exclusive expertise will achieve the best intervention results. Managed care evolved whereby teams, comprising of multiple professionals, provide services to an individual (Kongstvedt, 2003). There are different approaches to team working in EI namely an interdisciplinary approach and a trans-disciplinary approach. For inter-disciplinary working, a team of different disciplines, work together to develop jointly planned objectives and programmes (Bray, Ross, & Todd, 2006). Using an inter-disciplinary model each professional conducts their own discipline specific assessment followed by ongoing communication among professionals about the results of the assessments (Paul & Norbury, 2012). An interdisciplinary approach necessitates bringing together the knowledge and skills of individuals from many disciplines in order to ensure complex problems receive the comprehensive attention they require (Guralnick, 2000). Research suggests that good inter-disciplinary communication leads to improved patient and family outcomes (i.e. high levels of patient and family satisfaction, symptom control, reductions in length of stay and hospital costs) (Hearn & Higginson, 1998). There is very good evidence to suggest that the most effective model for a rehabilitation service is an inter-disciplinary design (Chapey, 2001). However, Frost (2005) argues that working together does not always lead to effective working.

For young children with disabilities a trans-disciplinary team approach is considered best practice (Rabidoux, 2005). The trans-disciplinary approach views the whole child’s development as integrated (Kilgo et al., 2003) and unlike other models all team members can facilitate all goals through information sharing (O’Connor & Walls, 2004). Key principles of the trans-disciplinary model are that team members and the family conduct a comprehensive developmental assessment together; parents are full active members of the team sharing roles and responsibilities with the professionals involved; one professional serves as the primary contact with the family, avoiding duplication of services (Kilgo et al., 2003). Fitzgerald, Ryan, and Fitzgerald (2015) interviewed 12 parents and facilitated two focus groups of parents from two EI teams in Ireland. They found that there is confusion in
Ireland as to which model, multi-disciplinary or trans-disciplinary, to implement in EI services. They indicate that key principles of trans-disciplinary working and in particular the key worker system should inform EI services in Ireland. Davies (2007) outlined 10 model components to support practice when using a family-centred, trans-disciplinary model of EI service delivery called “team around the child” based on work by Limbrick (2004). The components include: philosophy, family role, key worker role, team interaction, lines of communication, and staff development, and the assessment process (Davies, 2007). Mullins (2008) also found that Irish parents advocate for the key worker role in EI services.

The Developmental Systems Approach (DSA) (Guralnick, 2001) is a conceptual and structural framework, compatible with a systems perspective, involving three interrelated levels. The framework was constructed to support international EI services in the design, implementation and evaluation of their services. The framework involves understanding the relationship between: level of the child; environmental influences; and family resources. Carroll et al. (2013), in the published paper in Appendix A, acknowledge that although some components of DSA are notable in Irish EI service provision, for example screening, access, comprehensive inter-disciplinary assessment and early childhood programmes; other components such as assessment of families, development and implementation, monitoring and outcome evaluation, and transition planning are not as distinguishable.

Davis (2011) highlights that it is important to understand that the same term, to define the approach to team working, can be applied in different ways and suggests using the term ‘integrated working’. Integrated working can be viewed as a continuum from co-operation to integration (Frost, 2005; Stone & Rixon, 2008). In terms of team working, cooperation involves sharing of information whilst maintaining professional independence (Stone & Rixon, 2008). Teams work collaboratively; plan jointly, concurrently and sequentially (Davis, 2011). However, Frost (2005) noted that working collaboratively does not necessitate agreeing and sharing goals. Where services are delivered in a coordinated manner, the service is perceived as being deliberate with coordinated planning which is cognizant of each professional’s/agency’s aims, goals, practices and values (Frost, 2005; Stone & Rixon, 2008). An integrated
service is one that is shared and co-located (Glenny & Roaf, 2008). Furthermore, process based integrated working includes whole systems approaches with teamwork, shared protocols, clear lines of accountably and team/shared decision-making (Fitzgerald & Kay, 2008; Harker, Dobel-Ober, Beridge, & Sinclair, 2004; Stone & Rixon, 2008). In order to further develop EI practice in Ireland, it is important to identify the processes that support and hinder EI working practices from multiple perspectives. The development of EI services needs to be supported by an evidence base and underpinned by theory within the Irish context.

2.6 Relationship-Based Care

Relationship-centred care is healthcare that values and attends to the relationships that form the context of care, as they set the environment and resources for care (Blau, 1964). A Relationship-based approach to EI involves all domains of development (Kalmanson & Seligman, 1992; McCollum, Gooler, Appl, & Yates, 2001; Weston, Ivins, Heffron, & Sweet, 1997). An infant’s strong, enduring relationship with a primary caregiver provides the infant with a sense of security and identity that is the foundation for a lifetime of relationships (Vacca, 2001). Children’s development is affected by the quality of parent-child interactions, family orchestrated child experiences, and providing for the health and safety of children (Guralnick, 2001). Corr, Milagros Santos, and Fowler (2015) highlight that families are essential to support the healthy development of their children. Today, parents, practitioners and researchers take it for granted that in order to understand the unfolding of developmental processes, one must look at the infant in the context of his environment and, most particularly, in the context of his/her relationships with the caregivers in his/her life (Weston et al., 1997).

The relationship between a parent and service provider has been shown to be a potential predictor of the success of intervention (Kelly & Barnard, 1999). An approach to intervention that is both family-centred and strengths-based helps families feel more confident and comfortable in supporting their children’s development (Wilcox & Shannon, 1996). Fialka, Feldman, and Mikus (2012) use the metaphor of ‘the dance’ to elucidate the unique working relationship between parents and professionals. There is an
expectation that parents and professionals collaborate and form a partnership (Office of the Minister for Children and Youth Affairs, 2007), however reaching this expectation takes time. EI systems involve multiple complex, relationships (Guralnick, 2001). These relationships may include: the child with developmental disabilities, their parents and service providers (Kelly & Barnard, 1999), or the whole family and service providers (McWilliam, 2010; Paige-Smith & Rix, 2011). Fitzgerald et al. (2015) note that the relationship between families and professionals needs to be based on participation rather than on expert roles.

Within EI, parents enter into a relationship with professionals within early intervention, as they need assistance from the professionals. Initially families may be hesitant and ambivalent whereas professionals are eager to share their expertise (Fialka et al., 2012). Relationships are complex. Without close communication and collaboration, there is a greater risk of fragmentation and/or duplication of services as well as unmet family needs. Furthermore, shared experience, trust, enjoyment, concern and caring in a relationship facilitate emotional closeness (Lee, Mancini, & Maxwell, 1990). Relationships in EI are paramount to practice and factors that are important to parents, children and professionals in the EI team setting need to be explored.

2.7 Theoretical Models Which Emerged as Relevant to the Study

An EI team can be described as a complex system as it is made up of multiple members, both families and professionals, who work together in different settings, for example, home, education and health care. All members interact with each other not only within one setting but also across settings. These interactions are interrelated and have consequences within the system. Through the application of the constant comparative approach as per Strauss and Corbin’s (1998) Grounded Theory several theories became relevant while making sense of the data. These theories notably, Family Systems Theory (Bowen, 1978), Social Exchange Theories (Homans, 1961; Thibaut & Kelley, 1959; Rusbult, 1980), Relationship Development Models (Altman & Taylor, 1973; Knapp & Vangelisti, 2005) and the Family Life Cycle (Turnbull, 2000) supported the researcher’s interpretation of the multiple perspectives shared
and in understanding the complexity of EI practice. Although some of these theories draw on dated literature using theories supports the development of a conceptual model (Seedhouse, 1997). Thus, this research creates an argument to understand these theories in the current context of EI services in Ireland.

2.7.1 Family Systems Theory

Systems Theory describes humans in context (Depoy & Gilson, 2011). Family Systems Theory (Bowen, 1978), a branch of General Systems Theory, provides a way to conceptualise family members as interacting with and mutually influencing one another. Within General Systems Theory there are the concepts of Interdependence where elements are mutually influential in the relationship. Families are systems of unique, interconnected individuals with interrelated elements and structure. In Family Systems Theory, the family is regarded as a unit that functions as a dynamic system. Each family member has unique characteristics, a relationship to each of the other family members, and to the family as a whole. Each family member influences, and is influenced by, each of the other family members. Any change in the characteristics of one member, or in the relationships between family members, affects the entire family system. Family Systems Theory presumes that child and family have mutual influences. The child’s characteristics and actions affect other family members as well as the overall functioning of the entire family. Likewise, the family influences the development of the child. Hence, these interactions have patterns. However Family Systems Theory may not be applicable to understand family violence and does not fully address gender inequality issues. There are boundaries to the family system, which functions by the Composition Law (Constantine, 1986) where the whole is more than the sum of the parts. One of the concepts within Family Systems Theory (Bowen, 1978) states that a triangle is a three-person relationship system involving interdependent partners who rely on each other. Doherty and Baird (1983) maintained that the minimum fundamental unit of health consists of the triangle that includes a clinician, a patient and a family. Furthermore, Rolland (1988) expanded the therapeutic triangle to the therapeutic quadrangle consisting of the health system, the patient, the family and the illness. While, Doherty, McDaniel, and Hepworth (1994) extended this theory to a ‘pentagon’
to include the medical family therapist, health care team, patient, illness, and family. Within the disability field, Carpenter (2005), identified a triad of primary support within a family to include: child, mother and father with varied patterns of interaction depending on their support network.

2.7.2 Social Exchange Theory

Within EI multiple relationships exist between the multiple members within multiple settings. Social Exchange Theory (Homans, 1961) states that ‘relationships grow, develop, deteriorate, and dissolve as a consequence of an unfolding social-exchange process, which may be conceived as a bartering of rewards and costs’ (Burgess & Huston, 1979, p. 4). This theory is based on the idea that relationships develop as a result of cost-benefit analyses (Homans, 1961). This theory was developed within the American cultural context and may not be applicable to other cultural contexts. According to the theory human interaction is like an economic transaction, in that you may seek to maximise rewards and minimise costs. Levinger (1976) discussed marital success as dependent on all the rewarding things within the relationship. The constructs of this theory include disclosure, relational expectations, and perceived rewards or costs in the relationship. Rewards are defined as the benefits, the pleasures, satisfactions, and gratifications a person enjoys from participating in a relationship (Thibaut & Kelley, 1959). However, the specific rewards and costs of the relationship are not clearly defined. The costs of social exchange relationships can involve punishments experienced, the energy invested in a relationship, or rewards foregone (Blau, 1964). When relationships conform to the norms of reciprocity and when the pattern of exchange is perceived as being fair, individuals develop trust and perceive that they will not be exploited (Blau, 1964). Exchange theorists would expect commitment to develop within a relationship when partners experience high and reciprocal levels of rewards that facilitate the experience of trust (Sabatelli, 1999). Within exchange relationships levels of involvement, dependence, and resources contribute importantly to the different patterns of interaction observed within personal relationships (Thibaut & Kelley, 1959). Understanding these relationships is fundamental and although interpersonal relationship models have relevance within EI practice, they have not yet been
considered within EI service provision and within the Irish context. Exploring the factors that support and hinder these relationships in EI is necessary to support effective practice.

**2.7.2.1 Interdependence Theory**

Within the multiple relationships within the EI system, balancing interdependence can be explained through the exchange of rewards and costs (Stafford, 2008). Thibaut and Kelley’s (1959) Theory of Interdependence is part of Social Exchange Theory. Thibaut and Kelley (1959) argue that individuals enter relationships with an awareness of societal norms for relationships and a repertoire of previous experiences. They proposed the concept of Comparison Level to understand how satisfied an individual is with a relationship. They propose that within an intimate relationship an individual assesses the outcomes of a relationship and compares these outcomes to available alternatives. According to exchange theorists, satisfaction with a relationship alone does not determine the likelihood that a relationship will continue. The stability of a relationship may be determined by understanding the Comparison Level for alternatives, dependence, and barriers. Kelly et al. (1983) note that in personal relationships, interdependent partners exchange resources, influence thoughts and behaviours, growth and learning over time and meet each other’s needs. People will be satisfied when their outcomes meet or exceed their comparison levels. Although Interdependence Theory has relevance within EI practice, it has not yet been considered within EI service provision.

**2.7.2.2 The Investment Model**

Rusbult (1980); (Rusbult, 1983; Rusbult, Drigotas, & Verette, 1994) developed the investment model, which is an extension of the interdependence model. Investments, also referred to as resources, are attached to the relationship and help predict outcome. If the relationship ended the investments would be lost or would decrease in value. Intrinsic investments are related to time and effort invested directly in a relationship and extrinsic investments develop over time and are related to resources or benefits, identity and being part of a group (Rusbult, 1983). Understanding the investment factors that contribute to EI
practice needs to be considered within EI service provision.

2.7.3 Relationship Development Model

A variety of descriptive models exist to explain the developmental nature of relationships within a person’s life. Altman and Taylor (1973) propose Social Penetration Theory whereby self-disclosure increases as people develop their relationships within their life. They assert that the breadth and depth of the penetration is dependent on who is in the relationship and the degree of intimacy. They propose four relationship stages: Orientation, Exploratory Exchange, Affective Exchange, and Stable Exchange. Other models of relationship development are based on personal romantic relationships. For example, Knapp and Vangelisti (2005) expanded Social Penetration Theory and identified five stages, which couples and friends go through, as they get closer in a relationship, moving from strangers to close relational partners. These included: Initiating, Experimenting, Intensifying, Integrating, and Bonding. Levinger (1983) also focused on romantic relationships and proposed that the natural development of a relationship follows five stages: Acquaintance and Acquaintanceship, Buildup, Continuation, Deterioration, Termination. These models highlight that interpersonal relationships are dynamic systems that change continuously during their existence. These changing relationships develop, as proposed by Social Penetration Theory, to become intimate ones (Griffin, 2011). While these models focus on interpersonal relationships within intimate relationships, models also exist to explain the relationship within professional relationships. Although all relationships are different Guerrero, Andersen, and Afifi (2011) identify that it is helpful to consider relationships from a developmental perspective. In the field of disabilities, Fialka et al. (2012) also suggest the process of this relationship formation as a developmental one proposing three developmental stages from ‘Colliding and Campaigning’ to ‘Cooperating and Compromising’ to the ‘Creative Partnering and Collaborating’. Limbrick (2012) proposed an integrated pathway, involving five overlapping horizontal phases to connect multiagency processes and interventions. These phases include: Meeting Phase, Learning Phase, Planning Phase, Support Phase and Review Phase. Within nursing, the nurse-client relationship progresses through three distinctive

Guerrero et al. (2011) define interpersonal relationships as relationships between individuals who mutually influence each other, share some degree of behavioral interdependence within repeated interactions. Furthermore, close relationships include the characteristics of interpersonal relationships along with the features of ‘emotional attachment, need fulfillment, and irreplaceability’ (Guerrero et al., 2011, p. 7). Levinger (1983) discussed marital success as dependent on all the rewarding things within the relationship. The communication exchange process can be described as interpersonal communication in all types of relationships and relational communication in close relationships. (Guerrero et al., 2011). Communication is dynamic and reflects and influences the nature of a relationship. Although interpersonal relationships models have relevance within EI practice, they have not yet been considered within EI service provision.

2.7.4 Family Life Cycle
Family life cycle represents the changes/transitions families experience over the years, such as changes in family characteristics, interaction, and function (Turnbull, Turnbull, Erwin, & Soodak, 2005; Turnbull, 2000). There are two types of changes/transitions namely expected and unexpected. One expected change or transition is the transfer from preschool to primary school when the child reaches the school age. This is usually planned so that everybody in the family prepares for it financially and emotionally. On the other hand, the unexpected transition refers to some changes that a family does not plan or expect (Turnbull et al., 2005; Turnbull, 2000). The birth of a child with a disability may be such an event in a family life cycle and may bring many unexpected issues. Boss, Doherty, LaRossa, Schumm, and Steinmetz (1993) recognised that if a child is born with a disability, the normal stress associated with this stage of the life cycle is exacerbated. According to Developmental Task Theory, Thomas (1992) suggested that developmental tasks for parents with a child with a disability are more difficult. Middleton (1998) notes that it takes exceptional parenting to compensate adequately for the discriminating
pressures inherent in our society. The interaction between young children and the environment is the foundation of their social, emotional, cognitive, and communicative development (Baird & Peterson, 1997). Environmental changes over time affect the family as well as the child. Exploring the factors that hinder and support transitions for families and professionals during their EI journey is important so as to advance practice.

2.8 Child Participation in EI

While it is true that children with disabilities have impairments and they need support, the Social Model of Disability would assert that people and society fail to adapt systems to support families. Research has shown that some barriers to listening to children include funding, time, bureaucracy, leadership and staff training/experience (Badham, 2000; Davis, 2007; Davis & Hogan, 2004). In keeping with EI philosophy, research is shifting to focus on enhancing young children’s participation and their communicative participation (Ragavendra, 2013). Hearing the voice of children is vital in order to understand their experiences (Department of Health and Children, 2000; Government of United Kingdom, 2014) and their voices must inform practice (Whitehurst, 2006). Article 3 of the UNCRC established the principle that all children should enjoy the "freedom to seek, receive and impart information and ideas of all kinds" (Office of the United Nations High Commissioner for Human Rights, 1989). Nevertheless, children were virtually excluded as active participants in the research process and were rarely asked to tell their own stories (Grover, 2004). This has resulted in a scarcity of research involving young children and school aged children with intellectual disabilities (Kelly, 2007). Furthermore, leading researchers in the field promote the facilitation of children with disabilities in research (Franklin & Sloper, 2006; Sloper & Beresford, 2006; Tisdall, 2012; Whitehurst, 2006). Children’s voices being heard are vital in order to understand their experiences and to maximise their participation and that of their families (Department of Health and Children, 2000). There is an understanding that services should ‘involve service users and front-line providers in the planning, delivery and evaluation of services’ (Office of the Minister for Children and Youth Affairs, 2007, p. 35). It is recognised that children have different experiences and knowledge to adults (Christensen
& James, 2008; James & Prout, 1997) and that we cannot rely on adult proxies
to give valid accounts of children’s experiences (Beresford, 1997; Markham &
Dean, 2006; Markham, van Laar, Gibbard, & Dean, 2009). Hence,
participation of children in research is essential, supporting the view of
children as competent social actors, with their own agency and voice,
acknowledging children as experts of their childhood (Carter, 2009).
Nevertheless, it is important to recognise that parents are adept interpreters of
their infant’s signals (Press et al., 2011) and that the skills of speakers and
listeners influence successful communication (McCormack, McLeod,
McAllister, & Harrison, 2010). Dickins (2004) also recognises that listening to
and consulting with young disabled children, with complex needs, requires the
listener to use communication techniques and interpretation skills.

It is important to involve children not only in research focusing on
understanding childhood but also on research exploring their experiences of
the ‘wider’ social world (Uprichard, 2010). Research is gradually emerging
involving school-aged children with speech, language and communication
needs (SLCN), (Lyons, Jones, & Roulstone, 2013; Markham, 2011; Merrick &
Roulstone, 2011) and young children with SLCN (Press et al., 2011; Roulstone
et al., 2013). Within the field of disabilities, research is also developing to
facilitate the participation of school-aged children with disabilities (Beresford,
Tozer, Rabiee, & Sloper, 2004; Mitchell & Sloper, 2011; Porter, Daniels, Feiler,
& Georgeson, 2011) and of young children with disabilities (Paige-Smith & Rix,
2011). Multiple data sources were used to record and represent the children’s
everyday lives, including Baby Cam (Press et al., 2011), observations,
interviews and KiddyCam (Roulstone et al., 2013) and narrative observations
and photographs of daily events (Paige-Smith & Rix, 2011). Paige-Smith and
Rix (2011) used ethnography to explore child agency, identity and experience
of EI with two young children with Down syndrome. Using the Mosaic
approach (Clark & Moss, 2001) the researchers conducted 10 visits with each
family and collected the child’s views through photographs and first-person
narrative observation. They used Grounded Theory to analyse the data and the
researchers clearly stated the process of analysis. Paige-Smith and Rix (2011)
were both involved in the data collection process and it is unclear how they
ensured the trustworthiness of the data. They found that the children’s
participation and empowerment during their EI learning situations were through choice of activities and through child-focused play (Paige-Smith & Rix, 2011).

2.8.1 International Classification of Functioning – Children and Youth Version (ICF-CY) (WHO, 2007)

The ICF (WHO, 2001) and ICF-Y (WHO, 2007) classify health-related functioning in a holistic way taking account of biopsychosocial perspectives that may contribute to overall well-being. Three lists of codes are used to classify a person’s health-related functioning: one list of body functions and structure; one list for the domains of activity and participation (which includes has two qualifiers i.e., performance and capacity); and a third list of personal and environmental factors. Bjorck-Akesson et al. (2010) confirmed that the ICF model and ICF-CY are feasible and useful in early childhood intervention and habilitation services. Their findings were based on several studies including those involving young children. The children’s findings indicate that a child’s perception of engagement and motivation needs to be considered in the participation component. Bjorck-Akesson et al. (2010) indicate that the ICF-CY could support inter-disciplinary profiling of a child’s functioning across diverse cultural contexts. However, they stress that the implementation of this model in clinical practice is a lengthy process. Researchers argue that a challenge exists in capturing the multidimensional nature of participation in everyday activities and propose inclusion of the subjective experience of involvement in activities and participation that would add to the ICF framework (Granlund et al., 2012; Hammel et al., 2008; Lyons, Brennan & Carroll, 2016).

Simeonsson (2016) suggests that the UNCRC (1989) dimensional framework and the codes of the ICF-CY (WHO, 2007) are applicable to document how a child’s rights are realised in terms of a child’s experience of limitations of functioning and access to their environment. He suggests that by assigning a universal qualifier to codes it will assist EI professionals in defining nature and severity of disability (Simeonsson, 2016). He also suggests that EI professionals can document the extent to which environments are responsive to a child’s needs, document a child’s limitations in performing activities or
participation and document barriers to ICF-CY (WHO, 2007) environmental codes (Simeonsson, 2016). Bjorck-Akesson et al. (2010) highlight that when considering a child’s participation motivation and engagement need to be considered. Furthermore, participation of a heterogeneous group of young children with developmental disabilities requires the researcher to use an open and flexible approach in the use of different research tools to aid communication (Franklin & Sloper, 2009; Kelly, 2007; Mitchell & Sloper, 2011; Paige-Smith & Rix, 2011). In conjunction with the ICF-CY (WHO, 2007), professionals need to consider the subjective point of view of the families and the children themselves when considering individual child factors alongside environmental factors, such as opportunities for participation, in intervention planning for children with disabilities (Lyons et al., 2016). The perspectives of the child need to be facilitated when considering the factors that support and hinder EI practice in Ireland.

2.9 Parent Participation in EI
Bronfenbrenner (1975) highlighted that intervention programmes, which involve parents directly on an ongoing basis, have greater benefit to the child. Ketelaar, Vermeer, Holders, and Hart (1998) reviewed seven intervention studies for children with cerebral palsy and concluded that parental participation in the intervention for the most part had a positive effect on child-related outcomes. Additionally, Shonkoff and Hauser-Cram (1987) conducted a meta-analysis of paediatric intervention programmes for young children with disabilities and found that interventions, which included parents and children working together, were found to be more successful than programmes that did not encourage parental involvement. However, in an analysis of 172 intervention studies, White, Taylor, and Moss (1992) reported no evidence of larger effect sizes for intervention programmes that included parental involvement. Shonkoff and Hauser-Cram (1987) and Ketelaar et al. (1998) exclusively included studies of young children (under five years of age). Accordingly, the effects of parental involvement may be greater in interventions for younger children, thus explaining the larger effects of parental participation reported by these reviews. Therefore, more
understanding of parental views is needed when designing intervention services (Cederman, 2006, 2007; Matthews & Rix, 2013; Paige-Smith & Rix, 2006; Rix & Paige-Smith, 2008) and an understanding of the processes in the intervention that facilitate these positive outcomes for young children. Lee (2015a), using a phenomenological ethnographic methodology explored one parent’s experience of family-professional partnership in the Individualised Family Service Planning (IFSP) process. This study used member checking and triangulation to ensure trustworthiness of the findings. Lee (2015a) found that professionals’ voice took priority in the IFSP meeting and that the concerns and choices of the parent were not always taken into account. The findings are similar to those of Dunst (2012) where the family-professional partnership develops from the perspective of the professionals.

2.9.1 Factors underpinning EI services
EI services are underpinned by a number of factors including the quality of the parent-professional relationship, collaboration, support, access to information, and clarification of roles (Bridle & Mann, 2000; Carroll, 2011; Matthews & Rix, 2013; Ward, 2009). Parents expressed feelings of pressure and guilt for not doing more for their child and lamented their role as an educator, which threatened other parental roles (Bridle & Mann, 2000; Matthews & Rix, 2013; Paige-Smith & Rix, 2006; Ward, 2009). Qualitative Irish studies of parents involved in EI services are few: O’Loughlin, Carroll, and Caulfield (2010/2011) and Ward (2009) interviewed purposive samples of five parents of children with developmental disabilities, respectively, about their specific EI programmes. Lyons, O’Malley, O’Connor, and Monaghan (2010) explored a small sample of parental perspectives of an EI service for children with speech and language impairments via focus groups. Ward (2009) found that parents were not involved in goal setting for their child during the initial stages of attending a service and Lyons et al. (2010) highlighted the need for contracting between parents and professionals. Lyons et al. (2010) in their qualitative study collected data pre and post therapy and found that professionals and parents need to co-construct a shared reference to support collaboration. Details on how the researchers ensured rigour are unclear. James and Chard (2010) interviewed seven parents of preschool
children with primary physical disabilities to explore their experience of their Irish EI service. Specific process barriers to the service delivery emerged such as: lack of support, lack of information and lack of continuity of care (James & Chard, 2010). Although, the study included a small sample of parents (n=7) the authors carried out in-depth interviews and clearly demonstrated their process of analysis. Fitzgerald et al. (2015) in a Grounded Theory study explored parents’ experiences of multi-disciplinary and inter-disciplinary models of practice within two EI services in Ireland. They found that although the parents’ EI journey was fraught with questions, they were broadly satisfied. Parents engaged in private therapy to supplement the inconsistent fragmented services. Parents in this study were concerned that these inconsistencies in interventions would negatively impact their child’s development. Parents wanted a ‘one stop shop’, key workers, collaborative report and from their perspective less time wasting on paper work and team meetings. This study included a small sample with 30% of the invited participants taking part. Methods to ensure the trustworthiness of the findings were not included nor were views of children and professionals involved in the services.

In the UK, Bridle and Mann (2000) shared the findings of their conversations with parents of children with disabilities and found that difficulties occurred when parents felt intervention was imposed on them, rather than being supported to encourage their child to play and develop creatively. The number of parents included in the study is unclear. The philosophical underpinnings of the researchers were not stated. The researchers in the study were parents of children with Down syndrome (DS), which could be viewed positively as the researchers had an intimate view of the ‘lived experience’ of EI. Also in the UK, Paige-Smith and Rix (2006) interviewed four parents and Rix and Paige-Smith (2008) interviewed nine parents of children with DS, thus limiting the transferability of their results. They found that family-centred EI practice requires parents to take on the role of the child’s educator impacting the pedagogic experiences of the parent and the child, which can often lead to conflict.

2.9.2 Parental Empowerment

Information sharing and professional support are factors that impact on
parental empowerment and the power balance in the therapeutic relationship (Foran & Sweeney, 2010; Fordham, Gibson, & Bowes, 2012). Fordham et al. (2012) quantitatively measured family-centred practice in EI services, where a low response rate (31.4%) was obtained. Thus, results need to be interpreted with caution, as the responses by the self-selected sample are unlikely to be representative of all the families who availed of the services in the study. Foran and Sweeney (2010) interviewed seven parents from one specific EI service in Ireland. Five themes emerged from their qualitative study: the Pathway to Early Intervention, Trusting Others, Making Connections, a Juggling Act, and the Unknown Journey. These themes emerged from a small sample of parents and details to support the trustworthiness of the data were lacking. Knowledge and clarification of parent and therapist expectations and roles and dialogue between parents and professionals prior to engaging in therapy is important to the successful outcome of therapy (Baxendale, Frankham, & Hesketh, 2001; Glowgowska, Campbell, Peters, Roustone, & Enderby, 2001; Lyons et al., 2010). Baxendale et al. (2001) used mixed methods, parental questionnaires and in-depth interviews, to explore the perceptions of parents engaging in a Hanen Parent Programme for early years language intervention. The researchers did not describe the data analysis in detail nor strategies to ensure rigour and reflexivity. The results reported were primarily qualitative with little reporting of the quantitative results found. However the study found that parents’ expectations of the therapy process are often different to those of the therapist. Glowgowska et al. (2001) explored the attitudes of 81 parents who were receiving speech and language therapy. The parental attitude scale used was not a validated measure. However, the methodology was well described and the authors acknowledge that further analysis is required to make the findings more robust.

Dempsey, Keen, Pennell, O’Reilly, and Neilands (2009) found that professional support and information sharing could mitigate parent stress. Although this American study had a low response rate of eight percent (n=33), parent stress was linked to perceptions of their parenting role, management skills, feeling isolated and support. The researchers used phone interviews to complete the survey instruments with parents of children (aged 4-7 years) attending two EI programmes. The study emphasised the importance of
considering how support, which is offered to families, is actually provided. However, the response rate is extremely low indicating the results need to be interpreted with caution, as the responses by the self-selected sample are unlikely to be representative of all the families who availed of the two EI programmes in the study. McConkey, Truesdale-Kennedy, Chang, Jarrah, and Shukri (2008) in their cross-cultural multi-method study, found parents of children with developmental disabilities, especially mothers, experienced high levels of stress and services did not always address their needs nor offer continual support. This study involved the self-selection of participating families. Carlhed, Bjorck-Akesson, and Granlund (2003) interviewed eight parents of children (aged 2-5 years) and also found that parental satisfaction with intervention was not simply about making resources available but very much dependent upon the parents’ feelings of being listened to. The results stress the importance of good relationships between families and professionals both an individual interpersonal level and at an organisation intervention level. Although the study included a small convenience sample, the researchers used strategies such as peer checking to ensure the trustworthiness of the findings. They concluded that parents’ perceptions of EI, in particular of support, are complex with multiple interaction factors.

Summers et al. (2007) found that for mothers the quality of the parent professional relationship can influence parental empowerment and impact child and family outcomes. There was a large sample size in this study, which adds credibility to the results. In a meta-analysis of 47 studies, Dunst et al. (2007) found that help-giving practices by professionals were most strongly related to self-efficacy beliefs of parents and impacted on family outcomes. The results of the majority of studies were correlational; therefore reasonable caution was highlighted with assuming causality. Bachner, Carmel, Lubetzky, Heinman, and Galil (2006) in a cross-cultural research study, using a one-item outcome measure, found that parents were better able to cope and felt more supported by the caring attitude of therapists and by their own involvement in therapy. Carlhed et al. (2003) also found that the genuine interest of the professionals created positive experiences. Peterander (2000) used a Likert index questionnaire to investigate the impact and challenges of creating parent-professional co-operation in EI. This study found that professionals explaining
interventions, parents observing professionals during interventions, parent professional collaboration on methods and goals, and the quality of the parent-professional relationship facilitated parent-professional cooperation. The use of a Likert scale may have limited the results, as it is uni-dimensional and can fail to measure the true attitudes of respondents. Swanson, Raab, and Dunst (2011) found that involving parents in learning new knowledge and skills is related to self-efficacy beliefs, empowerment, enhancing the quality of the parent-child relationship and parents’ capacity to affect changes in children’s development. This American study used a multi-baseline design with a small purposeful sample. Dunst and Dempsey (2007) measured family-professional partnerships using four scales with 150 participants. They found that collaborative goal setting and decision-making are essential for developing the parent-professional partnership. However, the researchers used convenience sampling and over a half of the sample had an identified disability. Thus the results need to be interpreted with caution. Bailey, Hebbeler, Scarborough, Spiker, and Mallik (2004) completed a national telephone survey in the USA reflecting parental perspectives on entry to EI services. 18% of the sample (n=3338) was not aware of a written plan for goals and services. 22 % of families wanted more involvement in decision-making. The majority of families were highly satisfied with the EI services they were receiving. The phone interviews included a limited number of structured questions, more detailed interviews would allow for more in-depth analysis. The study only included families who were enrolled in EI services at the time of the survey.

2.9.3 Experiences of Family-Centred Practice
In Australia, there is an expectation that EI providers operate in a way that is consistent with family-centred practice (Tomasello, Manning, & Dulmus, 2010). EI services for children with intellectual disability in Western Australia adopt the model of family-centred care (Wilkins et al., 2010). Wilkins et al. (2010) conducted a postal survey using a validated questionnaire, the Measure of Processes of Care (MPOC-56). There was a good response rate of 57% (n=165), which adds strength to the study. The respondents being parents of children aged birth to six years with intellectual disability living in Western Australia indicated that their family-centred care service provision was
satisfactory. This satisfaction was linked to ‘respectful and supportive care’ and dissatisfaction was linked to ‘general information’. Wilkins et al. (2010) found that frequency of contact with the healthcare professional was positively associated with parental ratings of family-centred care. Similarly, Fordham et al. (2012) found that families’ positive experiences of family-centred care were highly correlated with the professional support they received. In Sweden Bjerre et al. (2004) and in Holland van Shie, Siebes, Ketelaar, and Wermeer (2004), using translations of the MPOC, also found that frequency of contact impacted on ratings of family-centred care made by parents. Bjerre et al. (2004) analysed the questionnaires of 510 respondents (response rate 60%) and found the Swedish translation of the MPOC to be sufficient in sensitivity to use as a tool to evaluate services. Convenience sampling was used which can limit the generalisability of the results. In van Shie et al.’s (2004) study 427 parents of children aged between 1 and 18 years completed the survey (MPOC-NL), obtaining a response rate of 71.6%. They found that the Dutch version of the survey (MPOC-NL) has strong psychometric features. The study included a convenience sample and 94.8% of the respondents were mothers. Wilkins et al. (2010) found that families of young children were most satisfied with aspects of family-centred care that reflected interpersonal relationships with professionals. Wilkins et al. (2010) also suggest that there are differences in the professionals’ implementation of family-centred care. Frequency of contact with Occupational Therapists was positively correlated with parents’ perceptions. Furthermore, parents’ perceptions of family-centred care were not associated to the same extent with frequency for Speech and Language therapy and Physiotherapy.

Ziviani, Darlington, Feeney, Rodger, and Watter (2014) interviewed a purposive sample of 10 parents of children with physical disabilities in relation to their EI service in Australia. Numerous researchers from different disciplines coded the data using content analysis; however how they checked the trustworthiness of the data is unclear. Member checking, by sending summaries of the interviews to the parents, was used however the outcome of which is not stated. The results indicate that low frequency of therapy appointments impacted negatively on the quality of communication between providers and parents. Parents in the study indicated that they wanted to be
informed and prepared for key transition events in the future. Parents in the sample were least satisfied with how their service was coordinated. These findings were similar to those found by James and Chard (2010) where parents, within an Irish service, had to take on the role of coordinator and that although the parents stated that the parent-professional partnership was important, in reality the partnership varied. In USA, legislation, IDEA Part C states that all families are entitled to a service coordinator (Bruder, 2005). However, Shannon (2004) in a large Grounded Theory study involving 22 American families and 20 EI professionals found that many families did not know they had a service coordinator and families needed to be ‘highly motivated’ and ‘persistent’ to obtain services. The recruitment process for inclusion was unclear. Several methods were used to establish rigour, such as triangulation, peer review, member checking and memoing however the outcome of this process was unclear.

Davies (2007) stresses that when exploring parental experience, it is important to understand what contributes to or detracts from a positive experience when engaging with EI services. In Wales, Pickering and Busse (2010) conducted a mixed method study to explore experiences of family-centred care of three community services. Twenty-nine EI staff completed a Measure of the Processes of Care for Service Providers (MPOC-SP) questionnaire, and took part in focus groups. Ten parents of children with disabilities were interviewed. The design of the focus group and interview questions was based on the themes of interpersonal sensitivity, respect, and information giving from the MPOC-SP. Data was analysed using an edited approach, and transcripts were verified by the parents. The parents in the study identified a continuum of service and working with a trusted professional as important factors to their service experience. They also found that parents viewed the ‘Team Around the Child’ meetings as supporting their decision-making, however this model of service delivery varied (Pickering & Busse, 2010). The authors found that the questionnaire alone did not provide rich data and the qualitative component of the study was necessary. Hiebert-Murphy, Trute, and Wright (2011) in a large qualitative Canadian study involving 39 mothers and 22 fathers of children with disabilities, investigated outcome measures of family-centred service co-ordination. They found four
core elements for effective childhood disability programmes which were service coordinators with relationship skills, service coordinators with practice skills, adequately resourced service system and service delivery organised around family needs.

Lee (2015b) used multiple methods to explore how three families, who had recently commenced their engagement with EI services in New York City, engaged in and viewed the EI process. The parents expressed that they had little control in the decision-making process and found the IFSP meeting process was a documenting exercise. The parents perceived that rules, procedural requirements, and bureaucracy impacted on their participation, which may subsequently impact the quality of the service provision (Lee, 2015b). The findings highlighted the role of the service coordinator as an advocate for families and they also indicated that the parent themselves needs to also advocate for their child (Lee, 2015b). There is a need to identify the factors that support and hinder EI practice in Ireland from the parents’ perspectives. There is a need to identify the factors that support and hinder EI practice in Ireland from the parents’ perspectives.

2.10 Professional Participation in EI

Strong professional and parent relationships facilitate joint problem solving, and increase parent willingness to try new ideas (Minke & Scott, 1995). Where strong parent and professional relationships exist, parents feel comfortable in honestly sharing information with professionals (Piggot, Hocking, & Paterson, 2003). Communication skills were identified as important to professionals’ work with families (Iversen et al., 2003; MacKean, Thurston, & Scott, 2005). Recognising parents’ expertise in EI and responding to parents’ needs and wishes is important for professionals in their relationships with parents (King et al., 1998; McWilliam et al., 1998; O’Neil & Palisano, 2000). A common ground exists incorporating therapy and the home environment to help the child's development. Parent involvement in this goal setting is also important (Dunst et al., 2007; Dunst, Raab, Trivette, & Swanson, 2010). A number of key ingredients that support practitioner relationships include: building authentic relationships by being direct, honest, and supportive; having consistent, predictable, regularly scheduled meetings for
team members to establish and maintain close communication, identify issues to address, express needs, feelings, ideas, and participate in group problem-solving and decision-making; and support from a supportive facilitator (Poulsen & Cole, 1996). In Ireland, Whyte and Kelly (2009) conducted a mixed method review of early services within Mid-Leinster area using questionnaires with parents, interviews with parents and staff and observations of children. They found many indicators of international best practice in particular working in partnership with families at every stage of the intervention. Carroll (2011) interviewed four professionals, three managers and six parents from one EI team in Ireland. Although the sample was small and self-selecting, there was evidence of inter-disciplinary collaboration and a will to work in an integrated manner with families. The team professionals highlighted that there was a lack of information sharing and attributed this to systemic weaknesses, such as, the lack of a coordinator for the team, the lack of adequate time to meet as a team, the lack of structure within meetings and the lack of a shared working location. Pickering and Busse (2010) found, in their Welsh study, that training staff to work with families in a family-centred way and training in communication with children would be beneficial. The main themes that emerged from their interviews with professionals were awareness of parenting style and flexibility and adaptability in practice. There was a perception that some families needed more support and some were not able to collaborate with professionals (Pickering & Busse, 2010). Dunst et al. (1991) highlight that although there is recognition that family-centred practice is an effective model for EI practice there is an ‘implementation lag’ in knowledge translation. There is a need to identify the factors that support and hinder EI practice in Ireland from the professionals’ perspectives.

2.11 Study Research Question, Aims and Objectives

The overarching research question that was pursued in this study was: What are the process constructs that underpin early intervention services in Ireland? To assist in answering this research question, the following research aims and objectives were considered:

- Study Aims
1. To understand early intervention services from the stakeholders’ perspectives
2. To build a model of facilitating and hindering constructs to facilitate best practice and support integrated care for early intervention service provision in Ireland

- **Research Objectives**
  1. To explore the stakeholders’ accounts of their experiences with their EI team.
  2. To identify and explore factors which facilitate and inhibit EI services from the stakeholders’ perspectives.
  3. To illuminate the processes within EI practice.
  4. To explore and evaluate the engagement of children with disabilities in the research process.
  5. To determine conceptual constructs which frame a potential best practice model for Ireland.

2.12 **Chapter Summary**

Early intervention services internationally are different and complex. They are situated in contexts that are unique in terms of culture, policy, legislation, underpinning philosophies and people. Research within the Irish context is slowly emerging establishing an evidence base to support the development of EI services within the Irish context. This chapter supports Diclemante et al.’s (2013) view that multiple theories are needed to elucidate a complex phenomenon. This chapter reviewed a number of key theories underpinning the conceptual model which was illuminated by the data summarised in Table 1.

*Table 1: Key Theoretical Contributions underpinning the Conceptual Model which illuminated from the Study.*
The Irish Government set down a commitment in 2014 to support quality evidence-based EI practice and to support children in expressing their views. These commitments are reinforced by the UN (2015) and UNCRC (1989). A continuum of family-oriented practice is acknowledged and evidence in relation to current EI practice suggests that services are striving towards family-centred practice. There is recognition that the voices of all the different stakeholders involved in EI is needed to obtain a holistic picture from the multiple perspectives to frame future practice. There is a need for further qualitative exploration of EI to develop an understanding of what constructs are important for families and professionals involved with EI services in the Irish context.
3. Methodology

3.1 Introduction

This chapter presents the philosophical assumptions derived from an interpretivist paradigm which underpinned the research with regard to ontology, epistemology, axiology and methodology. This chapter also presents the rationale for combining a qualitative case study research design (Stake, 1995) with a Grounded Theory (Strauss & Corbin, 1998) methodology and demonstrates how Grounded Theory was used to collect and analyse the data from the case study. Laws and McLeod (2004) highlight that this combination allows the researcher flexibility within the research site, which was an EI disability service in the Republic of Ireland, and can facilitate the illumination of a phenomena. This chapter also explores how the participants were identified, how the data was collected and analysed, how the interpretivist paradigm guided the selection of tools, instruments, participants, and methods and discusses ethical considerations pertinent to the research.

3.2 Philosophical Assumptions for the Research Design

The ontological foundation of the study was interpretivism. Interpretivists believe that multiple, constructed realities exist rather than a single true reality (Ponterotto, 2005). Therefore, from an interpretivist paradigm, reality is subjective and created through social interaction. Furthermore, reality is influenced by the context of the situation, the individual’s experience and perceptions, the social environment, and the interaction between the individual and the researcher. The epistemology underlying an interpretivist position acknowledges the dynamic interaction between the researcher and the participant in the construction of reality (Ponterotto, 2005). To facilitate this construction close interpersonal contact is required with the participants. This paradigm is most appropriate as it assumes that multiple realities exist and the research and the participant co-create an understanding of the phenomenon relative to the time and the place (Patton, 2002). The axiology underpinning an interpretivist position indicates that the researcher must acknowledge and describe her values. According to Denzin and Lincoln (2008, p. 31) ‘all research is interpretive’ with the researcher’s beliefs and feelings about the
world guiding the study. Interpretative researchers attempt to understand phenomena from the participants’ perspectives (Orlikowski & Baroudi, 1991). The interpretivist paradigm guided the researcher in the selection of tools, instruments, participants, and methods used in the study. The methods used included semi-structured interviews, theoretical sampling, and constant comparative method, multi-method, participatory, reflexive, and adaptable.

3.3 Research Design

Each EI programme is unique and coupled with no international uniform model informing practice leads to a lack of transferrable successes and lack of uniformity. Based on the diversity of how EI services function and the heterogeneity of the client population who use the services in Ireland, qualitative exploration is needed to understand the processes within EI from the perspectives of families and service providers (Sandall, Smith, Mclean, & Broudy-Ramsey, 2002). The qualitative research paradigm is appropriate in instances where insights, experiences, descriptions and clarifications are required to explore a particular topic (Creswell, 2007; Patton, 2015). Phenomenology aims to translate the lived experience of participants into words and meanings when exploring a particular topic (van Manen 1997). This research study aimed to inform practice rather than focus on the lived experiences of participants. The aims of the study, the interpretivist philosophical stance and the uncertainty and complexity of the phenomena demonstrated by a lack of research in the area, informed the use of case study (Stake, 1995) as the research design and Grounded Theory specifically that of Strauss and Corbin (1998) as the methodology. Interpretative Within the field of social sciences the use of qualitative case study is less well established and is a developing area in health services research (Crowe et al., 2011). Grounded Theory research is research that facilitates theory building that is ‘faithful to and illuminates the area under study’ ( Strauss & Corbin, 1990, p. 24). The researcher aimed to combine case study and Grounded Theory. Interpretive researchers can combine case study design and Grounded Theory as they complement each other when building theory (Diaz Andrade, 2009). Furthermore, DiClemente et al. (2013) stress that theory should be relative to
the context in which it is used, thus grounding the theory in praxis. The following sections aim to provide rationale and evidence for using qualitative case study research design (Stake, 1995) to stimulate the advancement and development of concepts and theory, through the use of Strauss and Corbin’s Grounded Theory as the methodology. The combination of these methodologies offers new insights into their application within qualitative inquiry. Acknowledging that the context of health care research is unique, qualitative research is becoming more mainstream in healthcare research and important for informing practice (Morse, 2005).

3.3.1 Rationale for Case study

Qualitative research in general and case study research in particular is a debated topic (Eisenhardt, 1989). Case study has a wide variety of interpretations. It is recognised that case studies can follow either quantitative or qualitative approaches (Stake, 1995) or any mix of both (Yin, 2003, 2014). Case study research is the most widely used qualitative research method in information systems research (Darke, Shanks, & Broadbent, 1998), and is an established research approach in management studies (Haunschild & Eikhof, 2009). Within the field of social sciences the use of qualitative case study is less well established and is a developing area in health services research (Crowe et al., 2011). However, Baskarada (2014) states that qualitative case study continues to be misconstrued. Stake (1995, p. xv) perceives case study research as ‘naturalistic, holistc, ethnographic, phenomenological, and biographic’ rather than quantitative and deductive. This thinking is reflected in Gillham’s (2000, p. 1) definition of a case as ‘…a unit of human activity embedded in the real world…. which can only be studied or understood in context’. Stake (1995, p. xi) explains that ‘a case study is expected to catch the complexity of a single case’. For this study Stake’s (1995) definition of case study was used as it is congruent with the researcher’s underlying theoretical perspective of interpretivism; it allowed case study research design to be used in an instrumental way to investigate the phenomenon being explored. In case study design binding the case by time and place (Creswell, 2007), by time and activity (Stake, 1995) or by definition and context (Miles & Huberman, 1994) helps
maintain the scope of the study. An EI team service for children with disabilities in Ireland in 2012 was the focus of the study; hence the team bounded the study.

A good case study researcher aims to develop a theoretical framework no matter whether the study is explanatory, descriptive, or exploratory (David, 2006). Walton (2005, p. 129) argues that ‘case studies are likely to produce the best theory’. Crowe et al. (2011) acknowledge that the characteristics of an interpretative case study focus on theory building by attempting to understand different perspectives. They also state that by using an instrumental case study the particular case facilitates a broader understanding of a phenomenon. Yin (2003, p. 10) states that case studies “are generalizable to theoretical propositions and not to populations or universes”. He highlights that the goal is “to generalize theories (analytical generalization)” (Yin, 2003, p. 10). In order to achieve this goal Yin (2011) argues that a sound argument of the propositions must be presented at a complex conceptual level rather than at the level of specific findings. However, Diaz Andrade (2009) state that researchers using case study design need to argue for the authenticity of their conceptual findings as data analysis can be recognised as a weakness in case study design. In qualitative and interpretive case studies the researcher is directly involved in the process of data collection and analysis (Creswell, 1998; Morse, 1994a). Case study research relies on multiple sources of evidence, with data needing to converge in a triangulating fashion (David, 2006). The phenomena must be viewed and explored from multiple perspectives in keeping with triangulation as a primary principle of case study design (Baxter & Jack, 2008). Miles and Huberman (1994) support the use of multiple data sources, which is a hallmark of case study research (Yin, 2003), and Patton (1990) suggests that it can also enhance data credibility.

3.3.2 Rationale for Strauss and Corbin’s Grounded Theory
Grounded Theory research is research that facilitates theory building that is ‘faithful to and illuminates the area under study’ (Strauss & Corbin, 1990, p. 24). There are several key points of difference between the research method of an evolved Grounded Theory study (Charmaz, 2014; Strauss & Corbin,
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1998) and that of a traditional Grounded Theory approach (Glaser & Strauss, 1967). Strauss and Corbin’s Grounded Theory offers a more flexible approach when compared to other Grounded Theory constructions (Corbin & Strauss, 2008). This flexibility allowed the researcher combine this specific methodology with case study, as they were congruent with the researcher’s underlying interpretivist theoretical perspective. This methodology was used in this study because the researcher wanted to cover contextual conditions and understand their possible impact on the phenomenon of the study and it provided clear procedural steps for data collection and analysis, to facilitate the generation of theory. Multiple stakeholders’ perspectives were deemed crucial in contextualising the EI team, a concept supported by the use of case study. A description of the team itself was not the primary focus of the study but the team was instrumental in learning about the phenomenon of what facilitates EI. The researcher sought to understand the team in their context. Ragin and Becker (1992, pp. 3-9) suggest that by selecting an EI team, the researcher has selected a ‘real’ unit of social reality embedded in reality.

Strauss and Corbin’s model of Grounded Theory was utilised in the study because Strauss and Corbin acknowledge the importance of a multiplicity of perspectives and “truths” (Corbin & Strauss, 2008; Strauss, 1987; Strauss & Corbin, 1990, 1998). They acknowledge that ‘interpretations must include the perspectives and voice of the people who we study’ (Strauss & Corbin, 1994, p. 274). Strauss and Corbin’s (1990) model of Grounded Theory analysis added to the coherence, contributed to convergence and added structure to guide data collection and analysis. In line with Strauss and Corbin’s model of Grounded Theory the literature served as an additional source of data, and a means of theoretical sampling; it gave a context for the data and played an important role in validating the theory (Strauss & Corbin 1998, p. 53). The literature review commenced prior to and during data collection (Appendix D), which is different to a traditional Grounded Theory approach (Glaser & Strauss, 1967). Clear explanation not generalisation is the goal when using a grounded theoretical approach with theories being the researcher’s interpretations of the participants’ perspectives (Strauss & Corbin, 1994, p. 279). Strauss and Corbin (1990, p. 41) describe theoretical sensitivity
as the “awareness of the subtleties of meaning of data” and elaborate that “one can come to a research situation with varying degrees of sensitivity depending upon previous reading and experience with or relevant to that area”. Therefore, in adopting the Strauss and Corbin’s (1998) model of Grounded Theory, the researcher acknowledged her past experiences working in an EI service as a Speech and Language Therapist which provided her with a deep level of insight into the research area of EI.

3.3.3 Case Study and Grounded Theory

Based on the diversity of how EI services function and the heterogeneity of the client population who use the services in Ireland, qualitative exploration is needed to understand the processes within EI from the perspectives of families and service providers (Sandall et al., 2002). Because research in the field of EI in Ireland is in its infancy, building theory from case study research is also very appropriate (Eisenhardt, 1989). Using a case study research design together with Strauss and Corbin’s model of Grounded Theory allowed for the generation of rigorous theory. Interpretive researchers can combine case study design and Grounded Theory as they complement each other when building theory (Diaz Andrade, 2009). According to Morgan (2015) when conducting qualitative research, case study can be used to frame the research questions and Grounded Theory can be used as a strategy to collect and analyse data. However, the combination of case study and Grounded Theory is a contested area (Laws & McLeod, 2004). They note that in carrying out case study research, the researcher has a major challenge in choosing a suitable way to analyse the data. There is lack of clarity around the role case study research plays within the process of theory building and furthermore, case study research is perceived as a method and not by itself a theory building methodology (Dooley, 2002, p. 346). Merriam (1998, p. 20) noted that within qualitative research, Grounded Theory could be regarded as a function of the research and case study could be seen as a form of qualitative research that could be used together. Laws and McLeod (2004) state that the purpose of case study research is to gain an in depth understanding of the situation and meaning for those involved. They identify that in case study research the
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interest is in process rather than outcomes. Steenhuis and de Bruijn (2006) suggest that using Grounded Theory within case study research offers an excellent mechanism for generating an unproven theory and allows the theory to explicitly emerge without the tight focus on the phenomena. Dooley (2002) suggests that Grounded Theory is particularly useful in the conceptual development phase of theory building.

Laws and McLeod (2004) highlight that the combination of case study and Grounded Theory allows the researcher flexibility within the research site, and facilitates the illumination of a phenomena. Case study design allows the researcher to deal with a rich variety of data sources (Merriam, 1998) and allows for the development of new theory that can link to mainstream deductive research (Eisenhardt & Graebner, 2007). However, Miles and Huberman (1994) stress that more inductive case studies, with an interpretivist underpinning, may be considered of lesser quality than testing oriented designs. This may be due in part to the multiple meanings of qualitative research and multiple meanings of both case study and Grounded Theory building. Therefore it is important when combining case study and Grounded Theory for the researcher to clearly state which methodology is the overarching one (Fernández, 2004). In this study the overarching methodology is that of Strauss and Corbin’s Grounded Theory.

3.3.4 Substantive and Formal Theory

The role of a theory is to ‘provide the best comprehensive, coherent and simplest model …to reveal the obvious, the implicit, the unrecognised and the unknown’ (Morse, 1994b, pp. 25-26). Theory provides a means to clearly understand a complex problem and offers ‘contextual structure’ (Borkowski, Smith, & Akai, 2007). The qualitative research paradigm is appropriate in instances where insights, experiences, descriptions and clarifications are required to explore a particular topic (Creswell, 2007). Goulding (2002) states that in Grounded Theory substantive theory is developed from a particular area whereas formal theory has explanatory power and can be applied to a wider context. This study sought to develop a substantive theory, which can be represented by a conceptual model through the collection and interpretation of
data from multiple perspectives within one EI disability service. This study did not have the scope to develop a formal theory, such as data from other EI disability services in Ireland.

3.4 Sample
Within the Irish context, EI services for children with disabilities are provided by multi-disciplinary teams to children from birth to five years who are experiencing significant difficulties in two or more areas of their development (Carroll et al., 2013) in the published paper in Appendix A. The way that teams function varies across the country of Ireland. Teams typically include families, parents and children with disabilities, and a variety of professionals, including Occupational Therapists (OT), Physiotherapists (PT), Speech and Language Therapists (SLT), Nurses, Psychologists, Social Workers (SW), Family Support Workers (FSW) and in some teams, a Team Leader.

3.4.1 Identification of the Case
A staged approach to sampling was used. Initially a purposive approach was employed to select EI services in Ireland. Creswell (2007, p. 112) describes this approach as: “intentionally selecting participants who have experience with the central phenomenon or key concept being explored”. Five EI teams within two Health Service Executive (HSE) Administrative Areas were invited to take part in the study (Appendix E). Two of these teams were located within the HSE Dublin Mid-Leinster Area. These two EI teams provided assessment and intervention in a family-centred way with reference to the Integrated Care One Network (ICON) model of practice. The teams had been functioning in this way for over two years before the research commenced. These two teams were in a rural location with the HSE as the main service provider. The three additional teams were located in the HSE South and were implementing new family-centred multi-disciplinary teams to provide assessment and intervention in accordance with the assessment of need requirements from the Disability Act, 2005. These three teams were urban and a collaboration of service providers (non-governmental organisations and HSE). Permission to contact the five EI team services for the study involved, in the first instance,
discussions with the area disability coordinator. Following this, the researcher contacted each identified team leader and subsequently met with three of the five team leaders. Following the recruitment phase, one EI team accepted the invitation to participate.

This EI team was part of a bigger organisation with an active interest in research. The team provided an EI service for children, aged from birth to five years, with intellectual disability. The team was managed by a team leader who was responsible for leading the team, reporting to senior management within the organisation, conducted the initial visit with each new family who was referred to the team and set up and chaired the team meeting. At the time of the research children were referred to the team via an intake forum following a multi-agency forum where professionals come together to discuss a child’s needs and design a pathway of care. This team’s ethos was one of family-centred practice (Dunst, 1995), following the ‘team around the child’ (TAC) approach, defined by Limbrick (2007, p. 3) as ‘an individualised and evolving team of the few practitioners who see the child and family on a regular basis to provide practical support’. The professionals had regular meetings called ‘team around the family’ meetings to discuss individual children and their progress. Families were not present at these meetings. A comprehensive trans-disciplinary team based assessment was the norm for this team with coordinated input from the various disciplines as appropriate. The team worked closely in one location. The team comprised of 18 professionals which included: four Nurses, three Speech and Language Therapists, three Physiotherapists, two Occupational Therapists, one Social Worker, one Care Assistant, one Family Support Worker, one Dietician and two Psychologists, and over 100 families. Thirteen of the staff worked full-time on the team with five working part-time. Tertiary to the team were Medical Doctors, Paediatricians and Administration Support Staff. The intervention approach used by the professionals on the team encompassed both medical and social models. Some children received both home and clinic-based interventions while others received clinic-based only.
3.4.2 Identification of Participants within the Case

A purposive approach was employed to sample the team in order to gain a broad representation of backgrounds and experiences, representations from all those involved in the team were included (Patton, 2015). Subsequently, the researcher met with the EI team leader to discuss the recruitment procedure, outlined in tables 2 and 3, which involved recruiting families and professionals (Creswell, 2007). The team leader, who acted as the gatekeeper, was asked to select parents, children aged between two and five years, and professionals who met the inclusion criteria. For inclusion all participants were involved in the selected EI team when the study commenced and up to six months in the immediate past and were willing to participate. They had English as their first language as resources did not allow for the recruitment of interpreters.
**Table 2: Selection and Recruitment Plan A: Parents and Children**

<table>
<thead>
<tr>
<th>STEP 1</th>
<th>The team leader purposively identified five children and five parents (who met the study criteria).</th>
</tr>
</thead>
<tbody>
<tr>
<td>STEP 2</td>
<td>The selected families received an information leaflet (Appendices F&amp;G).</td>
</tr>
<tr>
<td>STEP 3</td>
<td>The team leader contacted these families by phone to ask their permission to give their contact details to the researcher.</td>
</tr>
<tr>
<td>STEP 4</td>
<td>If a family did not give permission, the team leader selected another family using a rolling random method.</td>
</tr>
<tr>
<td>STEP 5</td>
<td>The team leader contacted the researcher with the details of the families who agreed to participate. It is important to note that up until this point all data was held by the service.</td>
</tr>
<tr>
<td>STEP 6</td>
<td>The researcher contacted the parents directly to arrange the interviews.</td>
</tr>
<tr>
<td>STEP 7</td>
<td>For the child participants, the parent consented for the researcher to meeting their child for the research.</td>
</tr>
<tr>
<td>STEP 8</td>
<td>The child assented to participate in the interactions with the researcher.</td>
</tr>
<tr>
<td>STEP 9</td>
<td>For the child participants, the researcher checked at the beginning of each interview and throughout the interview that the child was willing to participate. The researcher was alert and sensitive to the child’s behaviours throughout the process.</td>
</tr>
</tbody>
</table>
Table 3: Selection and Recruitment Plan B: Professionals

<table>
<thead>
<tr>
<th>STEP 1</th>
<th>The team leader identified 10 professionals purposively to include a range of the health professionals.</th>
</tr>
</thead>
<tbody>
<tr>
<td>STEP 2</td>
<td>The selected professionals received an information leaflet (Appendix H).</td>
</tr>
<tr>
<td>STEP 3</td>
<td>The team leader asked the professional’s permission to give their contact details to the researcher.</td>
</tr>
<tr>
<td>STEP 4</td>
<td>If a professional did not give permission the team leader selected another professional using a rolling random method.</td>
</tr>
<tr>
<td>STEP 5</td>
<td>The team leader contacted the researcher and provided details of the professionals who agreed to take part.</td>
</tr>
<tr>
<td>STEP 6</td>
<td>The researcher contacted the professionals directly to arrange an interview.</td>
</tr>
<tr>
<td>STEP 7</td>
<td>During the study theoretical sampling involved the recruitment of further professionals and the team leader followed steps 2-6 to recruit these professionals.</td>
</tr>
</tbody>
</table>

In following a Grounded Theory approach, theoretical sampling was used following early analysis and identification of themes to pursue theoretical lines of enquiry (Strauss & Corbin, 1998). Therefore, further sampling occurred as categories emerged from the data (Strauss & Corbin, 1998). For example, following the initial professional and parent interviews, the importance of the roles and involvement of the childcare assistant and the family support worker on the team emerged. Hence, these professionals were also interviewed. Interviews with parents and professionals discussed team meetings and the team assessment format. Therefore, observations of a team assessment and a team meeting were undertaken. The literature served as an additional source of data, and a means of theoretical sampling; it gave a context
for the data. Creswell (2007, p.112) describes this approach as: “intentionally selecting participants who have experience with the central phenomenon or key concept being explored”. Theoretical sampling rather than the number of participants drove the study. Therefore, the selection of the case was important in terms of theoretical sampling (Eisenhardt, 1989). Theoretical sampling in Grounded Theory is a very important procedural technique as further data is collected based on concepts derived from previous analysed data in the study (Strauss & Corbin, 1998). Suddaby (2006) stressed that the direction of new data collection follows the categories that emerge from the interpretations of the data. This indicates the links between data collection and analysis (Suddaby, 2006). Theoretical saturation was achieved when repetition of phenomena occurred. Strauss and Corbin (1998) highlight that this is one of the primary means for verification of the Grounded Theory process.

3.4.3 Sample Size
Qualitative research is generally small scale, as it is not concerned with statistical generalisability (Pope, Mays, & Popay, 2007). In this study the case was an EI team working with children with disabilities in Ireland in 2012 (Stake, 1995). In case study design the number of participants should be sufficient to illuminate the case being explored. Crouch and McKenzie (2006) suggest that a relatively small number of participants will facilitate the researcher’s close association with the respondents, and enhance the validity of in-depth inquiry in naturalistic settings. The number of participants selected in a Grounded Theory study depends on a number of factors, including scale of the study, level of detail required, resources available, topic, and research questions (Bruce, 2007). Sample size for Grounded Theory relies on the point of theoretical saturation (Irwin, Panbacker, & Lass, 2008). Saturation occurs when the analysed interviews with participants no longer elicit trends or themes not raised by previous participants (Maxwell & Satake, 2006). Given that an individual can generate hundreds or thousands of concepts, large samples are not necessary to generate rich data sets (Starks & Trinidad, 2007). A review of the literature indicates that saturation normally occurs between 10 and 30 interviews (Morse, 2000). By using a case study approach (Stake, 1995) the
researcher aimed to build a stronger understanding and a more compelling argument for a phenomenon and to construct a credible conceptual model.

3.5 Data Collection Methods
A variety of methods were used in the data collection process to facilitate the participant of the children and adults in the study. Multiple methods were used with the child participants and semi-structured interviews with the adult participants. In total, 31 interviews were carried out. Interviews with the professionals took place at their place of work, and parents’ interviews took place in their homes as did data collection with child participants. The average length of the interviews was 50 minutes. In total approximately 25 hours of audio recording was transcribed and analysed. Also, two observations were conducted one of a team meeting and the second of a team assessment.

3.5.1 Methods for Child Participants
Children’s involvement is vital in order to understand their experiences and to maximise their participation and that of their families (Department of Health and Children, 2000). Clark and Moss (2001; 2011) developed the Mosaic approach, which adopts an interpretivist approach for listening to children’s perspectives, within a research context. There are six components to Clark and Moss (2011) framework for listening; multi-method process, participatory, reflexive, adaptable, focussed on children’s lived experiences and embedded in practice. Clark and Moss (2011) facilitated a deeper understanding of the complexities of children’s everyday lives. Clark and Moss’s (2001; 2011) framework was used to guide the data collection process because it views children as ‘beings not becomings’ (Quortrup, Bardy, Sgritta, & Wintersberger, 1994) and listens to children’s voices. The child participants were all individuals with heterogeneous experiences and diverse interests and needs. The multi-method process involved interactions with each child, use of a Microsoft SenseCam (Hodges et al., 2006), SenseCam images, pictures, Talking Mats (Murphy, 1997) and observations. Multiple interactions also allowed the needs of the child to be respected (Irwin & Johnson, 2005) and strengthened the trustworthiness of the data (Dockett & Perry, 2007). It allowed the researcher
to listen to the children and facilitated their views to become embedded in the research process. Clark (2005) argues that the Mosaic of narratives and images help the researcher develop an understanding of the child’s priorities. Methods of data collection with children with disabilities were in accordance with best practice guidelines (Whyte, 2006).

Prior to the initial interaction with the children in the main study, the researcher and the primary caregiver had a telephone conversation on how best to facilitate their child’s participation and engage in the interaction. Each interaction involved the child, researcher and one or both parents, was audio recorded and took place in the child’s home. The researcher engaged in active listening, and took field notes following each interview. A total communication approach was used, where non-verbal communication such as body language, facial expression, signing, gestures and pictures were valued as much as spoken language (Fargas-Malet, McSherry, Larkin, & Robinson, 2010).

At the end of the first interaction, the researcher gave the parent/s a SenseCam for the child to wear over the subsequent few days. There was one SenseCam available for the study; subsequently two children were selected to use the SenseCam based on nearest travel distance from the researcher. The SenseCam, developed by Microsoft Research UK, is a passive wearable camera, fitted with a wide-angle (fish-eye) lens, which results in nearly everything in front of the camera being photographed. It takes photographs automatically and the images provide a visual account of daily tasks and activities from the child’s perspective. It offers a novel route to the collection of observational data. The use of the SenseCam provided the children with a means to share their lives from their perspective (Wang, 2006). The researcher collected the camera and a record sheet (noting the date and length of time the child wore the camera) prior to the second interaction. The images from the SenseCam informed the second interaction with two of the children. SenseCam Image software was used to process all the SenseCam images. During the second interaction, the researcher used Talking Mats (Murphy, 1997), along with the print outs of SenseCam images of toys, people, places, activities from the child’s world (where applicable), and other pictures based on child’s preferences. The tools were varied and reflective in accordance with the
research question and the individual abilities and preferences of the children.

3.5.1.1 Development of Tools for Child Participants

By promoting and facilitating children’s participation we are advancing childhood research and adding to research generally (Tisdall, 2012) and responding to our ethical responsibility to explore ways to make their participation a reality (Merrick, 2011). Three children with developmental disabilities were recruited from a different EI team to that involved in the main study. The focus of their inclusion was to check the feasibility of the participation of children in the research. The successful outcome of this feasibility study, led to the development of a protocol to facilitate children in the research process (Appendix J). The published paper in in Appendix C, discusses how children with disabilities were included in the study. Data involving eight children (three from the feasibility study and five from the main study) were included in the paper. The children participated in both the feasibility study and main study in the same way. Due to the extensive amount of pictorial data that emerged from the feasibility study, only two of the five children recruited for the main study used the SenseCam data collection tool.

3.5.2 Data Collection Methods for Adult Participants

Semi-structured in depth interviews were most appropriate for collecting data on participants’ perspectives and experiences and they have the benefit of uncovering issues that were not anticipated by the researcher (Palinkas et al., 2015). Goulding (2002) also states that semi-structured interviews are favoured because they generate rich and detailed accounts form participants. The adult participants were interviewed in a place that was convenient for them. General interview guides informed the semi-structured interviews, one for the parent participants (Appendix K) and another for the professional participants (Appendix L). The interview guides supported the interviews and the researcher adopted a flexible engaging approach, which allowed the discussion to lead into areas of relevance for the participants (Goulding, 2002; Turner, 2010).
3.5.3 Observations
Two observations took place during a ‘team around the family’ meeting and a team assessment. For both observations the researcher acted as a non-participant observer and informally documented the events, behaviours and interactions (Marshall & Rossman, 2011). For the observation of the team assessment, the researcher sat with the child’s parents in an observation room, which allowed the researcher to observe while being out of the child’s and professionals’ view.

3.6 Analysis
The following section explains how the researcher used Strauss and Corbin’s model of Grounded Theory within a case study research design to generate a core category. The researcher immersed herself in the data, using a constant comparative approach and questioning the data thus aiming to reconstruct meaning from the data (Strauss & Corbin, 1990, 1998). Coding involved the process of grouping evidence and labeling ideas so that they reflected the broader perspectives (Creswell, 2007, p. 132). The convergence of data from the multiple sources added strength to the findings promoting a greater understanding of the case (Baxter & Jack, 2008, p. 554). Multiple sources of evidence are a hallmark feature of case study, however a clear method of analysis is not evident in the literature. Walsham (2006) suggests that there is a need for more material on how to carry out case study research from inception to publication.

Strauss and Corbin (1998) advocate the use of a clear method to data analysis: open, axial and selective coding, the conditional/consequential matrix and diagramming. Strauss and Corbin (1998, p. 199) describe the matrix as “an analytic device to help the analyst keep track of the interplay of conditions/consequences and subsequent actions/interactions and to trace their paths of connectivity”. Strauss and Corbin (1998) developed the process by which the core category is identified to acknowledge the role of the researcher as the author of a theoretical reconstruction. Strauss and Corbin’s Grounded Theory method of analysis helped the researcher identify themes in all the data by fracturing or breaking the information down into themes and
core categories (Appendices P, Q, R, S). Therefore, in adopting the Strauss and Corbin (1998) model of Grounded Theory, the researcher acknowledged her past experiences working in an EI service as a speech and language therapist which provided her with a deep level of insight into the research area of EI. McCann and Clark (2003, p. 15) suggest that the use of memoing is the researcher’s dialogue with the data; ‘it is both inductive and deductive and allows the researcher to deal with any preconceptions she has about the study’.

Following the initial coding, code memos were written which focused on conceptual labeling (Appendix U). During the axial and selective coding phases, analytical memos (Appendix U) were written and augmented with researcher reflexivity. Miles, Huberman, and Saldana (2014) state that analytical memos are the researcher’s reflections and thinking processes. The researcher prioritised memoing during the research process capturing thoughts and linking ideas together. In flexible designs such as this Patton (2002) advocates the use of an audit trail therefore the researcher kept a reflective diary which included thoughts, feelings, biases that might influence all aspects of the research process and how they were managed (Davis, Watson, & Cunningham-Burley, 2000; Driessnack, 2006). The researcher was reflexive by considering her stance as a researcher and the power relations in the research process (Davis et al., 2000; Emond, 2006; Goodenough, Williamson, Kent, & Ashcroft, 2003; Groves, 2008; Mauthner, 1997).

The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging data from the research field. This means that the researcher considered not only the voice and perspective of all those involved in the team, that is, parents, children and professionals, but also the interactions between them. The interview data from the child participants were coded to identify themes. Content analysis was used to make sense of the pictorial images from the SenseCam. These images were grouped into events to form a pictorial diary of the child’s experiences and the researcher interpreted the photographs, examining and describing them as thoroughly as possible (Carroll and Sixsmith, 2016b) presented in the published paper in Appendix C.
The systematic procedures for data analysis are imperative for rigour, particularly in the constant comparison of data to emerging categories (Creswell, 1998, p. 56). There is no strict formula for presenting theory, however the researcher has an obligation to explain the data theoretically but should provide theoretical meaning and explanation rather than descriptive data (Goulding, 2002). In keeping with the view of Corbin and Strauss (2008, p. 319), the findings section presents the conceptual model with no quotations in order to explain the conceptual message. The conceptual model is presented as an integrated set of hypotheses and not by illustrations from the raw data (Glaser, 1978). The presentation of the findings section is abstract in keeping with Yin’s (2011) view that propositions should be presented at a complex conceptual level rather than at the level of specific findings. However, to support authenticity of the conceptual model low levels of description are provided in Appendix Q.

3.7 Rigour of Grounded Theory within a Case Study Design

Without rigour, research is worthless, becomes fiction, and loses its utility (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Haunschild and Eikhof (2009) note that there is a demand for qualitative researchers to justify both methodology and results. Therefore, the concept of “trustworthiness” in place of the terms reliability and validity proposed by Guba and Lincoln (1981) was imperative in this research combining Strauss and Corbin’s Grounded Theory and case study research design. They suggested criteria for qualitative research such as credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). The researcher aimed to understand the team in their context. The researcher wanted to develop a conceptual model from the exploration. Grounded theory research is research that facilitates theory building that is, ‘faithful to and illuminates the area under study’ (Strauss & Corbin, 1990, p. 24). As with any research study issues of rigour and trust are important. The major methods for ensuring rigour are intricately linked with the notion of reliability and validity (Morse, 2000). Graham and Thomas (2008) emphasise that by selecting and adhering to a specific version of Grounded Theory the researcher will ensure rigour and integrity of the research findings. The
Methodology

The researcher integrated criteria for interpretative qualitative case study and Grounded Theory from (Cohen & Crabtree, 2008; Diaz Andrade, 2009; Gilson, 2012; Yin, 2011) shown in Table 4, which outlines the techniques used during the research process to ensure trustworthiness.

The complete transcriptions, from each interview and interaction, were imported into the NVivo software package (version 10) to support the qualitative analysis. NVivo was used as a tool to manage and organise the extensive data from the multiple data set to support the analysis. However, as (Patton, 2015, p. 442) reminds us: “the analysis of qualitative data involves creativity, intellectual discipline, analytical rigor and a great deal of hard work”. Hence, computer programmes can facilitate the work of analysis but cannot replace the understanding, interest and creativity of the researcher. The core feature of the qualitative data analysis was the coding process. The researcher immersed herself in the data, used a constant comparative approach, questioning the data, aiming to reconstruct meaning from the data (Strauss & Corbin, 1998).
### Methodology

**Table 4: Procedures to Ensure Trustworthiness for this Interpretive Qualitative Case Study Using Grounded Theory**

<table>
<thead>
<tr>
<th>Criterion of Trustworthiness</th>
<th>Case Study Tactic</th>
<th>Grounded Theory Principles</th>
<th>Techniques used in the Study</th>
</tr>
</thead>
</table>
| **Confirmability** (Construct validity) | Use multiple sources of evidence | Corroboration Theoretical Saturation | Research Design:  
1. Triangulation of multiple sources of data  
2. Aimed to produce rich, substantive account of the complex perspectives.  
Data collection and analysis phases:  
1. Theoretical sampling  
2. Memoing (Appendix S)  
3. Peer review (Appendix I)  
4. Peer debriefing  
5. Member checking  
6. Prolonged engagement |
| **Credibility (internal validity)** | Look for patterns in the data  
Consider explanations for the experience analysed  
Triangulation  
Consider negative cases to test and refine argument | Coding techniques | During Data analysis:  
1. Researcher mentally immersed in the data and at the research site  
2. Constant comparative approach  
3. Open coding (Appendix O)  
4. Axial coding (Appendix Q)  
5. Selective coding (Appendix R)  
6. Theoretical sensitivity |
| **Transferability** (external validity) | Use theory in single-case studies | Theoretical generalisation | Theoretical sensitivity |
| **Dependability** (reliability) | Use case study protocol  
Develop case study database | Chain of evidence | Built into the research design:  
1. Tools for data collection with children were trialed in the feasibility study and protocol was developed to support the participation of the children (Appendix I)  
2. Data recorded, analysed and carefully analysed  
3. NVivo software package used  
4. Member checking, peer review, debriefing used. |
In terms of prolonged engagement, the researcher collected data over a six-month period and conducted multiple interviews with different people and conducted observations. The researcher used meetings with her supervisor during the data collection and analysis phases to debrief. At the end of each interview the researcher checked with the participant that her initial impressions from the interview were accurate. Peer checking was also used comprising of a panel of three experts in their respective fields (Social Work, Nursing, Speech and Language Therapy) to obtain a multi-disciplinary perspective that reflected that of the EI team (Lincoln & Guba, 1985, p. 239). They all worked in healthcare with extensive practice experience, with masters level education and had knowledge and experience of qualitative data analysis. They provided different viewpoints on the data (after Patton, 2002) and added credibility to the findings (Strauss & Corbin, 1998, p. 97). The experts were given detailed background information on the study and a questioning guide (Appendix L). They appraised the findings and verified that the description of the phenomenon was faithful (Koch & Harrington, 1998). Hence, the conceptual model, which emerged from the study, is one that is rigorous and trustworthy.

3.8 Ethical Considerations/Issues in this Study
The research underwent three independent reviews and received full ethical approval from National University of Ireland, Galway, University College Cork and Health Service Executive, Dublin Mid-Leinster Research Ethics Committees.

3.8.1 Informed Consent
Parents and professionals were fully informed of the research and were advised that they had the right to withdraw at any stage and confidentiality was assured. Prior to collecting data each adult participant provided written consent (Appendix N). In all instances of research with children, where parental consent was obtained, the agreement of the children to take part in the research was also requested (Ireland & Holloway, 1996; Scott, Wishart, &
Therefore for the child participants, the researcher employed the following procedure:

1. The researcher contacted the parents of the children identified through the selection process.
2. The parent provided written consent (Appendix O1) for their child and together with their child (Appendix O2) to take part and gave permission for the researcher to meet with their child for the research.
3. The child assented to participate in an interaction with the researcher.

The approach to the interaction was based on the child’s level of ability.

During child interactions, the child’s parents were present at all times and able to withdraw their child if they wished to at any point in the process. The extent to which proxy responses accurately reflect the views of the child with special needs are disputed and the subject of some debate (Markham & Dean, 2006). The parents were well briefed and understood that they may be probed where necessary to give supportive evidence to statements. The key to successful data collection with people with an intellectual disability is flexibility and sensitivity to the requirements of the individual.

3.8.2 Assent

Stancliffe (1999) states that “a well-informed guess may be preferable to no information in cases where the person is unable to communicate her/his own views”. National Federation of Voluntary Bodies (2008) states that for a person with a disability the presumption should be of capacity rather than incapacity. They also state that where children do not have the capacity a guardian (usually a parent) appointed must give consent. However, there should also be an opportunity for the child to express assent. The researcher facilitated the participation of the children in both the feasibility study and the main study in this research and allowed them to have a voice and included those for whom obstacles may make participation difficult. The age, level and type of disability of the child dictated how the child’s own assent and participation was achieved. Due to the range of ages and abilities of the children each child’s participation was assessed on an individual basis and ways
to best facilitate the children’s participation to engage and interact was discussed at length with each child’s parents. The researcher checked at the beginning of each interaction that the children were willing to participate. The researcher looked for verbal and non-verbal signs of the child’s willingness to partake or withdraw. Examples of refusal techniques included: turning head away, pushing researcher away, leaving the room, or falling asleep. The researcher was alert and sensitive to the child’s behaviours throughout the process.

At the time of data collection, the researcher had extensive clinical experience of working as a SLT with this client group in the context of EI services. The researcher was experienced in communicating with children with significant communication needs using Lamh (Augmentative Sign Language System for children with disabilities), communication boards and other systems of communication such as PECS (Picture Exchange Communication System) and observing children’s communication both verbally and non-verbally. The researcher used these skills along with play, photographs, and observation together with their parents. Each interaction involved the child, researcher and one or both parents, was audio recorded and took place in the child’s home. The parents’ role was one to support the child and the researcher during their interactions. Thus, supporting the view that the parent and researcher worked in partnership and also to ensure that the research was carried out to the appropriate ethical standards.

3.8.3 Risks and Benefits
Through the interview process sensitive issues may have arisen for parents and children when communicating their experiences. Therefore, a Public Health Nurse outside the team was contacted prior to each interview to seek their support in case of problems arising post-interview and should post-interview support be required. The need for this service did not arise. The individual participants may not have benefited directly from the research, however research for the practice of EI teams is crucial and essential to ensure that young children with disabilities receive effective and evidence-based care. This
study aimed to contribute to the health and social gain of the Irish population and provide evidence-based data for services within the Irish context.

3.8.4 Confidentiality and Data Protection

The importance of confidentiality is stressed in research governance guidelines but confidentiality could not be sustained if the child revealed information that the interviewer felt should be passed on in the child’s best interests such as child protection (Coad & Lewis, 2004). All participants were given unique identifiers to ensure anonymity. All recordings and transcripts of interviews and paper format documents were stored in a locked filing cabinet in the Speech and Language Therapy Department National University of Ireland Galway. Electronic data was stored on a password-protected computer. In compliance with National University of Ireland Galway regulations, data will be stored for five years before being destroyed.

3.9 Conclusion

This study sought to understand EI services from the stakeholders’ perspectives and to build a conceptual model of constructs that facilitate EI service provision in Ireland. The research was embedded in the theoretical perspective of interpretivism. The aims of the study, the philosophical stance and the uncertainty of the phenomena demonstrated by a lack of research in the area, informed the use of case study (Stake, 1995) as the research design and Grounded Theory (Strauss & Corbin, 1998) as the methodology. In this chapter, the researcher argued that using a case study design in conjunction with the Grounded Theory approach as proposed by Strauss and Corbin, allowed the researcher to generate theory from a bounded case (Stake, 1995) in a coherent, systematic and rigorous manner. The combining of these approaches in qualitative research is a point of critical debate. The researcher is not suggesting that any type of case study and any Grounded Theory approach can automatically be linked; more specificity is required in the context of the research study undertaken. This study justifies the use of Strauss and Corbin’s (1998) Grounded Theory within a case study design (after Stake, 1995) with recognition of the synergistic relationship between the two.
4. Findings

4.1 Introduction
This chapter presents the findings of the study, illustrating the processes which frame a best practice model for Ireland. This conceptual model illuminates the processes within EI which include: Consequences, Driving Factors, Restraining Factors and Macro-Level Context. The conceptual model involves the people within the EI relationship working within a synergistic interdependent relationship. The child, within his/her microsystem, is involved with his/her family and with professionals involved in EI. The conceptual model is embedded within the context of health and education organisations and the legislative context at the exosystem level of the child’s life. Through the analysis process 285 codes emerged from the open coding phase (Appendix P). The researcher distilled these codes during axial coding and 15 categories emerged (Appendix R). The categories were further distilled to four emergent themes (Appendix S). Through constant comparative analysis, reading and interpretation the central phenomenon of synergistic interdependent relationships in EI was illuminated from the data. In this chapter the conceptual constructs developed through the analysis process outlined in Table 5 form the conceptual model presented in figure 5 at the end of this chapter. These constructs are presented systematically in order to demonstrate how the conceptual model emerged from the analytical process. This chapter also provides details on the profile of the participants who took part in the study.
Table 5: Outcome of Axial and Selective Coding

<table>
<thead>
<tr>
<th>AXIAL CODING</th>
<th>SELECTIVE CODING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Categories</strong></td>
<td><strong>Themes</strong></td>
</tr>
<tr>
<td>Enabling</td>
<td>Consequences</td>
</tr>
<tr>
<td>Disabling and Imbalance</td>
<td></td>
</tr>
<tr>
<td>Rewards</td>
<td></td>
</tr>
<tr>
<td>Costs</td>
<td></td>
</tr>
<tr>
<td>Team Profile</td>
<td>Driving Factors</td>
</tr>
<tr>
<td>Child Profile and Influence</td>
<td></td>
</tr>
<tr>
<td>Parent Profile and Influence</td>
<td></td>
</tr>
<tr>
<td>Professional Profile and Influence</td>
<td></td>
</tr>
<tr>
<td>Relationship Stages</td>
<td>Restraining Factors</td>
</tr>
<tr>
<td>Investment</td>
<td></td>
</tr>
<tr>
<td>Dependence</td>
<td></td>
</tr>
<tr>
<td>Alternative Services</td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td></td>
</tr>
<tr>
<td>Interaction Process</td>
<td></td>
</tr>
<tr>
<td>Organisational Factors</td>
<td>Marco-level Context</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
</tbody>
</table>

This chapter addresses the following research objectives.

1. To explore the stakeholders’ accounts of their experiences with their EI team.
2. To identify and explore factors which facilitate and inhibit EI services from the stakeholders’ perspectives.
3. To illuminate the processes within EI practice.
4. To explore and evaluate the engagement of children with disabilities in the research process.
5. To determine conceptual constructs which frame a potential best practice model for Ireland.
4.2 Profile of Participants

The final sample of participants in the EI team included five children with disabilities, six parents and 17 professionals. The child and parent participants (outlined in Table 6) were from different families. All families were nuclear families. Child participants were aged between two and four years.

Table 6: Family Participant Sample

<table>
<thead>
<tr>
<th>Family Participant</th>
<th>Child Gender</th>
<th>Age (years)</th>
<th>Length of time with EI (years)</th>
<th>Referral Age</th>
<th>Diagnosis</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>5 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 2</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 3</td>
<td>Male</td>
<td>4</td>
<td>4</td>
<td>5 months</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Child 4</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 5</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Not yet</td>
</tr>
<tr>
<td>Parent 1</td>
<td>Male</td>
<td>4</td>
<td>2</td>
<td>2 years</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Parent 2</td>
<td>Male</td>
<td>4</td>
<td>4</td>
<td>3 months</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Parent 3</td>
<td>Male</td>
<td>5</td>
<td>5</td>
<td>6 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Parent 4</td>
<td>Female</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Not yet</td>
</tr>
<tr>
<td>Parent 5&amp;6</td>
<td>Female</td>
<td>2</td>
<td>2</td>
<td>5 months</td>
<td>Down syndrome</td>
<td>Not yet</td>
</tr>
</tbody>
</table>

The sample of professionals (outlined in Table 7) included four Nurses, three Speech and Language Therapists, three Physiotherapists, two Occupational Therapists, one Social Worker, one Care Assistant, one Family Support Worker, one Dietician and one Psychologist. All professionals worked in the
organisation between 4 and 27 years, with an average length of time in the organisation being 9.7 years. Professionals worked on the EI team between 2 and 15 years, with an average length of time of 5.4 years. Six professionals previously worked in other organisations between 3.5 years to 10 years, with an average length of time of 6.9 years.

*Table 7: Professional Participant Sample*

<table>
<thead>
<tr>
<th>Number</th>
<th>Profession</th>
<th>Time (years) working in current organisation</th>
<th>Time (years) with EI service</th>
<th>Fulltime or part-time in EI service</th>
<th>Experience (Years) with any other service/organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof 1</td>
<td>Psychologist</td>
<td>12</td>
<td>12</td>
<td>Part-time</td>
<td>10</td>
</tr>
<tr>
<td>Prof 2</td>
<td>Dietician</td>
<td>4</td>
<td>2</td>
<td>Full-time</td>
<td>4</td>
</tr>
<tr>
<td>Prof 3</td>
<td>Nurse</td>
<td>4</td>
<td>2</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 4</td>
<td>Nurse</td>
<td>16</td>
<td>2</td>
<td>Part-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 5</td>
<td>Nurse</td>
<td>16</td>
<td>4</td>
<td>Full-time</td>
<td>10</td>
</tr>
<tr>
<td>Prof 6</td>
<td>Family Support Worker</td>
<td>12</td>
<td>10</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 7</td>
<td>Speech and Language Therapist</td>
<td>7</td>
<td>4</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 8</td>
<td>Occupational Therapist</td>
<td>10</td>
<td>4</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 9</td>
<td>Speech and Language Therapist</td>
<td>6</td>
<td>6</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 10</td>
<td>Social Worker</td>
<td>7.5</td>
<td>7.5</td>
<td>Full-time</td>
<td>10</td>
</tr>
<tr>
<td>Prof 11</td>
<td>Speech and Language Therapist</td>
<td>5</td>
<td>4</td>
<td>Part-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 12</td>
<td>Occupational Therapist</td>
<td>14</td>
<td>8</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 13</td>
<td>Physiotherapist</td>
<td>8</td>
<td>1.5</td>
<td>Full-time</td>
<td>3.5</td>
</tr>
<tr>
<td>Prof 14</td>
<td>Physiotherapist</td>
<td>4.5</td>
<td>3</td>
<td>Part-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 15</td>
<td>Physiotherapist</td>
<td>5</td>
<td>5</td>
<td>Full-time</td>
<td>4</td>
</tr>
<tr>
<td>Prof 16</td>
<td>Care Assistant</td>
<td>7</td>
<td>2</td>
<td>Full-time</td>
<td>0</td>
</tr>
<tr>
<td>Prof 17</td>
<td>Team Leader &amp; Nurse</td>
<td>27</td>
<td>15</td>
<td>Full-time</td>
<td>0</td>
</tr>
</tbody>
</table>
4.3 Defining the Constructs within the Conceptual Model

Multiple interdependent influences impacted the central phenomenon of synergistic interdependent relationships in EI. The four themes are Consequences, Driving Factors, Restraining Factors and Macro-Level Context. Covariance existed between the influences and the consequences. Table 6 highlights the categories and themes that emerged from the study through the axial and selective coding processes.

4.4 Consequences

The child, parent(s) and professional(s) interact as part of an EI team and there are consequences of these interactions, which can be both positive and negative. There were a number of consequences to the interdependent relationship within EI. These consequences, both positive and negative, can be described in relational terms as identified in Table 8. These consequences were dependent on the impact of the influences within the triangular unit. The data illuminated that those involved in the relationship strove to find the balance between costs and rewards in the relationship.

<table>
<thead>
<tr>
<th>Positive Consequences</th>
<th>Negative Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling</td>
<td>Disabling and Imbalance</td>
</tr>
<tr>
<td>Rewards</td>
<td>Costs</td>
</tr>
</tbody>
</table>

4.4.1 Enabling

A positive consequence of the relationship emerged when all the influences in the relationship facilitated successful learning for the child to develop and grow. The relationship was deemed enabling when the relationship was relevant and valuable to all involved. An enabling influence encouraged Positivity; positive changes for the future. The terms Passion and Energy were used to describe characteristics of those involved and these characteristics were perceived as influential. The development of the Child’s Skills and his/her progress influenced this category as well as, the opportunity for all involved to
evolve and change during the relationship. Furthermore, the Empowering nature of the relationship enabled families and professionals to interact, communicate and help the children. The EI professionals needed Management Support to deliver the service in the way they wanted. The opportunity to give and receive feedback was also perceived as an enabler.

4.4.2 Disabling and Imbalance
A negative consequence to the relationship emerged when all the influences in the relationship caused hesitation/‘chilling effect’ and caused fear. The subcategory Withholding information created these effects. Professionals withheld information from parents and from fellow professionals. Parents also withheld information from professionals. This was linked to the people in the relationship exerting their influence and making choices about how much they wanted to communicate in the relationship. This may be linked to the relationship of the participants, as references were made to personality clashes between parents/children and professionals, thus acting as a disabler. The subcategory Conjectures created a ‘chilling effect’ on the relationship. Parents wondered what caused their child’s disability, asked ‘what if’ questions and looked for commonalities and uniqueness’s in their child’s disability or profile. Professionals made assumptions about what a parent thought and about who was working with the family. Parents and professionals made assumptions regarding the level of collaboration between everyone involved with their child.

When an influence acted as a manipulator it created an imbalance in the relationship and caused conflicts. ‘Waiting’ emerged for parents with regard to waiting for services and waiting to see how their child developed. This led to strong feelings for some parents as they felt ‘victimised’ by services. Parents spoke about the terminology used by the professionals and that the names of the assessments were confusing. There were references to professionals being ‘judgmental’ about parents during their interactions. Parents were uncertain, feeling that there was a lack of clarity about the service. Professionals too were uncertain with regard to the future of services and with the way the team was working. This lack of clarity led to Conflicts. The code vulnerability emerged for both parents and professionals where they felt isolated and exposed. The
subcategory of *Conflicts* were linked mainly to health professionals. These *Conflicts* related to scheduling and how professionals struggled and disagreed when scheduling appointments. Meeting the needs of families created clashes amongst some professionals and on occasion conflict arose when a professional misread information. Conflict with management arose relating to leadership and management at an organisational level. Feeling ‘invisible’ led the professionals to perceive that management lacked awareness of what occurred in the background of delivering EI. However, ‘defiance’ emerged where parents and professionals stood up and defied authority through engaging and providing the service within their own context.

4.4.3 Rewards

The participants were motivated to be in relationships that provided them with high level of rewards. Rewards from the relationships in this study included the subcategories of Social Rewards, Opportunity Rewards, Instrumental Rewards, and Emotional Rewards. Being involved in the EI service provided social rewards for some of the participants. In terms of Social Rewards interacting with people that they liked and enjoyed being around was perceived in a positive light. ‘Involvement’ with the service also ‘relieved stress’ for parents and professionals alike and there was a feeling of being ‘lucky’ with regards to the way the service was supported and delivered.

Involvement within the relationship provided Opportunity Rewards. All participants increased their ‘skills’, ‘knowledge’ and ‘confidence’ as a consequence of being involved in the service. For the parents such ‘skills’ included being able to transfer techniques learned in the clinic and at training courses to their homes and to other situations. The parents acknowledged their learning and understood how to put their knowledge to use. This development in ‘confidence’ helped parents carry out therapy tasks and use techniques comfortably. Parents also noted the importance of feeling confident about the care their children were receiving. Parents highlighted the feeling of ‘succeeding’. They perceived success in terms of doing well and their child making progress. This feeling of success was also linked to empowerment/enabling as a reward. Parents identified being educated and
learning through courses and therapy and interactions with the professionals. Opportunity Rewards for professionals also included ‘learning’. Professionals referenced their growth as a professional and the development of their professional intuition and insight, which facilitated their confidence building and reflective practice skills. The professionals identified continuous professional development as an opportunity through course attendance and reading to expand their knowledge. For the professionals ‘cover and relief’ when a professional was on leave was an opportunity of being involved with the EI team. Professionals had strong positive reasons for working in EI and professionals perceived that they were making a difference and making changes through their involvement with the children and their families. Parents identified that there were also ‘family benefits’ where interactions and therapy benefitted the rest of their family and not just the child with the disability. Another opportunity was the ‘availability’ of different types of quality interventions, such as, individual therapy, group therapy and home support. The parents noted the benefits of the supports and therapy provided in the home, such as home based nursing care.

Instrumental Rewards were illuminated by the data. These rewards referred to all participants helping one another to carry out and complete tasks and duties. ‘Credit’ was illuminated by the data where there was praise and credit paid to professionals and parents and courses. ‘Involvement’ with the service created awareness and enhanced parents’ knowledge and insight. Rewards included the ‘reinforcement’ of behaviours and skills, the ‘impact of therapy’ on the child’s progress, and the ‘impact of home intervention’. There was a perception that home intervention helped professionals, parents and the children, and that different environments impacted on a child’s interaction.

Emotional Rewards and Closeness implied that the participants had a sense of shared trust, experience, enjoyment, concern and caring. Participants were able to praise themselves, express relief and felt secure. Parents felt ‘prepared’ for future activities, events and situations. There were references to ‘enjoyment’ where the children enjoyed interventions and responded positively. For parents there was a sense of ‘coping’; coping with the disability, their child, and changes. There was also a sense of ‘appreciation’: appreciation for the service
and interventions. There was a sense of ‘contentment’ among parents and professionals and children demonstrated by an ability to express ‘amusement’.

4.4.4 Costs

People were motivated to be in the relationship when it provided them with low-level costs. These costs included: Opportunity Costs, Instrumental Costs, and Emotional Costs. Opportunity Costs related to participants having to give up something they wanted for the sake of the relationship. The concept of ‘time pressures’ illuminated from the data with both parents and professionals highlighting not having enough time. Parents noted the ‘struggling’ that existed for them being involved in their relationships with their child, family and professionals. Being involved in the EI relationship created added ‘financial burden’ for the family and the professionals. These costs related to expenses of equipment and travel expenses.

Instrumental Costs included perceived challenges within the relationship. These costs arose when there was more work for one person and when a person impeded the progress of another. Both professional and parent challenges were identified as well as challenges that involved all participants. ‘Unclear involvement’ was an instrumental cost. Uncertainty and lack of clarity existed around who was involved with a family and how and why they were involved. ‘Confusion’ was another cost and this related to uncertainty around what parents were expected to do and in relation to unclear instructions they were given. ‘Lost or missing information’ in relation to information getting lost and not getting relayed to the relevant people was highlighted. Some participants made reference to ‘inappropriate input’, suggesting that some therapy inputs were inappropriate, unsuccessful or unfruitful. Parents and professionals identified gaps in what was being offered and improvements to the service were identified. ‘Blame’ was noted as a cost with reference to a blame game and whose fault it was for costs. Further costs included the ‘monitoring requirements’ to note progress and the maintenance of records in terms of filing paper and electronic records. ‘Challenges’ specific to the professionals related to frustrations in delivering the service to families. Team
challenges included specific challenges in relation to team working. Parent challenges related specifically to parent concerns.

*Emotional Costs* included all negative feelings related to the relationship. Feelings included being ‘upset’, and/or ‘tired’. Parents specifically referenced difficult times in their family lives, with feelings of ‘guilt’, ‘devastation’, ‘and feeling overwhelmed. Parents felt ‘frustrated’ with the service, the system, and with professionals. Parents felt ‘pressure and stress’. Professionals had ‘worries and concerns’ in relation to the relationship. Both parents and professionals acknowledged that there were ‘bad days’ when they were feeling down. They acknowledged the ‘impact of disability’ on the family, on the child, on attachment and on their family system and how the disability challenged their expectations. They acknowledged the feeling of ‘loss’ in terms of loss for the ‘normal’ child, and the need to deviate from an expected life plan. Parents and professionals also expressed feelings of ‘anxiety’ in relation to themselves, and involvement on the team and within interventions. ‘Fear’ specific to interactions for both parents and professionals was highlighted; fear of asking and fear of telling. There were also feelings of ‘self-doubt’ showing vulnerability. Parents and professionals doubted their skills and abilities.

There were no social costs identified by the participants of this service during this study. Social costs refer to engagement in unpleasant social activities or being cast in a negative light because of an association with someone.

### 4.5 Factors Affecting the Synergistic Interdependent Relationship

Within the conceptual model (Figure 5), there were many factors influencing the synergistic interdependent relationships in EI. The relationship was dependent on driving factors, which included *People Influences* and *System Influences*. These influences are illustrated further in Figure 3 to indicate their driving and restraining influences on the equilibrium of the EI relationship. The child, parent(s) and professional(s) drove the relationships. They had their own profiles/characteristics to bring to the relationship and each person had influence, which they exerted in different ways in the relationship. Restraining
Findings

factors included: *Relationship Stages, Comparison, Alternative Services, Interaction Process, Dependence and Investment.* Everyone in the relationship worked together to maintain equilibrium between the influences that acted as drivers or restrainers.
Figure 3: Factors Affecting the Synergistic Interdependent Relationships in Early Intervention
4.6 Driving Factors: People Influences

Multiple interdependent influences impacted the central phenomenon. The system influences were contingent upon the critical attributes of the participants within the relationship.

4.6.1 Team Profile

Team structure refers to the team make-up and configuration. References to team development highlighted how the team evolved over time and how the relationship changed between the members. There were specific professional roles and duties. Parents had roles assigned in the intervention and in the home setting. Parents had views on who was working with their child and who was on their ‘core’ team. Confusion, overlap and ‘lack of clarity’ prevailed for some participants as changes in roles over time were noted. ‘Coordinated leadership’ was deemed important and team members had views on the job description of the team coordinator and stressed the need for this role. ‘Collaboration’ was the focus of the intervention. ‘Approaches to intervention’ were described, such as, child-centred, family-centred, and social model. Definitions and descriptions of EI and the service delivery were discussed.

4.6.2 Child Profile and Influence

In acknowledging the profile of the child it was imperative for professionals to understand their ‘personality’, their ‘needs’ in terms of services and therapy, and understand their ‘skills’ and ‘difficulties’. The child exerted their influence in their relationships in a number of ways. Their needs and difficulties dictated which professionals they met. Each child had his/her own interests, likes, and skills of recognition. Each child was different, was unique and had a level and range of skills. Their level of motivation in activities influenced the relationship and outcomes. Hence, when a child was interested they were motivated and engaged and this made a difference to the relationship. The children made decisions to participate during their interactions and within their relationships.
4.6.3 Parent Profile and Influence
In acknowledging the profile of the parent it was imperative to understand the parent’s ‘personality’, their ‘needs’ to support their child, and their ‘preferences’ in terms of therapy and/or ‘style’ of interaction. Each parent exerted their influence in the relationships in a number of ways. Parenting style and decisions about parenting were specific to each family. Parents had commitments outside the home and this impacted on parent’s flexibility. Parents influenced how they adapted to change, how they linked therapies to the home setting and how they made decisions about their level of involvement in intervention and services. Parents differed in their motivation, desires and need to be involved in therapy and therapy activities. ‘Meaningful knowledge’ facilitated parent influence. Knowing what to expect was important: being aware of what to expect of intervention, clarifying roles, and having clear boundaries. Knowing and being aware of limits created influence, as did knowing goals and knowing what professionals were working on. Furthermore, knowing about collaboration and professional discussions was important to parents. Parents demonstrated their influence through setting and determining goals for their child and through supplementing assessment by providing supporting evidence from other settings in which their child interacted. Parents had the knowledge and awareness of the home setting in terms of activities and communicating with their child.

4.6.4 Professional Profile and Influence
In acknowledging the profile of the professional it was imperative to understand the professional’s ‘training’, their ‘previous work experiences’ and ‘team working background’, and their work ethic. Each professional was different in terms of their interactions and goals and had different ways of dealing with differences of opinion and conflict. ‘Collaboration’ with families existed whereby professionals planned for interventions and inputs with families. However, professionals’ decisions were predominantly ‘expert driven’ and ‘authoritative’ where they made decisions without consulting parents. They made decisions about therapy interventions such as the setting and who would deliver the intervention and they identified and measured goals. They showed
‘authority’ by not allowing some parents to seek other therapy options. They also ‘informed’ and told parents rather than collaborated. Professionals used standardised assessments and informal assessments to plan intervention for the children. The child and parent profiles dictated the amount or level of interaction families needed. Therefore, the professionals made decisions based on the family profile. Professionals acknowledged that their ‘organisational skills’ influenced their ability to function well with families and colleagues. On one hand, professionals showed an understanding of parents’ situations and empathised with families, however on the other hand parents felt that they were not listened to, told not to worry, felt sidelined and felt their expertise was not considered. Professionals acknowledged the influence of ‘freedom’ whereby they had the freedom to make decisions, do things and make changes. They exerted their influence in the relationship by ‘protecting’ themselves and ‘pulling back’ and limiting interactions as they saw fit.

4.7 Restraining Factors: System Influences

Multiple interdependent influences impacted the central phenomenon. The system influences included: Relationship Stages, Comparison, Alternative Services, Interaction Process, Dependence and Investment.

4.7.1 A Trajectory of Relationship Development for Early Intervention

A predominant influence on the core category was the understanding that the process of the EI relationship happened through an overlapping five-stage developmental trajectory: initiating stage, experimenting stage, intensifying stage, integrating stage, transitioning stage. This developmental trajectory, outlined in Figure 4, incorporates adaptations of four of Knapp and Vangelisti (2005) five stages of relationship development within EI and proposes a new fifth transitioning stage, within the EI relationship.
Figure 4: A Trajectory of Relationship Stages in Early Intervention

Findings
4.7.1.1 Initiating Stage
This stage referred to getting involved in the service and with the team and the overall initiation of the process. For the participants the key elements within this stage included ‘referral’, ‘suitability’, ‘introduction’ and ‘assessment’. There was a ‘referral’ process to access EI, which was a requirement for all families. Professionals recognised the rise in children being referred impacted on this stage of the trajectory. ‘Suitability’ for the service required a child meeting particular criteria and it may also have been dependent on timing for the family. Unsuitability for the service may have happened following the assessment, for example, if it was not the right time for the family or the child did not meet the criteria. ‘Introduction’ to the team involved families and professionals meeting for the first time and may also have involved new professionals meeting their colleagues for the first time. There was an ‘assessment’ procedure for the assessment of the child and their family.

4.7.1.2 Experimenting Stage
This stage referred to the getting started and the early development of the relationship and setting of boundaries. Professionals supported new parents in their introduction to the service and were acutely aware of ‘giving a good impression’ to families. Creating these impressions was important for relationship building. During this stage, ‘therapy and/or ‘home interventions’ commenced with the family. Parents did make ‘first impressions’ in relation to the intervention, the team, and the professionals. Professionals during this stage were aware of ‘setting boundaries’ and tried to distinguish between their own professional and personal boundaries when interacting with parents. In this initial stage of the building of the relationship both families and professionals may have felt ‘awkwardness’ in their interactions together.

4.7.1.3 Integrating Stage
This stage referred to the development of a relational identity where parents and professionals saw themselves as part of a team where they disclosed and shared information openly. All participants felt ‘togetherness’ where they were not alone, felt united with someone and felt supported to continue the
relationship. ‘Closeness’ developed during this stage of the relationship as parents and professionals ‘acknowledged’ each other and the disability. Professionals felt part of the team, felt acknowledgement and felt accepted by their fellow professionals. This acknowledgement facilitated relationship building and the sharing of information. In this stage professionals acknowledged parents’ opinions and views and in turn parents felt listened to. All involved began to acknowledge the disability and its impact on assessment and treatment. There was also acknowledgement and openness to what occurred in practice versus the ideal.

Furthermore, parents’ ‘acceptance’ played a role during this stage. A ‘realisation’ occurred for parents of their child’s level of skill and level of difficulty. Subsequently this realisation facilitated acceptance of their child’s disability, acceptance of their level of ability, and setting of realistic expectations of achievement. Additionally, parents accepted the level of service being offered. They put up with or complied with service provision. Parents’ ability to accept advice and information also influenced the development of closeness. The importance of ‘communication’ for sharing information was key. Understanding how information was shared and communicated within the team promoted the development of the relationship. Linking with preschool and school services to share information and collaborate influenced the openness in the relationship. Families sharing and being open, together with professional openness to change, facilitated the relationship.

4.7.1.4 Intensifying Stage
This stage referred to the progression of the relationship to a closer one. ‘Connections’ and ‘trust’ emerged from the experimentation stage. The level of closeness for the participants deepened which was related to the affective exchange state. ‘Openness’ and ‘disclosure’ were clearly evident. This stage of relationship development involved families supporting themselves and getting support from their extended families and involved parents supporting other parents.
At this stage all involved had acclimatised to the relationship. There was now a ‘familiarity’ with situations, people, and places. With familiarity, reciprocity was evident whereby all involved work in harmony with each other. All involved adapted and made changes to accommodate others and themselves. Professionals also made changes to improve the service. Becoming ‘acclimatised’ to the relationship allowed the realisation to unfold that it takes time for changes to happen and for movement. Confining factors to the intensifying stage in the relationship include: ‘negotiation’, and ‘continuity of care’. The ‘negotiation’ involved discussions around ‘scheduling’ and coordination of appointments and ‘prioritisation’. This code was linked to the ‘adaptability’ of all involved and the influence of the people involved in the negotiation process. ‘Prioritisation’ involved discussions around whose needs and wants came first, for example, parent or professional, child or family. In some cases tensions arose as to whose need was priority in the relationship. Continuity of care included ‘frequency’ and ‘consistency’ of appointments and service. Subsequently, ‘consistency of care’ facilitated ‘familiarity’ and ‘acclimatisation’. The ‘negotiations’ and ‘prioritisation’ were influenced by the amount of interventions and support a family received.

4.7.1.5 Transitioning Stage

This refers to the ending of the relationship and moving on. Transitioning from the team to other professionals and other services, such as education, was fraught with ‘angst’ and ‘fear’ for parents. These feelings were linked to the emotional costs of the relationship and to the level of dependence the parents and children had in the relationship. Planning for transition featured mainly for professionals as they planned for the child’s transition from the team to primary education. ‘Positivity’ also emerged for all participants where they looked forward to the future.
4.7.2 Investment

Both ‘intrinsic’ and ‘extrinsic’ factors were identified within this category. ‘Motivation’ was recognised as an intrinsic investment factor in the relationship for all participants. Extrinsic investment factors were related to intervention such as ‘therapy activities’, ‘therapy programmes’, ‘parent courses’ and ongoing structure and routine for the child, and for professionals feeling part of the team was important.

4.7.3 Dependence

This category refers to parents’ and professionals’ skills and the needs that parents had or were perceived to have. This category identified that the parents perceived that they have more to loose from the termination of the EI relationship. This led to the recognition that being involved in EI fostered dependency. There was both parent-focused dependence and professional-focused dependence. Parents were dependent to some degree on the professionals, as they needed the professionals to share their knowledge and skills. The degree of dependency was impacted on by alternative services that were available to the parents. Parent focused dependence related to their need for professionals because they lacked insight. Parents themselves commented that they lacked insight and required professionals to model techniques for them to understand. Attention was given to the journey parents and children have to make and the recognition that the children have lifelong needs. This lifelong need requires the expert - professionals. Parents commented on their inexperience; feelings of not being skilled and requiring expert professional help.

Professional focused dependence related to meeting needs of those who were involved in interventions. Meeting the needs involved ‘protecting’ or ‘minding’ of families within the relationship. This is linked to the ‘non-disclosure’ or ‘withholding’ or ‘masking information’ or ‘shielding’. Meeting the needs also involved ‘modeling skills’ and ‘integration’. This referred to professionals modeling and using skills and techniques, showing how integration of goals and skills can happen in the home and in other settings. Professionals may foster parents’ dependency or parents’ feelings of
dependency. Parents became dependent on the professional as they had the expertise and the skills.

4.7.4 Alternative Services
This refers to the alternatives that people perceive they have outside the relationship (Tribaut & Kelly, 1959). Parents expressed that they were often ‘fighting’ for the services they received. Some families expressed how they engaged with other services outside the organisation and often withheld this information for the professionals. For some parents having other intervention options was considered important.

4.7.5 Comparison
Comparison refers to participants’ expectations of the kind of outcomes in the relationship. This is based on participants’ past relational experiences, personal observations and perceptions of other people’s relationships. Parents and professionals made observations in relation to the value of EI, roles and duties of all involved in the team, and made perceptions of the organisation and of the child. Parents appraised their child by making ‘peer comparisons’ by comparing their child to their peers in terms of development and needs. They also made ‘sibling comparisons’ by comparing their child to their siblings in terms of child rearing practices and interactions. Participants also made comparisons to other services and organisational structures. Comments were made in relation to the differences between developmental disabilities and autistic spectrum disorder in terms of the services, demands and the disorders. Parents and professionals had ‘expectations’ when it came to their involvement in the EI services; expectations of attending therapy, and of the different professionals involved. Professionals also had expectations of parents. Both parents and professionals had ‘hopes’ for the children and for their education.

4.7.6 Interaction Process
The important features were; who was in the interaction and the context of the interaction. ‘Interactions’ were between parents, child, and professionals and also included their interactions with others. ‘Contexts’ of interactions between
all participants were during assessment and interventions, both in therapy and at home. All participants interacted with other family members such as siblings and grandparents. Parents and children interacted in their home setting and in other social settings. The child communicated and interacted with parents during home and therapy activities and the child also communicated and interacted with professionals during therapy sessions or other activities. Parents interacted with other parents and they made choices during their interactions with professionals. These choices facilitated positive or negative interactions. Professionals interacted with families and used their communication skills. They also interacted with colleagues during ‘team around the family’ meetings, before, during and after therapy sessions. Key facilitators in the interactions were ‘respect’, ‘relationships’, ‘personalities’, ‘responsibility’, and ‘similarity of focus’. A positive relationship was important for participants and respect for each other and their beliefs. Similar goals and ways of interacting facilitated the interaction.

4.8 **Macro Level Context**

The context of the EI team was related to Education Services and Organisational factors. Within the subcategory, Education Services, participants highlighted the child’s educational future and educational system requirements in the Irish context. Organisational factors included service changes and the organisational change process and the impact of this change on the EI team.

4.9 **Key findings: Conceptual Model to support EI practice in Ireland**

This study addressed the overarching research question: What are the process constructs that underpin EI services in Ireland? The conceptual model, in Figure 5, which emerged from the study, identifies the core category synergistic interdependent relationships in EI. The core category refers to the synergistic interdependent relationships between the child, their parents and the professionals striving to find the balance to achieve positive outcomes. Multiple interdependent influences impacted this central phenomenon. These
included restraining factors and driving factors. The restraining factors included system influences, which were relationship stages, comparison, alternative services, interaction process, dependence and investment. These influences were contingent upon the critical attributes of the participants within the relationship. The consequences of the central phenomenon included: enabling, disabling, rewards, costs, and imbalance. Covariance existed between the influences and the consequences. A predominant influence on the relationship was the understanding that the process of the EI relationship happened through an overlapping five-stage developmental trajectory, which emerged from the data through memoing and the constant comparative approach.

These findings have addressed objective 1 through the inclusion of children, parents and professionals to share their experiences of their EI team and objective 2 by identifying the facilitating and inhibiting factors influencing the central phenomenon. The processes within EI were identified thereby addressing objective 3. The core phenomenon, synergistic interdependent relationships in EI, and its constructs are presented in a conceptual model that can support best practice in EI in Ireland, thus achieving objective 5.
Macro Level Context

Figure 5: Conceptual Model: Synergistic Interdependent Relationships in Early Intervention
5. Discussion

Ensuring the views of different stakeholders within the EI team were heard, this study involved multiple perspectives thus providing an in-depth response to the research question, study aims and objectives. This study met the research objectives set out at the beginning of the research process. It explored the accounts of children, parents and professionals of their experiences with their EI team, and it identified and explored factors, which facilitated and inhibited EI services from the stakeholders’ perspectives. The study also illuminated the processes within EI practice in Ireland and explored and evaluated the engagement of children with disabilities in the research process. Furthermore, this study led to several major contributions to knowledge. Firstly, this study provides a new and unique conceptual model for the Irish context to underpin and support EI practice in Ireland. The central phenomenon of Synergistic Interdependent Relationships emerged. From the data it was evident that multiple interdependent influences impacted the central phenomenon. These included: Relationship Stages, Comparison, Alternative Services, Dependence and Investment and Interaction Process. These influences were contingent upon the critical attributes of the participants within the relationship. The consequences of the central phenomenon included: Enabling, Disabling, Rewards, Costs, and Imbalance. Secondly, the conceptual model encourages an understanding of rewards and costs as outcomes of the EI relationship. Thirdly, interdependency existed between the influences and the consequences of the EI relationship. Each person in the relationship influenced the relationship through their personalities, their needs in terms of services and therapy, and their skills and difficulties, their therapy preferences and style of interaction.

This chapter provides an interpretation of the facilitating and hindering constructs from which the conceptual model emerged, and discusses how the study’s findings complement and contrast with existing knowledge. The key contributions and implications of the findings to early intervention practice, policy and research are discussed whilst incorporating findings from the three published articles (Appendices A, B and C).
5.1 Contribution to Existing Research

The experiences of the participants in the study align with several themes identified in previous EI research. The pivotal role relationships play in EI disability services is well supported (Carpenter, 2005; Shonkoff & Fisher, 2013). The importance of the relationship in providing a family-centred EI service was reinforced in this study. Furthermore, this study acknowledged that relationships within EI do include characteristics of interpersonal relationships noted by Guerrero (2011). During the relationship trajectory in EI, professionals need to listen to families to find out what their choices are and what their expectations are. Successful outcome of EI for the child is dependent on the child, parent, and professional relationship (Edelman, 2004). Interactions throughout the relationship development trajectory can arm families and professionals with the knowledge of what to expect from the relationship and give freedom to discuss what involvement means. For the children, their families and professionals in this study, feeling acknowledged, being heard and being open facilitated and deepened the relationship. Understanding how each partner in the relationship interacted and engaged in the therapeutic process facilitated the required reciprocal interaction. This insight focuses attention on the determinants of successful reciprocal interactions, which will allow for positive outcomes for families and professionals.

The EI practice of the team within the study was consistent with the principles of family-centred practice (Dunst, 2007) as the relationship between the participants promoted positive relationships between families and professionals, and the parents were involved in intervention provision and planning. Although policies direct the type of EI service, with family-centred practice being the fore riding approach (Carroll et al., 2013 (in the published paper in Appendix A); HSE, 2011), there was evidence in this study of varying degrees of family empowerment and involvement with the service. This is in keeping with the continuum of family-oriented services as described by Dunst et al. (1991). This study identifies that there is a perception of joint working, which is supported by policy and legislation. The Government of Ireland (2014) advises that the principle of family-oriented services needs to inform practice for children and young people. This study indicates that professionals during their joint team assessment for the most part are looking at the families through their own lens and doing their own assessment, therefore taking a professionally-centred view (Dunst et al., 1991). Lee (2015a) also found that decision-making was professional led and that the
professional's priorities came first. Dunst (2002) advocates that this only is one level of family-oriented service provision decisions. Professionals also demonstrated family-allied and family-focused services. Some families chose their level of involvement however it was unclear if they made informed choices in a truly family-centred way (Dunst, 2002).

The professionals came together to conduct a comprehensive assessment, which is a key principle of the trans-disciplinary model (Kilgo et al., 2003). The professionals in this study also came together in a coordinated way for families through their ‘team around the family’ meetings indicating inter-disciplinary practice is evident (Bray et al., 2006; Paul & Norbury, 2012). However, this process did not include families, which is a focus of trans-disciplinary team working (Kilgo et al., 2003). The findings indicate that the professionals are implementing an inter-disciplinary team working model and striving towards a trans-disciplinary model of practice. The team may need supports to progress their model of team working to a trans-disciplinary one, which is deemed best practice for children with disabilities (Rabidoux, 2005). This would involve parents becoming more active members of the team sharing goals and responsibilities with professionals (Kilgo et al, 2003). Parents and professionals may need support via training to support its implementation.

For all partners in the EI relationship, decisions were made with regard to their level of interaction. The EI team functioned within a healthcare system and within an organisational structure that placed demands on their practice. This indicates that the system influenced professionals in making decisions about where on the continuum of involvement they could be (Carlhed, 2003). This study found that professionals expected parents and children to interact in a particular way during intervention, for example, to actively engage in therapy sessions and for parents to carry out home activities. In turn, the way a parent and a child interacted during therapy affected the role/interaction style of the professional; therefore one was dependent on the other. Hence, there is a reciprocal relationship between these interdependent participants. Other studies also found that professionals expected parents to take a lead role in their child’s intervention, even if this was not the parent’s wish (Espezel & Canam, 2003; MacKean et al., 2005). Hence, parents may be compromised by their experience of EI. Similar to Matthews and Rix (2013) and Bridle and Mann (2000), parents in this study were trying to find the balance between their parenting roles and other commitments. Professionals in this study became more defiant, less tolerant and less flexible with families as they were trying to
find the balance between their own caseload demands and the needs of the family. Professional expectation of parent engagement is also highlighted by Matthews and Rix (2013). Bridle and Mann (2000) highlight that parents are forced to compromise if they wish to engage with services and in turn this can create difficulties with their relationship with their child. Parents had expectations of their own roles and have expectations and desires about the service they were using. Some were content and others strove for more. Children also had interests, likes and dislikes and expectations of their interactions with others (Carroll & Sixsmith, 2016b) in the published paper in Appendix C.

Some parents had clear views on who was working with their child and who was on their ‘core’ team. Professionals were willing to get to know families and they had a duty of care to each family. Although professionals were partners in the relationship, there is some evidence in this study to indicate some interactions were expert led. Expert interaction led to the professional, in some instances, overshadowing the child’s interests and communication, as they were engrossed in their own needs or requirements for their session. Within the relationship the perceptions of non-disclosure, guardedness and lack of exchange of information by professionals with families, led to uncertainty among families and contributed to the professional being more influential in the relationship. One could argue that the professionals were protecting the families or they were unaware that the families wanted to know detailed information. Carlhed (2003) argues that parents may feel insecure and confused when they are aware that many solutions exist. Furthermore, Carlhed (2003) argues that parents collaborate with professionals in the EI services through the exchange of information. She argues that it is the professionals who create the premise for this collaboration. The findings in this study acknowledge that professionals influence the therapeutic relationship through their level of sharing information.

There were tensions in the relationship and interactions between professionals and parents. Families within this EI team made decisions about where on the continuum of family-oriented services (Dunst et al., 1991; Carlhed, 2003) they wanted to be. However, from the data the families’ decision-making process is unclear. It may be based on parents’ wishes, on their levels of interaction or engagement in the relationship, or influenced by what services were on offer. The level of participant’s interaction depended on their level of motivation, acceptance, familiarity, personality, confidence, and dependency. Parents may have different commitments outside the family routine,
Discussion

which may impact their flexibility (Carpenter, 2008; Turnbull et al., 2007). Previous studies highlight that difficult times or the emotional stance of parents can influence their level of interaction (Rolland, 1994; Turnbull et al., 2005). As Miller (1994) noted when parents are armed with knowledge they can determine their own level of interaction. For these reasons, a service has to be flexible and accommodate these differences, features that were evident in this study. Lee (2015a) suggests that professionals could also provide services linked to emotional and psychological support together with services to meet their families’ tangible needs.

However, there was also evidence of acknowledgment of parents and enabling parents. As Foran and Sweeney (2010) highlighted parents are on an unknown journey, not knowing what to expect. Through EI parents and children can be empowered by giving them the skills and abilities to interact and communicate. Swanson et al. (2011) highlight that parents do feel empowered when they learn new skills that impact on their engagement with their child. Hence, feeling empowered may facilitate engagement. However, ‘empowerment is not synonymous with participation’ (Tones & Tilford, 2001, p. 403). According to Tones and Tilford (2001) participation may in fact foster empowerment and they acknowledge that the more empowered you are the more likely you are to actively participate. This study indicates that a number of factors such as expectations, personalities, frequency of interventions, roles of professionals, courses, preferences, openness, awareness, and acceptance influence this empowerment. Learning new skills through observing, explaining and understanding goals can help parent-professional cooperation (Peterander, 2000). Bachner et al (2006) acknowledge that involving parents in therapy fosters coping and feelings of being supported. Family-centred practice reflects an enabling model of helping, where the skills of families to care for their child with special needs are fostered (Dunst & Trivette, 1996). Family-centred practice also promotes a family’s ability to make decisions about their needs and preferences (Bruder, 2010). Reflecting shared decision-making in Irish EI practice requires a degree of openness by professionals to allow families to make informed decisions about their engagement and acknowledge their contribution. There is a need to allow families to make the choice regarding where on the continuum of family-oriented involvement (Dunst et al., 1991) they would be satisfied. Carlhed (2003) suggests that for positive outcomes, for families, combinations of approaches (child-centred, family-centred or both) and multiple perspectives on intervention (developmental and
functional) are needed. In moving forward with EI service provision in Ireland these combinations need to be considered. To enable successful collaboration training parents and professionals in the process of decision-making may be needed (Bailey, Buysse, Smith, & Elam, 1992).

Driving factors and restraining factors influenced the outcome of the EI relationship by either supporting or hindering the relationship. This study found that some parents depended on professionals and expected a cure or fix, other parents understood that they must do activities and reinforce strategies at home, and other parents believed that they must lead the intervention for their child and seek other options, while others were less engaged. Some assumed teacher roles and made materials and were highly motivated and possibly put pressure on themselves. Not all parents wanted to be involved at the same level. Bailey et al. (2004) also found that, when asked, less than a quarter of their sample wanted to be more involved in the decision-making. Furthermore, parents made comparisons and making peer comparisons may create and increase expectations, and increase involvement. However, peer comparisons may also create parent stress and subsequently put stress on professionals. We need to understand if parents are satisfied with their own level of involvement and feel secure and supported (Carlhed, 2003).

In the event of parents not engaging in the therapy environment or the child’s needs not being met or when a parent is struggling, the professionals in this study made a professional judgment when deciding to provide home-based interventions. However, this decision making process was not explicit and led to lack of clarity as to who got home support and who didn’t. This would indicate that it is important to ask parents about their understanding of home support, for example, is it perceived as therapy, as extra help, as space for themselves, to relieve stress or attend to other commitments. A factor that may contribute to the collaborative decision-making process for parents and professionals was knowledge of the child and the importance of knowing a child in their own home. Professionals and parents noted differences in interactions within the clinic setting and the home setting. This would indicate that it is a necessity for interactions in different locations to support accurate assessment and intervention and to support parents in their own homes. A common ground does exist to incorporate therapy and the home environment to help the child’s development and parent involvement in this goal setting is important (Dunst et al., 2007). Professionals need to facilitate parents’
understanding of the importance of their role in providing their child with everyday interest-based learning opportunities (Dunst et al., 2010). Children need to be aware that their interests and initiations are valued and parents’ capabilities within everyday activities need to be acknowledged (Dunst et al., 2010). Professionals can facilitate the development of trust with families by supporting them to feel prepared, sharing expectations and by sharing information (Paige-Smith & Rix, 2011). This study highlights that professionals’ decision-making processes particularly in relation to extra home care support, need to be made more explicit so that parents can collaborate in this process with clarity.

Consistency of care facilitated familiarity and acclimatisation. Continual supports are recognised as important to meet family needs (McConkey et al., 2006). Working together over time and working collaboratively allowed familiarity and understanding of each other’s roles and goals to develop. Ziviani et al. (2014) report that lack of frequency of appointments impacted on the communication between parents and professionals. Frequency of contact with healthcare professionals has consistently been found to lead to positive experiences (Bjerre et al., 2004; Fordham et al., 2011; James & Chard, 2010; van Shie et al., 2004; Wilkins et al., 2010). For professionals who worked closely together with a child and parent, for example, Speech and Language Therapist, Physiotherapist, Occupational Therapist, they had integrated identities. There was a team ethos, a team identity. There was an element of the professional being familiar with the child and the parent being familiar with the process of intervention, which facilitated parents’ confidence to discuss their desired goals for their child openly with the professionals. Within this study, the team leader consistently visited every new family and carried out the initial interviews. Bruder (2010) supports this practice as she suggests that the service coordinator should be the first point of contact for families entering the EI system. The team leader in this study was a health professional with both relationships and practice skills to support families. Hiebert-Murphy et al. (2011) suggest that these skills are a requirement for service coordinators. Both James and Chard (2010) and Ziviani et al. (2010) stress that coordinating care for families is extremely important. In this study the role of the team leader facilitated and coordinated care for the families.

Closeness is key to all relationships (Lee et al., 1990) and people communicate to become closer to one another, to feel less isolated and to foster togetherness, collaboration, and interaction. This closeness is acknowledged in other studies where the
caring attitude of the professional (Bachner et al., 2006) and feelings of respect (Wilkins et al., 2010) facilitated empowerment and satisfaction. It could be perceived that the ‘team around the family’ meetings, used by the professionals in this study, are for the professionals to plan and share information. In turn, the professionals develop closeness. The team in this study adapted Limbrick’s (2007) ‘team around the child’ model to fit their local needs. Although children and their parents were not present at these meetings, their voices were heard as the professionals came together combining the views from parents and children with their own observations from both centre-based and home based interventions. One might argue that this could be perceived as tokenistic participation of families in their intervention while actually being professionally-centred. Interestingly, the parents in this study appeared ambivalent about their involvement in these meetings, whereas the meetings were perceived as ‘fundamental’ to the professionals. This raises the questions that: if parents knew what was involved and if time was allocated for them to be involved would they too see it as fundamental to the relationship? Furthermore, parents in study by Fitzgerald et al. (2015) perceived meetings as a ‘waste of time’. This highlights that it is important for parents to have the opportunity to decide on their own level of involvement at such meetings.

5.2 Contribution to Knowledge

5.2.1 Conceptual Theory, Models and Constructs
The conceptual model, figure 5, which emerged from this study, is a representation of the complex reality of an EI service in Ireland. Seedhouse (1997) acknowledges that a model can be deliberately used to address a complex phenomenon. Acknowledging the complexity of EI services multiple theories were needed to answer the research question, aims and objectives (DiClemente et al., 2013). The construction of the model was supported by multiple theories that reinforce the holistic, dynamic synergistic nature of relationships in EI. The conceptual model links with Interdependence Theory (Thibaut & Kelley, 1959), and the Investment Model (Rusbult 1980), Knapp and Vangelisti’s (2005) relationship development model.

Interdependence Theory (Thibaut & Kelley, 1959) relates to how rewards and costs, acknowledged in Social Exchange Theory, collaborate with people’s expectations of interpersonal relationships. The conceptual model that emerged from this study is
coherent with Interdependence Theory as this study determined that rewards and costs are relevant to EI practice. There are rewards and costs to any relationship. The participants aimed to maximise the rewards while minimising costs. The rewards, pleasurable and gratifying resources, exchanged within EI are: enjoying therapy, appreciation, contentment, collaboration, feeling like a team, feeling part of the team, feeling prepared. The costs, resources that result in a loss or punishment, exchanged in EI are: lack of disclosure, lack of acknowledgment, inappropriate input, outcomes, dissatisfaction, and fears. Interdependence theory recognises that how satisfied (comparison level) a person is in a personal relationship is defined by their previous experiences and expectations. In EI relationships, those involved in the relationship made comparisons. Comparisons within EI practice, which emerged from this study, include expectations, observations and parent comparisons. In EI practice, the comparison level of alternatives equates to Alternative Services. These are alternative intervention options that supplement a family’s current EI service in order for them to engage in the current relationship. Within Interdependence Theory, these Alternative Services are contingent on Dependence, which is itself contingent on the existence of both internal and external barriers. In the EI relationship, the professionals are reliant on families, and the families are reliant on the professionals. Within EI, whether a family seeks alternatives to their existing service is contingent on outcomes, expectations and comparisons. Fitzgerald et al. (2015) found that parents sourced private therapy services to supplement fragmented Irish EI services. They found that parents feared that inconsistent services would negatively impact on their child’s development or intensify their child’s disability. The families in this study needed the EI service, plus other services, depending on the comparisons they made and their family needs. Within this EI context, external barriers included lack of choice for services and lack of choice within services, and these barriers fostered dependency on the EI relationship. Internally, professionals had skills that families needed and desired, which subsequently created dependency. Webster and Berns Wright (1999) suggest that family relationship strength can be defined as how well parents and children want to get along with each other and their mutual desire for a lasting relationship. This could be extended to an EI team, which involves willingness and a mutual desire to establish and preserve a relationship. Rewards and costs are outcomes to the synergistic interdependent relationships in EI practice. The role rewards and costs play within the Irish EI context is extremely
important to acknowledge. This acknowledgement will facilitate successful EI services for those involved in the relationship.

The conceptual model places the Investment Model (Rusbult, 1980) in the context of EI. The intrinsic investments within the EI context include time and effort and the extrinsic investments include benefits, identity, being part of a group and dependency. Feeling part of the team leads to having good working relationships and supports feelings of relevance and inclusion. Parents may not feel listened to or relevant when there is not enough frequent contact and/or they are not aware of plans and goals. As you get to know someone better your awareness of him or her increases as familiarity increases (Knapp & Vangelisti, 2005). We need time to get to know someone. The more you know someone the more open you are with him or her. Parents use communication in the relationship and if the conversation flows, trust develops and a close relationships ensues (Guerrero, 2011). The relationship between families and professionals is dependent on the development of trust. The concept of emotional closeness takes time to develop. Frequency of contact may facilitate trust, however levels of frequency to establish this trust will vary from family to family depending on their needs. Bjerre et al. (2004) and van Shie et al. (2004) also support the importance of frequency of contact to facilitate relationships. Driving factors in relationship development are an individual’s personality and motivational attributes, acknowledged by Foran and Sweeney (2010) and Carlhed et al. (2003). Seeing each other and connecting with each other creates trust and facilitates openness and contributes to relationship building. These are important constructs to support relationships in EI practice in Ireland.

The conceptual model is also coherent with theories of informal personal relationships (Altman & Taylor, 1973; Kelly et al., 1983;) and models of professional partnerships within disability (Fialka et al., 2012; Miller, 1994). This study discovered a trajectory of relationship development for the child with developmental disabilities, their family and the professionals within the EI relationship. This trajectory, specific to EI disability services, draws on Knapp and Vangelisti’s (2005) model and proposes a new fifth transitioning stage within the EI relationship (Carroll & Sixsmith, 2016a) the published paper in Appendix B. The five stages of the relationship trajectory, (Figure 4), acknowledge the importance of relationships in facilitating positivity within EI practice for children with developmental disabilities (Carroll & Sixsmith, 2016a) the published paper in Appendix B.
The Initiating Stage

This stage is very important as initial impressions can have lasting effects (Knapp & Vangelisti, 2005). Although families are initially partnered with professionals due to exceptional circumstances, the initial encounters become the first steps in the relationship. Within EI, rather than superficial short conversations in personal relationships (Knapp & Vangelisti, 2005), the initiating stage involves lengthy conversations, case history information, and observations by the healthcare professional that meets the family. At the beginning of the EI relationship Fialka (2001, p. 23) pointed out that ‘the nature of the circumstances forces an immediate intimacy that is awkward’. The intimacy of the initiating stage in an EI relationship links theories of both personal and professional relationships together (Knapp & Vangelisti, 2005; Fialka et al., 2012). Families share details thus allowing their lives to be explored by professionals. Successful progression through the initiating stage of the trajectory facilitates the development of trust and awareness. The Initiating stage (Carroll & Sixsmith, 2016a) in the published paper in Appendix B, is the beginning stage of supporting parents as advocates for their children with developmental disabilities by arming them with information, encouragement, and optimism (Miller, 1994). To progress through Stage 1, the first encounter for a family is pivotal and should be a ‘get to know you’ encounter. Parents can share their expectations for their child, how they wish to be involved, and what they want to achieve. The child involved in the encounter can be facilitated to share their expectations, their likes and dislikes, interests and skills. The professional(s) involved in the encounter can share their expectations for the child, how the professionals on the team will be involved, explain the initial team assessment process and share what professionals want to achieve and help recognise that all partners are entering into a relationship that will evolve. Yung (2010) stresses that professionals and families need to have high quality conversations that illuminate the ecology of the child’s family. She suggests the use of an ecomap (Hartman, 1995) as a tool to facilitate these conversations about resources and supports with families (Yung, 2010). Bruder (2010) recognises the importance of the assessment process to identify the child and family needs together with the services and supports required to meet these needs. Successful progression through the initiating stage involves professionals listening to families to find out what their choices are and what their expectations are (Fialka et al., 2012), thus facilitating the
development of trust and awareness. Following the initial assessment within EI, some families will progress to the experimenting stage of the relationship, however others may not. Subsequently these families may transfer to another specialist team and the initiating stage will recommence with a different set of professionals.

The Experimenting Stage

In EI this stage is a deeper one than that in personal relationships proposed by Knapp and Vangelisti (2005) and is linked to the co-operating phase identified by Fialka et al. (2012). Fialka et al. (2012, p. 13) supports the initiating stage stating that the participants enter a new dance as new dance partners not knowing each other’s ‘rhythms, moves and styles’. Stage 3, the integrating stage, involves the participants becoming closer and getting deeper in their relationship through openness and acceptance. To facilitate the integrating stage of the EI relationship it is important to understand how families and professionals want to engage together. This is supported Guerrero et al.’s (2011) view whereby individuals mutually influence each other and that the interpersonal communication is dependent on who is in the relationship. In EI, unlike in personal relationships, the least involved or engaged partner in the relationship may not/is not indicative of the partner with the most influence. The least involved or engaged person in the EI relationship may not be engaging because they do not have the skills to engage, are unsure, tired, or in the early stages of the relationship trajectory. The highlights that importance of understanding the level of involvement a family and can or are willing to take in the relationship. Therefore it is imperative to ascertain the degree of involvement on the continuum of oriented services, which suits a family (Dunst et al., 1991; Carlhed, 2003). Establishing boundaries is very important at Stage 2, the experimenting stage, in the building of the relationship. Progressing through Stage 2 in the trajectory involves sharing information about the EI philosophy that underpins the service, identifying the child’s interests, their learning opportunities, clarifying the roles of all involved in ongoing assessment and intervention, and exploring ways that information will be shared. McWilliam (2010b) acknowledges that the development of a meaningful plan is very important and suggests the use of the Routines-Based Interview (RBI) (McWilliam, 2005). McWilliam (2010b) argues that the RBI is a powerful tool that facilitates the development of functional goals and focuses on establishing positive relationships with the family. When a routine is established between a parent and child there is an element
of success there. Subsequently, the professional wants to build on this success and build on both the child’s and parent’s motivation. Furthermore, by using this RBI (McWilliam, 2005), families and professionals can combine their expertise to guide goals and to understand roles in the intervention planning process. Interactions in different locations would support accurate assessment and intervention of the child and their family and would support parents in their own homes.

The Integrating Stage

During the integrating stage (Carroll & Sixsmith, 2016a) in the published paper in Appendix B, professionals gain a deeper understanding of a parent’s roles, motivation, involvement, and interaction style. Hence, parents learn from the earlier relationship stages what to expect and how they can be involved. In practice, one size does not fit all; hence conversations with families are needed about what all participants understand involvement and engagement in therapy looks like. Subsequent conversations may involve discussing how this involvement and engagement will proceed. The uniqueness and individuality of each family needs to be facilitated. Contracting with families (Lyons et al., 2011) in these initial stages of the relationship is important. This is because it would allow for the sharing of expectations and what every member’s involvement will look like. It could be argued that these conversations should occur in the experimenting stage, however this study highlights that to support the decision-making process, families and professionals need to experience intervention and acquire knowledge. Therefore, using the information developed from the initiating and experimenting stages, the integrating stage can facilitate and implement interest-based child learning opportunities within the context of their everyday activities (Dunst et al., 2010). For children, their families and professionals, feeling acknowledged, being heard and being open facilitates the deepening relationship to progress to the next stage. Bruder (2010) recommends the development of an individualised family service plan (IFSP) for each child and family facilitated by the service coordinator. At this stage of the trajectory, this would allow for children, parents and professionals to collaboratively devise a plan that reflects the child’s and families’ priorities and strengths along with measurable, obtainable goals (Bruder 2010). The application of the relationship stages trajectory as a tool can provide support for family-centred practice through promoting and accommodating individual
participants to take part in the development of a meaningful plan (Carroll & Sixsmith, 2016a (in the published paper in Appendix B); Bruder, 2010).

The Intensifying Stage

In EI this stage involves frequency of contact, which is also a requirement of both Fialka et al. (2012) and Knapp and Vangelisti (2005) models. Through frequency of contact familiarity is fostered. According to Knapp and Vangelisti (2005) personal relationships intensify with relationship negotiation, frequency of contact, deeper connections and trust. This study found that frequency of intervention led to better relationships and facilitated the continuity of care needed to intensify the relationship in EI. This would imply that the relationship is dependent on frequency of contact, a feature of the intensifying stage (Carroll & Sixsmith, 2016a) in the published paper in Appendix B. During the intensifying stage in EI, there is reciprocal interaction learned through experience, resulting in understanding and recognition and respect with the development of close bonds and links between professionals and families. Familiarity fosters anticipation of somebody’s reaction and interaction and you adapt your interaction to suit the situation and the partner in the conversation (Altman & Taylor, 1973).

Relationships between all partners require frequency of contact. In practice, limited therapy time and limited frequency of contact due to organisational contextual factors results in lack of continuity and impacts on meeting needs. Understanding how each partner in the relationship interacts and engages in the therapeutic process will facilitate the required reciprocal interaction. In practice, professionals with increasing caseloads and administration duties may lack the time necessary to become familiar with each other and develop synchronous and collaborative ways of working. In practice for the various family members to be involved in daily family routines and activities they need time to incorporate therapy goals into daily life. They may also need support, for example, the role of a key worker could be expanded to provide the regular professional support and provide continuity of care.

The Transitioning Stage

The families of a child with developmental disabilities will continually require specialist intervention services throughout their lives or at different phases in their lives. They will transition from the EI team to another team. Due to the developmental trajectory of the relationship within EI, the relationship ends when the child reaches six years of age or
when he/she enters the primary education system. The fifth stage the transitioning stage is as important as the initiating stage for all participants in the relationship. Transition is the last component of the developmental systems model (Guralnick, 2001). Ziviani et al. (2010) stress that families want and need to be informed and prepared for key transition events. According to Guerrero et al. (2011) close relationships are irreplaceable, providing fulfillment and emotional attachment. The EI relationship involves interdependent participants and they rely on each other. As families and professionals in EI are interdependent participants, they share resources, influence thoughts and behaviors, grow and learn over time and meet each other’s needs (Kelly et al., 1983).

Creating an understanding and an expectation for children and their families that transitions will happen during their time in an EI service is important. This may happen during the initiating stage where the family will commence with a new professional and this partnership will progress through the relationship development trajectory. The child, their parents and the professionals will progress to form close bonds. Preparation for the transition to primary education is a must. Fialka (2006) suggests that in preparation for the ‘goodbye’ a checklist for the personal dimensions of taking leave should exist alongside the professional checklists. This reinforces the personal nature of the relationships in EI. Rous (2008) developed a set of recommendations for transition for young children with disabilities. However, Bruder (2010) stresses that transitions are continuous for children with disabilities in EI practice and that the field of EI should embrace transition as an ongoing process.

5.2.2 Practice
This study proposes a unique model for EI service delivery in the Irish context. This study found that the context of EI in Ireland is complex underpinned by policy and legislation. This conceptual model can support partnership practice in EI and can make a significant contribution to EI practice in Ireland because it was developed in an Irish setting of service provision and culture. It is conceptually coherent for the context of EI services in Ireland. The conceptual model acknowledges that a synergistic interdependent relationship exists in the EI context. Finding the equilibrium between the restraining factors and the influencing factors will facilitate the desired outcome to be achieved. Concepts within the model explain that the relationship is a journey and acknowledges the steps of the journey and focuses services to consider the rewards and costs to the EI
relationship. When we are considering outcomes to service delivery professionals need to consider how rewarding and enabling the service is to all involved in the relationship. Balancing interdependence in the EI relationship is crucial to support positive outcomes. Understanding the interdependent nature of the complex relationships in EI will facilitate rewards for all involved. Finding this balance requires an acknowledgement of the constructs within the relationship and conversations about process and outcomes for individual families. This balancing act is core to EI practice and regard must be given to the driving and restraining factors within each partnership. The goal of the relationship is one where the rewards exceed the costs. In order to meet this goal, attentive consideration needs to be given to the profile and influence of each individual within the relationship. This would involve finding a balance between parent need and professional goals for the child, between parent commitments and professional scheduling, between child’s needs and family needs, and between child’s needs and professional goals. The concept of the relationship trajectory is paramount and how the position of the individual on this trajectory influences their interaction, expectations and level of involvement. The concepts of familiarity, synchronicity and togetherness become evident as the relationship progresses. This research proposes considering the relationship stages as momentous in the development of EI relationships between partners. Figure 6 indicates how the relationship trajectory can be facilitated in practice. In practice, a service is guided by its context, organisational systems, policies and procedures.
## Discussion

1. **Awkward intimacy**
   - ‘Getting to know you’
   - Quality Conversations
   - e.g. Ecomap
   - Listening
   - Supporting
   - Encouraging

2. **Roles**
   - Boundaries
   - Understanding service, interests and ways to share information
   - e.g. Routines Based Interview

3. **Closeness**
   - Deeper understanding
   - Flexibility
   - Accommodating differences
   - Meetings
   - e.g. Individual Family Service Plan

4. **Frequency**
   - Familiarity
   - Empowering
   - Reducing dependency

5. **Planning for all in relationship**
   - e.g. Checklist for personal dimensions of taking leave

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**Figure 6: A Trajectory of Relationship Development for Early Intervention Practice**
In practice, understanding the role of each partner in the relationship, their extended roles, involvement, expectations and motivations will lead to rewards and enabling outcomes to the EI relationship. It is important for service providers and families to understand how each partner influences the relationship. Awareness of roles allows for clear boundaries and decisions. Unclear roles or inaccurate perceptions of roles impacts on boundaries and will subsequently impact on interactions between all involved. Clear boundaries are interdependent with clear roles and may influence interactions and expectations. Providing time to get to know someone and negotiate will facilitate an understanding of expectations and allow participants to find a balance in the relationship. The continuity of care and the continuous sharing of information between the professionals, the parents and the children will facilitate trust and shared decision-making and may subsequently reduce conflicts and discord that may otherwise occur. Listening to children’s perspectives can influence how professionals and families collaborate to devise a plan to reflect the child’s and families’ priorities and strengths (Bruder, 2010). Including children’s perspectives can support the implementation of interest-based child learning opportunities within the context of their everyday activities (Dunst et al, 2010).

While the relationship trajectory for practice is presented as a linear process (figure 6), each participant in the relationship may have different restraining and driving factors at different stages of the trajectory. Furthermore, Turnbull et al. (2007) suggests that a family’s level of involvement may change as their circumstances change through the family life cycle. Difficult times or the emotional stance of parents can play a part on their level of interaction in the relationship. Professional must understanding that parents have other commitments and may lack flexibility due to these commitments. Rolland (1994) argues that a family-based intervention would consider the different points in the disability trajectory and the consequent impact on how the family is able to function and the differing demands on each person. This conceptual model accommodates individual circumstances and components of the theory; for example, the relationship development trajectory model (Carroll & Sixsmith, 2016a) the published paper in Appendix B, will facilitate partners in the relationship.
Bruder (2010) believes that outcomes for EI practice include the child being socially competent and seen as an active learner supported by knowledgeable and resilient parents. Within a family-centred practice one of the outcomes is empowerment of parents and children (Dunst, 1995) and if empowered they will not feel overly dependent on professionals (Andrews & Andrews, 1986). For children, their parents and professionals being empowered will guide the progression to the next stage on the developmental trajectory. Furthermore, progressing through the developmental trajectory will allow for all participants to reach the transitioning stage feeling empowered, looking forward to the future and ready for another journey with a new team and onto the next phase of the child’s life. The conceptual model, which is coherent with existing conceptual and theoretical knowledge, can make a significant contribution to support EI practice.

5.2.3 Policy
This research provides evidence from the stakeholders’ perspectives about the meaning and experience of EI services in the Irish context. There is little previous work on the processes that facilitate EI services, hence this research provides original findings and answers the call to provide clear conceptual models to support families (Turnbull et al., 2007). There is recognition that EI services vary substantially across the world (Ramey & Ramey, 1998). Guralnick (2008) suggests that his Developmental Systems Approach has provided an international consensus related to inclusion, cultural competence, and evaluation. Carroll et al. (2013) in the published paper in Appendix A, support the use of this framework in Ireland and identified that some components of the framework are distinguishable in Irish EI service provision. The conceptual model of constructs found in this study provides an explanation from multiple perspectives about EI services in the unique Irish context, which can inform service development in Ireland and across the world. Better Outcomes Better Future (Government of Ireland, 2014) is a policy framework currently guiding government and interagency collaboration for children and their families. This policy framework sets out five outcome areas for children and families, two of which are: to be achieving in all areas of learning and development; and to be connected, respected and contributing to (Government of Ireland, 2014). A priority area of this policy is to better support parents and families
through prevention and EI programmes. The conceptual model emerging from this study, can inform the implementation of this policy framework as it supports the collaboration of children, families and children with disabilities.

The national programme, ‘Progressing Disability Service for Children and Young People’, is implementing structures for disability services within the changing primary health care context (Health Service Executive, 2009). The guiding principles for disability services to ensure best possible outcomes for children are: clear pathway, co-ordination, team working, equity, and being child and family-centred. The conceptual model of constructs can facilitate best practice and support integrated care, thus supporting the work of the National Co-coordinating Group for this national programme. This conceptual model could underpin national EI services, which would provide uniformity. This would then allow international comparative analysis in the future. This study also facilitated the inclusion of children with disabilities to have their voice heard within the research process on their EI service (Carroll & Sixsmith, 2016b, the published paper in Appendix C). This study provides an example to support the recent Irish Government Strategy (Department of Children and Youth Affairs, 2015) which is aiming to ensure that children and young people have a voice in decisions that affect their lives. In Ireland we need to be mindful of policies and legislation to support practice and strive to develop the capacity of professionals to implement changes and to develop capacity of parents to become coordinators of their child's care.

5.2.4 Methodological
This study involved children with disabilities and their families, thus improving the quality of the research by facilitating them to share what is important to them. The research provided children with disabilities and their families a voice in an academic context about their range of experiences. The methodology used captured the heterogeneity and complexity of family views and experiences. It also provided a voice for service providers to share their experiences and perceptions of the service they provide in the changing healthcare environment. Involving children with disabilities to share their voice was challenging and the researcher explored ways to facilitate their participation. Young children with developmental disabilities are a heterogeneous group with complex speech, language and communication needs.
Rabiee, Sloper, and Beresford (2005) argue that they may be excluded from research studies due to lack of appropriate data collection methods. Christensen (2004) advocates that research with children should be an on-going process so that the researcher can take account of the context within which children can respond. However, the author did not observe the children while they wore the SenseCam, a method Christensen (2004) emphasises as important to establish a trusting social relationship with children. Clark and Moss (2001) claimed that their method could be adapted for use with children with disabilities, however they do not specify how. However, their approach could be perceived as positivist as they use photo counts and indicate that during observations the researcher should adopt a detached style.

Consulting with young children with disabilities requires the listener to use communicative techniques and interpretative skills (Dickens, 2004), which can have a substantial influence on communication (McCormack et al., 2010). This research suggests that the techniques and the skills of the researcher were an integral factor in the successful engagement of the children with disabilities in this research. The researcher was a speech and language therapist, with a professional qualification in the nuances of communication facilitation (American Speech-Language and Hearing Association, 2008). Carroll and Sixsmith (2016b) the published paper in Appendix C, argue that the researcher was not only a competent researcher but also had clinical competence to actively engage with the children in ways that another researcher may not. The researcher’s specialist expertise and experience in working with children with disabilities facilitated the interactions and allowed the interactions to flow as the researcher understood sign language and made consistent attempts to interpret the child’s communicative intentions, which is supported by McCormack et al. (2010) and Dickens (2004). Carroll and Sixsmith (2016b) the published paper in Appendix C, suggest that listening to young children with disabilities has the potential to positively influence the services they receive. Their inclusion in EI research provides a more truly holistic approach to EI practice.

Based on the diversity of how EI disability services function and the heterogeneity of service users, qualitative exploration was needed to understand the processes in the context of EI from the perspective of families and service providers (Sandall et al., 2002). Data analysis can be recognised as a weakness in Case Study design but a strength in Grounded Theory. However, qualitative analysis
has long been criticised for a lack of explication in the literature, a criticism that can be leveled at the combination of approaches such as that used in this study. This study demonstrates that with the provision of a clear rationale supported by the literature and rigorously applied to the research process and a clear audit trail, combining approaches can constructively contribute to qualitative inquiry. The complexity of the research context in this study is supported by the need to include numerous theories in the development of the conceptual model. The central point of a Grounded Theory, the core category, integrates all of that theory’s various aspects and acknowledges the role of the researcher. Strauss and Corbin’s (1998) model of Grounded Theory provided clear procedural steps for data collection and analysis. Therefore, Strauss and Corbin (1990) describe theoretical sensitivity as the “awareness of the subtleties of meaning of data” and elaborate that “one can come to a research situation with varying degrees of sensitivity depending upon previous reading and experience with or relevant to that area” (p. 41). Grounded Theory research facilitates theory building that is, ‘faithful to and illuminates the area under study’ (Strauss & Corbin, 1990, p. 24). The use of multiple data sources not only enhances data credibility (Patton, 1990), it adds multiplicity of perspectives and “truths” (Strauss & Corbin, 1998; Corbin & Strauss, 2008). In adopting a Ground Theory methodology the researcher acknowledged her past experiences working in an EI service as a Speech and Language Therapist, which provided her with a deep level of insight into the research area of EI.

5.3 Limitations

While the study has documented strengths it is important to acknowledge limitations. The study was based on one team in a particular cultural environment, and the author acknowledges this as a limitation. However, clear explanation and transferability were the goals when using Strauss and Corbin’s Grounded Theory, with the theory being the researcher’s interpretations of the participants’ perspectives (Strauss & Corbin, 1994). The similarities across participants emerged more than the differences and therefore there is the potential for more explicit links to be made between the data generated with the children and their relevance for EI services. It could be argued that the case was a self-selecting case as five teams were contacted and only one accepted the invitation. The child, parent and professional
participants were selected by the team leader, which may have influenced the selection. The team who participated in the study was part of a non-governmental agency that placed research as a priority in the delivery of their services. This priority may have allowed the participating team to allocate time to be involved in the study. The positive outcome of the study may have also have been attributable to the motivation of all participants, especially the motivation of the parents, who facilitated the inclusion of their children in the research. There is also the potential that the parents of the children who took part were more ‘tuned in’ to their children. The data collection process with the child participants could be criticised for being non-standardised and that the analysis of the findings are the researcher’s interpretations and may not take account of the child’s own insights. The data collection process of the study was limited by the time that was allotted to collect the data with only five children taking part in the study, and two wearing the SenseCam.

As with any research study issues of rigour and trust are important (Patton, 2002). This research was conducted in a rigorous manner supporting the trustworthiness of the conceptual model, through the use of an audit trail, peer review, persistent observation, prolonged engagement and use of multiple perspectives. Hence, the substantive theory illuminated from the study is one that is rigorous and trustworthy. This is the first iteration of the conceptual model and it needs to be explored and developed further by other people. It needs to be tested with other team profiles, within other team contexts and with larger samples of children and parents and professionals. The value of the substantive theory is that other people can use it and it recognises the centrality of family (child and parent) in EI in the Irish context.

5.4      Dissemination

A multi-faceted approach was used in disseminating the findings to different stakeholders. The process of dissemination included dissemination to participants themselves, managers within the non-governmental agency, and both the academic and professional practice community both in Ireland and internationally.
5.4.1 Stakeholders

- For the professional participants, and to all the professionals in EI and managers within the organisation, an oral presentation of the study was presented in November 2014. An overview was provided in a handout on the presentation (Appendix P) which was also given to each person who attended the presentation.

- For family participants of the research, and to all families involved with the EI team a factsheet (Appendix Q) was distributed by the organisation on the researcher’s behalf.

- An executive summary (Appendix R) and the published papers (Appendices A, B, C) were also sent to the organisation.
5.4.2 Research and Practice Community

Three peer reviewed publications in international journals (Appendices A, B, C) where the researcher was the primary author of each paper.


Three peer reviewed presentations at international conferences


* Two peer reviewed presentations at national conferences


- Three Published Articles (Appendices A, B, C) were sent to the Project Coordinator of the Progressing Disability Services for Children and Young People in June 2016.
- Meeting with the National Leads of the Progressing Disability Services for Children and Young People.
- Developing a policy briefing paper based on the research findings.
- Teaching on the Masters in Early Intervention at Trinity College Dublin.
- Teaching on the undergraduate Speech and Language Therapy professional qualification course at NUI Galway.
- Member of a Management Committee formulating a COST Action proposal for Early Intervention across Europe.
- Presentation scheduled at the Health Promotion Research Center Seminar Series at NUI Galway.
- Co-editing a book focusing on participation of children with disabilities in EI.
- Writing a scoping review paper of EI services in Ireland.
- Writing a synthesis of theories paper to unpin EI.

5.5 Implications

The trajectory of relationship stages can be used as a tool to provide an enhanced focus to all involved by helping all participants recognise and explain where they are on the developmental journey in EI and where they are going. The model is developmental in nature and it is important that participants go through each stage within their EI relationship. Having explicit awareness of the relationship stages will help children, their parents and professionals understand that it is a developmental journey from initiation to transition. For the professional, understanding the stage(s) a child and their parents are at on the relationship journey within EI will influence and facilitate a deeper understanding of family needs and expectations. In turn, this recognition will influence the professional’s interaction with the family. Subsequently, fostering closeness and authenticity in the
relationship as well as supporting the problem solving and decision-making, which are key ingredients to support relationships (Lee et al., 1990; Summers et al., 2007; Edelman, 2004).

Hearing the voice of children is vital in order to understand their experiences and to maximise their participation and that of their families (Department of Health and Children, 2000; Government of United Kingdom, 2014; Department of Children and Youth Affairs, 2015). Further research is warranted to include children with disabilities in sharing their experiences of services alongside parents and professionals to develop research within the field of EI. The importance of facilitating research ‘with’ children rather than ‘on’ children is increasingly recognised and promoted. Systems can make this participation in research activities a reality through the use of, an asset based participatory methodological approach, a variety of data collection tools and a skilled interviewer in the nuances of communication facilitation. The research is valuable in terms of adding to the evidence base for researching with children. There is opportunity to use the SenseCam with more children extending the time where families can have the camera to use during other daily activities, to ensure that the images are representative of a child's life. The use of a variety of tools, combined with parent expertise and the skills of the researcher, allowed the children to give a picture of their skills, needs and interests. This process helped identify what motivated the children, identified their capacity to make decisions and explored their interactions in their home context. Using multiple methods to gain an understanding of children in the EI context and their contribution the relationship is key to positive outcomes to the relationship. The UN’s (2015) sustainable development goals set five core actions, two of which state to develop the capacity of early childhood professionals and to support the inclusion of children. The study supports the inclusion of children with disabilities in research to inform the development of a conceptual model. All professionals within EI have skills to work with young children with disabilities. Speech and Language Therapists can contribute to these skills where children have complex communication needs. The ideology of EI is participation of children in their everyday activities and in research. The skills of the Speech and Language Therapists lend themselves to facilitate their participation and to facilitate other professionals engaging with children with complex communication needs.
Further research is required to test this conceptual model and its constructs within other EI teams in the country and also within other teams internationally.

The implications of the dissemination process have supported the ongoing development of the EI service that was involved in this study. The dissemination at conferences both nationally and internationally has helped inform clinicians. The publications in peer-reviewed journals provide the academic field and practitioners with the evidence to support decision-making. The context of EI in Ireland is complex. The conceptual model emerging from this study supports the evidence base within the Irish context has the potential to inform national policy and guidelines. Because the concept of working in inter-disciplinary and trans-disciplinary EI teams is relatively new in Ireland there is an urgent need to underpin guidelines for practice with contextual evidence. Irish polices now exist to support the development of EI services. The findings of this study provide a conceptual model from practice to support policy. The constructs could be used to support the development of standards or guidelines for EI practice. These could also be used to inform quality indicators for practice. In Ireland, clear measurable goals for EI services Ireland together with strategic and operational plans to support the national policies. The findings can underpin a common framework with common constructs to scaffold the complexity of EI practice across Ireland and support the progression of involving families in the delivery of services.

The findings from this study provide evidence, in the form of a conceptual model, to support the Government’s commitments to provide quality and informed practices for children with disabilities (Government of Ireland, 2014). The conceptual model provides a tool to support professionals working with families and the study ensured children were supported to express their views. The study also brought focus on transitions within EI practice. Children in the study were facilitated to express their views in a safe and inclusive way and their views were listened to. Their inclusion supports the Department of Children and Youth Affairs (2015) strategy, which focuses on a rights-based approach to involve children in decision-making.

According to Lynham (2002) an informed conceptual model ‘provides an initial understanding and explanation of the nature and dynamics’ of a phenomenon (p. 231). Disseminating the findings from this study will allow policy makers and
managers to understand the processes that were illuminated by this study. However, the author is aware that there needs to be planned steps to inform EI practice in Ireland. Van de Hen & Johnson (2007) argue that there is a knowledge transfer problem, a gap between theory and practice. Lynham (2002) states that there is a relationship between theory and practice to application. Acknowledging that conceptual models illuminate research on practice Lynham (2002) suggests that further studies are needed to confirm or reject a model. Subsequently, an application phase can confirm the usefulness of the model in practice. Refinement and development of the conceptual model would be ongoing. McWilliam (2016) suggests four implementation stages for applying a model to practice. Firstly, the implementation team would need to explore the readiness of a service. Secondly, the implementation team would acquire the resources needed to support the implementation. The third stage is where the implementation is supported at a practice level, an organisational level and at a system level. McWilliam (2016) suggests that for full implementation more than 50% of people are using the innovation with fidelity and good outcomes.

5.6 Recommendations
The research findings from this study have the potential to facilitate the ongoing development of EI practice in Ireland.

The author recommends that:

1. EI teams understand the key factors, which support and hinder EI practice in order to support positive outcomes for the child and their family.

2. EI teams understand and use the Trajectory of Relationship Stages, which will support positive relationships between professionals, children and their families, thus positively influencing the outcome of EI practice. The application of the relationship trajectory as a tool, within Irish family-centered practice, would allow an understanding of each individual participant’s motivation to participate.

3. EI teams provide opportunities for children with developmental disabilities to participate in their service through professionals listening to them in everyday practice and to support their inclusion
in research. The knowledge and skills of the Speech and Language Therapist in EI can be recognised to support other team members to make this participation a reality.

4. Training for EI professionals and families to support family-oriented practice and shared decision-making.

5. Directors of services and policy makers use the contextual evidence to support national best practice guidelines.

6. EI services need to develop strategic and operational goals for practice together with practice quality indicators.
5.7 Conclusion
To conclude, the conceptual model is a generic model, and can be used as a tool with potential transferability to other EI programmes. This conceptual model is all-inclusive, combining the views of children, parents and professionals. The model is a shared model for all involved in EI disability services and it respects individuality. Equipped with the knowledge that each person in the relationship can influence the relationship combined with an awareness of what the restraining factors are for each individual, the EI relationship journey can begin, progress and end smoothly for children with disabilities. Recognising and acknowledging where each participant is on the relationship development trajectory will facilitate the development and progression of the relationships. The model highlights the importance of transitions in EI. The findings of this study advocate for a partnership approach between children, parents and professional in both research and intervention (Dunst et al., 2007; Carpenter et al., 2004). This study supports a way to inclusion, for togetherness, for partnership and makes participation of young children with disabilities and complex communication needs a reality. Through this research service providers and families shared information that can augment EI service dimension and provide contextual evidence to support better care, improved services and further health research in Ireland. At a practice level professionals and families need to support each other in the shared decision making process within family-oriented practice. All stakeholders, professionals, families and children with disabilities need to work collaboratively acknowledging the level of engagement, commitment, skills and knowledge each person brings.
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Appendices


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- Provided final approval of the version to publish.
The Progression of Early Intervention Disability Services in Ireland

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**ABSTRACT**

The Republic of Ireland is an island situated in North West Europe inhabited by 4.6 million people with 2.8% aged between 0-4 years with a disability (Central Statistics Office, 2012). The Irish Government funds the Irish health services, which in turn directly and indirectly funds disability services. Education and Disability legislation have developed in parallel with an apparent increasing congruence with both moving towards a rights based approach. Today, Early Intervention disability services are delivered by both statutory and non-government agencies with wide variation. There is no national consistency in service provision. Some components of the Developmental Systems Approach can be discerned in Irish service provision and these include: screening, access, comprehensive interdisciplinary assessment and early childhood programs. However, assessment of families, development and implementation, monitoring and outcome evaluation, and transition planning are not as identifiable. Guided by legislation and organisational restructuring, Early Intervention provision in Ireland is in a state of flux with an emphasis on developing national uniformity of family centred Early Intervention services.

**Key Words:** Ireland, children, disability, early intervention services.
Introduction

This paper presents the historical context of the development of the Irish health services, focusing on disability services for children to provide the background to the structure and activities of Early Intervention Services as they are configured today in the Republic of Ireland. Current legislation underpinning service provision is reported from both a health and education perspective with reference to the current status of services for children with disabilities under the age of 5 years. The applicability of components of the Developmental Systems Approach (Guralnick, 2001) to Irish service provision is explored and finally future recommendations for service improvements in Ireland are made.

1. History of early childhood services.

The industrial revolution in the early to mid-nineteenth century is often cited as a pivotal time for people with disabilities in western societies. Prior to this they were not segregated from the rest of society (Quinn & Redmond, 2005). In Ireland in the 18th century developing health and welfare provision was directed at the ‘sick poor’ on a charitable basis with philanthropic and voluntary funding and support (Harvey, 2007). Overtime, the sick poor were divided into those poor perceived as worthy of support, the so called ‘deserving poor’ which included orphaned children and people with disabilities, and the ‘undeserving poor’. Service provision in terms of health, welfare and education developed, albeit slowly, with an increasing role played by religious orders and the State gradually emerging as a service provider (Considine & Dukelow, 2009). In Ireland, from the mid-nineteenth century, people with disabilities outside the home environment were supported under the Poor Law, predominantly in workhouses. This is in contrast to many other western countries. It was not until the early twentieth century that particular provision was made for people with disabilities in specific residential institutions (Quinn & Redmond, 2005). In the 1920s, with the founding of the Irish State, funding was limited and health services were not a financial priority (Harvey, 2007). There was continued reliance on religious orders and voluntary bodies for the
provision of disability services for children through residential homes and special schools (Sweeney & Mitchell, 2009).

In parallel, the concept of a universal national health service first emerged in the 1940’s (Harvey, 2007). The afore mentioned financial constraints coupled with opposition from the medical profession, Catholic Church and Department of Finance resulted in the incremental development of a universal health service over the latter half of the twentieth century (Harvey, 2007). In 1966, the Public Health Nursing service was introduced. This amalgamated the domiciliary nursing service, midwifery and district nursing services provided by local authorities and non-government agencies (National Council for the Professional Development of Nursing and Midwifery, 2005). A universal child public health service was offered with Public Health Nurses (PHN) attending “to the public health care of children from infancy to the end of the school going period” (Department of Health and Children, Circular No. 27/66, para 7).

In the 1970s, services for children with disabilities were transformed by the organisational reconfiguration in both public health and disability services. Public and political disquiet and a belief that community care was more cost effective, resulted in a shift from large institutional care to smaller community settings (Quinn & Redmond, 2005). Over the latter half of the 20th century secular non-government agencies, such as, Enable Ireland (originally Cerebral Palsy Ireland), were established in response to expressed need. The Health Act (1970) changed the organisation of statutory services from local government at county level to grouping counties into eight administrative Health Board areas. In the early 1990’s, The Needs and Abilities Report (Government of Ireland, 1990) made a number of recommendations for the development of disability services and public health services nationally. It highlighted the need for community healthcare personnel, such as Public Health Nurses to receive training in the screening and detection of developmental disabilities. Furthermore, it asserted that regional multi-disciplinary Early Intervention
teams should be available to provide specialist services for infants and young children with developmental delay.

In 2000, the National Children’s Strategy outlined six operational principles to guide services for children, which to some extent mirror aspects of Guralnick (2001) and Blackman’s (2003) conceptualisation of Early Intervention service delivery. The need to establish a whole-system approach to delivering health care in Ireland was highlighted by the Health Strategy (Department of Health and Children (DoHC, 2001a). This strategy is based on four principles: equity, people-centeredness, quality and accountability. In 2001, the Primary Health Care Strategy was also launched (Department of Health and Children, 2001b). This strategy was based on a population approach to healthcare with the aim of meeting 90-95% of the needs of the Irish population within the primary healthcare setting. As a result of the Primary Health Care Strategy the development of multidisciplinary primary health care teams commenced.

On foot of the Heath Strategy (DoHC, 2001a) and the Primary Health Care Strategy (DoHC, 2001b), the Prospectus Report (DoHC, 2003) outlined the reconfiguration of the health boards into four administrative units under the control of the Health Service Executive (HSE) (Harvey, 2007). This organisational framework is again under review with a move towards clinical directorates, which will encompass a wide range of services, including personal and social services for people with disabilities (O’Shea, 2009). The uncoordinated and unstructured historical evolution of disability services coupled with the influences of a number of different organisations, with different philosophies of care, will influence the unified vision for the national health service.


In Ireland, the education and health sectors for children with disabilities under 5 years have developed along separate traditions (European Agency for Development in Special Needs Education, 2010). Education for children with
disabilities has been described as a ‘neglected area’ until the 1990s (Considine & Dukelow, 2009). At an international level, Ireland is a signatory to both The UN Convention on the Rights of the Child (1989) and the UN Convention on the Rights of Persons with Disabilities (2007) which affirm the right of all children to equal education without discrimination within the mainstream educational system. At a national level, the report of the Special Education Review Committee (SERC) (Department of Education and Science (DES), 1993) brought the concept of integrated education into the Irish context and set out the rationale for early education for children with special needs. The notion of inclusion of children with disabilities into mainstream education was supported by the 1998 Education Act. The White Paper on Early Childhood Education “Ready to Learn’ (DES, 1999) outlined the necessity of a preschool placement as a priority prerequisite, particularly for children with special needs. The Education for Persons with Special Educational Needs (EPSEN) Act (2004) provides the legislative framework for the provision of education for children with disabilities aged between 4-18 years. It is intended to ensure that persons with special educational needs can be educated where possible in an inclusive environment. Special Education needs are defined as a person who has a restriction in their capacity to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability (EPSEN, 2004). The current focus is to find every possible means by which a child with a disability can participate fully in mainstream education and in social and leisure activities. Nevertheless, models of disability in education policy are considered to have fallen short of a rights based approach for all persons with a disability (Considine & Dukelow, 2009).

Issues of health and education policy for children and adults with disabilities were addressed in the Disability Act (2005). The Disability Act (2005) protects the rights of people with disabilities and provides for an assessment of their health and educational needs, and assures appropriate planning will be undertaken on their behalf. In 2006, the Centre of Early Childhood Development (CECDE) made recommendations for practice and policy. They indicated that the National Council for Special Education (NCSE) in
collaboration with the Department of Health and Children (DoHC) should ensure that children aged between birth and 4 years have appropriate multidisciplinary team support with the inclusion of an early educational expert to support the child in early childhood settings.

In 2007, Part 2 of the Disability Act (2005) was implemented providing a statutory assessment system for children less than five years of age. It provided the statutory right for children to have an independent assessment of needs within a specified time frame and a Service Statement outlining the required services. The process is co-ordinated by an Assessment Officer who is employed by the HSE. The Disability Federation of Ireland (DFI) asserted that they are ‘deeply concerned that the operation of the Act is not nearly as effective as it could be’ (DFI, 2010, p. 1). Disability policy has progressed, and while it appears more coherent with a rights based approach than education policy, some have considered it not as robust in this regard as it could be (De Wispelaere & Walsh, 2007).

3. Current status of services

Contemporary services are in a state of change. In 2006, the Office of the Minister for Children was created. This provided national leadership to integrate equality and health and childcare functions in the State. On the 2nd June 2011, a diverse range of services for children, which were the responsibility of a number of government departments were consolidated into the Department of Children and Youth Affairs (DCYA). This brought together a number of key areas of policy and provision for children and young people including the Office of the Minister for Children and Youth Affairs (OMCYA), the National Educational Welfare Board (NEWB), the Family Support Agency (FSA) and the Irish Youth Justice Service (IYJS). The purpose of this extensive merger was to direct the effort to improve outcomes for children and young people in Ireland (DCYA, 2012). There is currently no national policy for universal or specialist Early Intervention services in Ireland. However, a National Early Year’s Strategy is currently being developed by the
Department of Children and Youth Affairs focusing on universal Early Intervention service provision.

To address the ad hoc development of children’s disability services, the Health Service Executive highlighted the need to reconfigure services for children with disabilities (HSE, 2010b) and initiated a national programme ‘Progressing Disability Services for Children and Young People’, in joint partnership with non-government agencies, the Department of Health and Children and the Department of Education and Skills. This Programme, which was launched in 2011, aims to implement the new structures for disability services within the context of the primary care model as directed by the Health Service Executive Reference Group Report (2009). The Health Service Executive Corporate Plan 2011-2014 (HSE, 2011) asserts that the aim of these services is twofold. Firstly, to provide geographically based services, which are timely and accessible for children with disabilities and their families. Secondly, to provide a singular clear pathway for assessment and intervention, with health and education working in partnership, to support children to reach their full potential.

The Standards Framework for the Delivery of Early Intervention Disability Services (HSE, 2010c) was developed in consultation with 100 stakeholders (professionals and families) in Early Intervention. Standard 1.1 of the Framework, it states that the team’s ethos is child and family centered and underpins the primacy of the role of parents and carers in their child’s development (HSE, 2010c). In 2011, the Health Service Executive set out principles to guide services: Bio Psychosocial Model, Equitable, Accessible, Family Centered, Integrated Team Approach, Accountability, Inclusion, Early Detection and Referral, Evidence Based, Evaluation of Outcomes, and Cultural Competence. Hence, the bio psychosocial model is currently the guiding framework for Irish Early Intervention services. The focus of intervention is on the child in the context of their family and considers the influence of the family on the child’s development (Dunst, Trivette & Hamby, 2007).
3. Components of the developmental systems approaches and their applicability to current services in Ireland

a) Screening/Referral

Best Health for Children Revisited (HSE, 2005) identifies Public Health Nursing as one of the key professionals in the delivery of child public health and therefore, ideally placed to identify children with developmental disabilities. Public Health Nurses, with support from other primary care team members, provide the National Child Health Surveillance and Screening Programme to all children under six years of age (Health Act, 1970). The current approach employed by Public Health Nurses to identify developmental delay is through developmental surveillance. This is a longitudinal process, which includes obtaining a comprehensive history, observation of the infant and the elicitation of parental concerns (Rydz, Shevell, Majnemer & Oskoui, 2005). However, this professional subjective assessment of a child’s development has limitations (Rydz et al., 2005). Most Health Service Executive areas include a developmental checklist in the child health record to support the Public Health Nurses in practice. However, Best Health for Children Revisited (HSE, 2005) cautions against the use of such checklists in the determination of the developmental status of the child, as it is not a standardised assessment. The American Academy of Pediatrics (2006) recommends any developmental concerns identified during child health surveillance should be followed-up with a standardised developmental screening tool. A recent national survey of the current practices, in the 32 Public Health Nursing areas, suggests that only 30%, of the 23 areas that responded are using the Ages and Stages Questionnaire (Squires, Twombly, Bricker & Potter, 2009) as an adjunct to developmental surveillance (Institute of Community Health Nursing, 2011).

Children who are identified as at risk of having a delay and/or disability may receive intervention at a primary care level through preventative and health promotion services, for example, Triple P (Sanders, Mazzucchelli & Studman (2003) and local support groups, such as, Community Mothers (Molloy, 2002). Children presenting with more complex needs are referred to Early
Intervention teams in the primary care network (DoHC, 2001b) for more specialist interventions. More specialist parenting programmes may then offered to support parents; for example, the Hanen Parent Programmes such as ‘More Than Words’ (Sussman, 1999) and ‘The Incredible Years’ (Sutton, Utting & Farrington, 2004). Some children are referred for Early Intervention Teams through the Disability Act Assessment of Needs Process. For children who have a diagnosable disability the referral pathway to these specialist Early Intervention services may be more direct. However, the identification of children with global developmental delay continues to be problematic (Marks, Glascoe & Macias, 2011) with many remaining undetected until school-going age (Hall & Elliman, 2003).
b) Access
Variations in access to services exist across Ireland (National Disability Authority, 2011). Access is dependent on the geographic area, the age of the child and types of disabilities or developmental concerns. Regional and county variations in referral/access criteria currently exist. For example, in the Mid West Region, children are accepted who have complex developmental needs requiring input from two or more therapy disciplines within a specialist team (Mid West Disability Services, 2011). In County Meath, a child must present with physical, sensory and/or learning disabilities, developmental delay or be on the autism spectrum and must require ongoing team-based interventions (Early Services Meath, 2008). In counties Longford and Westmeath, children must present with significant delay in two or more areas of development on a standardised tool (Sharif, n.d.). Consequently, accessing specialist Early Intervention services has been identified as stressful, fraught with questions and challenges for caregivers (Foran & Sweeney, 2010; O’Loughlin, Carroll & Caulfield, 2010/2011). In relation to access, the Health Service Executive (2010c) highlighted that consideration should be given to: (a) the needs (that is specialised versus general) and strengths of the child, (b) the needs and strengths of the family, that is: ability to travel, access to public transport and geographical location of the family, and (c) services should not be less if the location is more remote.

When a team receives a referral, there are again variations in pathways of care. There may be a multi-agency forum, for example, Kerry Early Intervention Intake Forum (Enable Ireland Kerry, n.d.) where professionals come together to discuss a child’s needs and design a pathway of care. Alternatively, services may have an intake multi-disciplinary meeting (Limerick Children’s Services, 2009) where referrals are discussed by the team and accepted if the child meets their criteria. To address the variations in access a national working group is working together to develop a single national system with no regional variations.
c) Comprehensive interdisciplinary assessment

As with other aspects of Early Intervention in Ireland the application of comprehensive interdisciplinary assessment varies with long waiting lists for service delivery and disparity in speed of service delivery across the country (Central Statistics Office (CSO), 2010). Although, most geographical areas have Early Intervention teams there is no standardised model of practice for team-based assessment. A comprehensive assessment is the norm in established teams, with coordinated input from the various disciplines as appropriate. A variety of models of team working are used. For example, Enable Ireland North East (n.d.) use an inter/trans-disciplinary model of service and Cederman (2006) found that trans-disciplinary team based assessment is carried out in some areas. Teams may work closely in one location or across different locations. Team composition varies and may include all or some of the following disciplines: physiotherapist, speech and language therapist, nurse, paediatrician, medical doctor, occupational therapist, social worker, psychologist, early childhood educator, family support worker, administrator and dietician. A consultant geneticist and genetic counsellors are available as a national service. Location of assessments may vary between centres, homes, or pre-schools. Following assessment professionals are guided by national best practice guidelines for informing families of their child’s disability (National Federation of Voluntary Bodies, 2007).

The Assessment of Needs Process is working well in areas where Early Intervention services are integrated and where the process is aligned with team assessment and intervention (National Disability Authority, 2011). However, the process has shown that divorcing assessment from intervention can mitigate against providing responsive, family-centered Early Intervention services and supports (NDA, 2011). The requirement of a diagnosis to enter the resource allocation system for school supports and for entry to some discipline specific services, has led to the Assessment of Needs being accessed in order to obtain a diagnosis. Payne and Coughlan (2010) explored staff perspectives of the Assessment of Need process and found that there were inconsistencies in Assessment Officers expectations and requirements; the
process was time-consuming and created pressure; and assessment of need applicants were being prioritised over children on intervention lists. However, children did receive a comprehensive assessment, a Statement of Need and there was consistency in report writing. The National Disability Authority (2011) state statutory guidelines need to be developed to add clarity to the Assessment of needs process and should include any developments from the disability working groups and take account of the views of parents of children with disabilities.

d) Early Childhood Intervention Programme

The Health Service Executive (2010c) state that service provision should be individualised as one size does not fit all and that the needs of each individual and family should be considered. Following comprehensive team assessment, some teams formulate an Individual Family Service Plan (IFSP) (Limerick Children’s Services, 2009; Brothers of Charity Southern Services, n.d.). The plan aims to be directed by the assessment findings, the family’s concerns, priorities, and resources. Ward (2009) found that parents were not involved in goal setting for their child during the initial stages of attending a service. Evidence of inter-disciplinary collaboration and a will to work in an integrated manner with families does exist in Ireland (Carroll, 2011). Whyte and Kelly (2009) found many indicators of international best practice, in the Mid Leinster area, notably the practice of working in partnership with families at every stage of the intervention. Interventions aim to follow a comprehensive plan to meet the needs of the child and the family. Interventions can include building family support, empowering the family, facilitating coping strategies, carrying out specific interventions, and/or teaching techniques and strategies. Interventions may be provided in an interdisciplinary way or as a single discipline, based on different priority/waiting list management criteria. A variety of intervention methodologies are used, for example, individualised or group. Interventions can be home based or centre based. Some services offer a key worker service. For example, Enable Ireland Cork Children’s Services (n.d) highlight that the key worker is a member of the team who supports and helps the parents and is the direct team contact for the family. Following multi-agency partnerships,
managers and parents reported improvements in the provision of responsive, team-based and family-centered services (Jacob, 2011). In other studies, parents reported satisfaction with gaining knowledge, skills and receiving support (O’Loughlin et al., 2010/2011) and when professionals acknowledged their attributes as parents (Ward, 2009). While there was evidence of good practice in Ireland, there were parents who expressed significant levels of dissatisfaction with information and continuity of care (Harnett, Dolan, Guerin, Tierney & Walls, 2007). Carroll (2011) found that parents were unaware of the management of their child’s records, which was a source of concern for parents.
e) Assessment of Families

In some teams, there is a tradition of both health and personal social services working together. Where these services exist a nurse or a social worker commence the initial interactions with families and provide an assessment of family strengths and needs. Quin and Redmond (2003) highlight that while the practice of joint health and social services structures provides for a holistic approach to the child and family’s needs, there may be a tendency to subsume all support into a medical model. Assessment of family strengths and needs are intertwined with the assessment of the child’s needs, with intervention and with the use of Individual Family Service Plans. The Health Service Executive Reference Group Report (2009, p. 15) recognises that ‘having a child with a developmental delay or disability puts significant additional stressors (emotional, practical and financial) on the parents and family. Their needs arising from these stressors must be factored into all interventions and care planning’. The Central Statistics Office (2010) highlighted that families had a mixed awareness of entitlements. However, in another Irish Study, caregivers were found to be aware of and actively using extra community and ancillary services to the Early Intervention team, such as respite care and home help support (Foran & Sweeney, 2010).

f) Development and Implementation of a Comprehensive Programme

Education and health provision for children with disabilities continues to develop in parallel (European Agency for Development in Special Needs Education, 2010). In 2010, the government commenced one year of free preschool education for every child in Ireland. This initiative has enhanced the availability of education services for all pre-school children in Ireland. However, there is little or no provision for children with disabilities who need individual support to access pre-school education. Children with disabilities may be able to access special pre-schools for children with disabilities run by disability organisations or privately run mainstream pre-schools. Interdisciplinary intervention for these children is mainly centre based with sessional interventions within the child’s education setting.
g) Monitoring and Outcome Evaluation

In Ireland, there is no standardised way to assess the quality of early childhood intervention. Although there is no universal team approach, there are numerous documents available to health professionals to facilitate monitoring, self-audit, evaluation and to identify areas for improvement. For example, Checklist for Assessing Adherence to Family-Centred Practices (Wilson & Dunst, 2005), Guidelines for local implementation groups on developing a governance structure and policies for children’s disability services (HSE, 2010a), and the Standards Framework (HSE, 2010c). The Health Service Executive guidelines suggest that to achieve best possible outcomes for children and families: explicit goals and objectives need to be set, responsive to each family’s priorities, regular evaluations and feedback from both team members and families, formal and informal evaluation of functional, clinical and personal outcomes. However, it is important to note that existence of a framework and guidelines does not ensure their implementation (Carroll, 2011).

It is deemed best practice that Early Intervention programs must allocate resources and time to evaluation as an essential way of determining the quality of the services that they provide (Fallon, 2000). A national group is working to develop a draft performance-reporting framework that supports partnership-based programme accountability and performance reporting, with a focus on outcomes for children with disabilities and their families.
h) Transition Planning

Children are discharged from Early Intervention services at 5 or 6 years of age, when they enter formal education. Their developmental and therapeutic services may be transferred to school aged disability teams where they exist. For many children they are referred to the primary care system. Foran and Sweeney (2010) highlighted that the transition from an Early Intervention service to primary education was a major source of anxiety for caregivers. This recent study indicates that the development of standards is required to enhance the smooth transfer for children and their families.

6. Future Recommendations for the expansion and improvement of services in Ireland.

The provision of Early Intervention services in Ireland is inconsistent across the country as a consequence of the historical influences and the ad hoc development of service provision. Ireland is in the process of addressing these inconsistencies. The Health Service Executive is the unifying body directing the vision of geographically based Early Intervention teams across Ireland. The EPSEN Act and the Disability Act provide the legal framework to support this vision. Interdisciplinary working is promoted by government strategies and policies, however the fidelity of the implementation of policy and legislation remains unclear. There is a need to focus on consistency of development through monitoring and evaluating child and family outcomes as well as system outcomes.

At the time of writing, no national Early Intervention policy exists in Ireland and the Health Service Executive organisational structure is in a state of flux. Paradoxically, almost three-quarters of a century after the concept of a universal health service first emerged, the vision of current Irish healthcare policy is to provide a single-tier health service supported by Universal Health Insurance (Department of Health, 2012). Guided by legislation and organisational restructuring, the developing Early Intervention system in Ireland is undergoing radical change. Early Intervention needs to be at the forefront of health and education services, facilitating seamless transitions between universal and specialist services for every child with special needs. The
development of services needs to be supported by a national Early Intervention policy which will ensure uniformity of service provision for each child with a disability in the Republic of Ireland. The future of Early Intervention in Ireland lies in the hands of working groups, implementation groups, researchers, teams and families.


http://www.enableireland.ie/parents/centres/cork/childrens-services


Sanders, M.R., Mazzucchelli, T., & Studman, L.J. (2003). *Stepping Stones Triple P: For families with a child who has a disability*. Brisbane, QLD, Australia:
Triple P International.


Appendix B  

Estimated percentage of contribution to the published paper:

First Author: 70%
Last Author: 30%

Nature of first author’s contribution:

The first author:

Led the writing of the paper and contributed substantially to development of the paper.

Drafted the paper and revised drafts based on the critical revision of the other authors.

Provided final approval of the version to publish.
A Trajectory of Relationship Development for Early Intervention Practice for Children with Developmental Disabilities

Background
Collaboration, through multiple complex relationships between families and professionals, is integral to Early Intervention (EI) practice for children with developmental disabilities (DD). The purpose of this study was to explain the processes involved from the multiple perspectives of all those involved in the team.

Methods: A Grounded Theory methodology was used. The sample included 5 young children with developmental disabilities, 6 parents and 17 professionals from an EI team. In total 31 interviews were carried out. Through an iterative approach to data analysis, the processes of the EI relationship were explored.

Results: The process of the EI relationship emerged from the data. The relationship process happens through an overlapping five stage developmental trajectory which includes: 1) initiating, 2) experimenting, 3) intensifying, 4) integrating and 5) transitioning.

Conclusion: The role of relationships between professionals, children and their parents in successful EI disability services is paramount. The EI relationship is a complex interdependent one which requires a roadmap of explicit stages, which can facilitate all involved in the relationship to work together. This study provides this roadmap in the form of a developmental relationship trajectory. Understanding the key factors, within each stage of the developmental trajectory, supports positive relationships between professionals, children and their families, thus positively influencing the outcome of EI practice for children with DD.

Keywords: Relationship, early intervention, child, disability, grounded theory.

Introduction
The premise of this research study is that while much is known about the value of relationships in family-centred practice insufficient attention has been paid to this in the context of Early Intervention (EI) service provision and practice for children with developmental disabilities. Guralnick (2001) defines early childhood intervention as a system designed to support family patterns of interaction that best promote child development. EI systems involve multiple complex, personal and professional relationships. These relationships may include child with developmental disabilities, their
parents and service providers (Kelly and Barnard, 1999), families and service providers (McWilliam, 2010; Paige-Smith and Rix, 2011). Carpenter (2005) acknowledged that, within a family system, patterns of interaction may vary and is dependent on their support network. Within EI practice, there is an expectation that parents and professionals collaborate and form a partnership, which has been shown to be a potential predictor of the success of intervention (Kelly and Barnard, 1999; Paige-Smith and Rix, 2011; Office of the Minister for Children and Youth Affairs, 2007). Thus collaborative relationships underpin EI disability services (Matthews and Rix, 2013; Bridle and Mann, 2000) and are key to enable the child with developmental disabilities to reach their full potential (Yung, 2010). Therefore, these collaborative relationships require deeper exploration.

Although all relationships are different, Guerrero et al (2011) identify that it is helpful to consider relationships from a developmental perspective. A relationship-based approach to EI involves all domains of development (Weston et al, 1997; McCollum et al, 2001). Guerrero et al (2011) define interpersonal relationships as relationships between individuals who mutually influence each other and share some degree of behavioural interdependence within repeated interactions. Lee et al (1990) define emotional closeness as existing when there is a sense of shared experience, trust, enjoyment, concern and caring in a relationship. Relationships within EI between the child with developmental disabilities, parent(s) and the professional(s) may be defined as close and interpersonal. Within EI research, establishing positive, trusting relationships between professionals and families takes time and their value in intervention is understated (King et al, 1998; MacKean et al, 2005). Understanding these relationships is fundamental and although interpersonal relationship models have relevance within EI practice, they have not yet been considered within EI service provision.

Initially, families may be hesitant and ambivalent about beginning EI services, whereas professionals may be eager to share their expertise (Fialka et al, 2012). Within the family life cycle, transitions such as changes in family characteristics, interaction and function occur (Turnbull et al, 2005). When unexpected changes occur, such as the birth of a child with a disability, parents’ emotional responses to these transitions may vary (Turnbull and Turnbull, 2001). These varied emotional responses may be explained through understanding the four dynamic stages of adaptation for parents where feelings can come and go (Miller, 1994). Rolland (1994) provides a family systems-illness model
explaining that relationships with families are developmentally orientated and interactions change at different points in the illness and disability trajectory.

The concept of children developing in an environment of relationships in early childhood is a fundamental one (Shonkoff and Fisher, 2013). A variety of models exist to explain the developmental nature of relationships within a person’s life. Altman and Taylor (1973) propose Social Penetration Theory, in which self-disclosure increases as people develop their relationships within their life. Knapp and Vangelisti (2005) expanded this theory by identifying five stages, that couples and friends go through to move from strangers to close relational partners. While these models focus on intimate interpersonal relationships, models also exist to explain professional - client relationships. Within the field of disabilities, Fialka et al (2012) propose three developmental stages in the relationship between professionals and families from ‘Colliding and Campaigning’ to ‘Cooperating and Compromising’ to the ‘Creative Partnering and Collaborating’. Although models exist to support our understanding of relationships, none are specific to the unique context of relationships within EI disability services. In essence, relationships are fundamental and understanding the uniqueness of the relationships from the perspectives of all involved will positively inform the development of effective EI practice.

This study aimed to explore children’s, parents’ and professionals’ experiences of EI disability services. Furthermore, the researcher aimed to develop a conceptual model of factors to facilitate and inform EI practice.

Methods
Based on the diversity of how EI services function and the heterogeneity of the client population who use the services in the country where the study took place, qualitative exploration was needed to understand the processes within EI from the perspectives of families and service providers (Sandall et al, 2002; Creswell 2007). A grounded theory methodology was used because the researcher wanted to cover contextual conditions and understand their possible impact on the phenomenon of the study. The use of multiple data sources not only enhances data credibility (Patton, 1990), it adds multiplicity of perspectives and “truths” (Strauss and Corbin, 1998; Corbin and Strauss, 2008). Strauss and Corbin’s (1998) model of grounded theory provided clear procedural steps for data collection and analysis. Two university ethics committees approved the study and the
data was collected in 2012. The ethical considerations included informed consent, opportunity for the child to express assent, confidentiality and opportunity for participants to withdraw at any stage of the research process.

**Participants and Recruitment**

Five EI teams within two regions in the country (one urban region and one rural region) were invited to take part in the study and one team accepted the invitation. The team, in the study, was part of a bigger non-governmental organisation with an active interest in research. The team provided an EI service for children aged from birth to five years with developmental disabilities. This team’s ethos was one of family-centred practice (Dunst, 1995), following the Team Around the Child approach. The Team Around the Child approach is defined by Limbrick (2007) as ‘an individualised and evolving team of the few practitioners who see the child and family on a regular basis to provide practical support’ (p. 3). The professionals had regular meetings called Team Around the Family meetings. A purposive approach was employed to sample the team, which included families and professionals (Creswell, 2007). The gatekeeper, who was the team leader, was asked to select parents, children, between the ages of 2 and 5 years, and professionals based on the criteria that all participants were part of this particular team. Further sampling occurred as categories emerged from the data (Strauss and Corbin, 1998).

The final sample included five children with developmental disabilities, six parents and seventeen professionals. The child and parent participants (outlined in Table 1) were from different families. All families were nuclear families. The professional sample included four Nurses, three Speech and Language Therapists, three Physiotherapists, two Occupational Therapists, one Social Worker, one Care Assistant, one Family Support Worker, one Dietician, one Psychologist and one Team Leader. Thirteen professionals worked fulltime and four worked part-time. Professionals worked on the team between 2 and 15 years (average 5.4 years). Six professionals had worked in EI in other organisations between 3.5 years to 10 years (average 6.9 years).

Insert Table 1 here
Data Collection and Analysis

In total, 31 interviews were carried out. Interviews with the adult participants were semi-structured. Interviews with the professionals took place at their place of work, and parents’ interviews took place in their homes as did data collection with child participants. Multiple methods were used to facilitate the participation of the five child participants, who had disabilities (Authors, 2014). Clark and Moss’s (2001) framework for listening was used to guide the data collection process. The multi-method process involved interactions with each child, use of a Microsoft SenseCam (Hodges et al., 2006), SenseCam images, pictures, Talking Mats (Murphy, 1997), and general observations. Each interview and interaction were audio recorded and notes were taken during and after the observations. The complete transcriptions of each audio recording were imported into the NVivo software package (version 10) to support qualitative analysis. The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging data from the research field. Strauss and Corbin’s Grounded Theory method of analysis helped the researcher to fracture or break the information down into themes and core categories through open, axial and selective coding (Strauss and Corbin, 1998). To establish trustworthiness of the data Lincoln and Guba’s (1985) criteria for qualitative research; credibility, transferability, dependability, and confirmability, was used through strategies such as peer debriefing, peer checking, audit trails and member checks. In keeping with the view of Corbin and Strauss (2008), the findings present the theory with limited quotations in order to explain the conceptual message (p.319).

Results

Two hundred and eighty five codes emerged from the open coding phase. The researcher distilled these codes during axial coding and 15 categories emerged. Through constant comparative analysis, reading and interpretation an understanding that the process of the EI relationship happened through an overlapping five-stage developmental trajectory (figure 1) emerged. This trajectory, specific to EI disability services, draws on Knapp and Vangelisti’s (2005) model and proposes a new fifth, transitioning stage, within the EI relationship. The trajectory acknowledges the importance of relationships in facilitating positivity within EI practice for children with developmental disabilities. The five stages of the relationship are outlined and described.
Figure 1

Relationship Stages in Early Intervention

<table>
<thead>
<tr>
<th>Stage 1: Initiating Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>At the beginning of the relationship parents wanted and needed support and this is an important factor in this ‘getting to know you’ stage. The key elements within this stage for the participants included: referral, suitability, introduction and assessment. There was a referral process to access the EI team, which was a requirement for all families. Suitability for the service required meeting criteria before assessment. In some cases, unsuitability for the service occurred following initial assessment. Referral to the team was dependent on diagnosis; for example, some families joined the team from birth, following a developmental assessment, or transferred in from another team.</td>
</tr>
</tbody>
</table>

Introduction to the team in the study, involved an initial home visit by the team leader. Families and professionals met for the first time at a team based assessment meeting. Parents reported that this was challenging for them as they did not know what to expect and did not know the people they were meeting. Not all parents could recall this event. Single discipline assessments also occurred and some parents, when feeling unprepared, found these challenging also. Parents perceived that the assessment experience was easier when the person conducting the assessments had commenced a relationship with them and their child and when parents understood the reasons behind the assessment. Professionals recognised preparation existed for families for certain assessments, for example, psychological evaluation. |
Stage 2: Experimenting Stage

In the context of EI this stage refers to getting started, developing the relationship development and setting boundaries. Professionals supported new parents to the service and were acutely aware of giving good impressions to families. During this stage, therapy and/or home interventions commenced with the family. Parents did make first impressions of the intervention, team, and professionals. Professionals tried to distinguish between their own professional and personal boundaries when interacting with parents. Both parents and professionals reported feeling ‘awkward’ during interactions.

‘If you are aware of roles and what somebody’s job is then you won’t be confused, you can engage and question appropriately’ (Parent 2)

For professionals, feeling part of the team led to good working relationships and feelings of relevance. For example, being named on a report led to professionals feeling included. Some parents viewed themselves working with the team, whereas others saw themselves as part of the team. At this stage of the relationship all participants made decisions about their level of involvement. Concern and lack of clarity arose at this stage in relation to roles and expectations, for example, ‘Therapists haven’t time to see everyone all the time’ (Parent 4) and it was unclear if professionals were ‘Expecting parents to be therapists’ (Professional 5).

Stage 3: Integrating Stage

During this stage of the relationship, closeness developed between the child, parents and professionals. All participants felt a togetherness where they were not alone, felt united with someone and felt supported to continue the relationship. The participants acknowledged each other and acknowledged the disability. For the professional, this stage facilitated the feeling of being part of the team. Feelings of acknowledgement and acceptance led to sharing of information between professionals. During this stage, professionals also acknowledged parents, their opinions and views and in turn parents and children felt listened to. Furthermore, parents’ acceptance played a role during this stage as a realisation occurred for parents of their child’s level of skill and the level of service being offered. Subsequently this realisation facilitated acceptance of their child’s disability, acceptance of the child’s level of ability and setting of realistic expectations of achievement. Additionally, parents’ ability to accept advice and information also influenced the development of closeness. Professionals highlighted that
some parents attended appointments and ‘disengaged’ emotionally and mentally for different reasons. Some professionals identified that some children ‘disengage’ due to being ‘therapied out’ as a result of engaging with other services outside the organisation. For children, there were mixed feelings about therapy activities. Child 4, was interested in doing all the therapy activities whereas for Child 1, therapy activities were not fun.

Families sharing information and being open, together with professional openness to change, facilitated the relationship. Professionals acknowledged that goal setting needed to be linked to parents' expectations and interests of the child and needed to be realistic. Children shared how they communicated, indicated their interests and shared what activities they were involved in. The children were active participators in their activities. Their level of participation in these activities varied and was dependent on their abilities and on the context of the activity. Being aware of how each child communicated and being able to interpret the child’s communicative signals facilitated interactions within activities and services. The children could show their likes and dislikes and make choices. Parents disclosed to the team leader when they felt unacknowledged in the goal setting process. The Team Around the Family meetings were seen as ‘the glue’ that kept the professionals together, allowing professionals to share information, decide goals, air concerns, discuss issues, and decide a care plan. Parents knew that this collaboration existed; with some wanting to be directly involved while others didn’t. One professional noted that it was ‘a discussion around the family’ rather than a team around the family meeting and suggested that families should be involved.

Stage 4: Intensifying Stage

This stage of relationship development involved families supporting themselves, getting support from their extended families and involved parents supporting other parents. Frequency of contact, along with trust, respect between participants led to good working relationships within the team. At this stage all involved had acclimatised to the relationship and familiarity developed. For child 4, his mother commented that:

‘It (therapy) became very familiar to him. The hello song at the beginning..’

With familiarity, reciprocity was evident whereby all involved worked in harmony with each other, adapting and making changes to accommodate others and themselves. Professionals also made changes to improve the service. Becoming acclimatised to the relationship allowed the realisation to unfold that it takes time for changes to happen. When professionals knew each other well and knew families well, they could anticipate
how the child and their parents would engage and interact. Confining factors to the
intensifying stage in the relationship included: negotiation and continuity of care. The
negotiation involved discussions around scheduling and coordination of appointments
and prioritisation. Negotiation linked to the adaptability of all involved and the influence
of the people involved in this negotiation process. Prioritisation involved discussions
around whose needs and wants come first, for example, parents’ or professionals’, or the
child’s or families? Continuity of care included frequency and consistency of
appointments and service.

There was a willingness to learn and work together and plan together to meet the
child’s needs. Togetherness was very important and for parents ‘knowing’ that the
professionals were ‘behind you, supporting you and helping you’ to meet the child’s needs. The
Occupational Therapists, Speech and Language Therapists and Physiotherapists
recognised that for success within their interventions home support/intervention was
needed and felt confident that the home support provided the opportunities for parents
to carry out the therapy goals. The professional set the goals in relation to their area of
expertise, however, they were embedded in established structures, routines, and child’s
interests within the home. It would appear that this process was inconsistent as it was
‘down to each individual case’ (Professional 8) and ‘dependent on the needs of the child’ (Professional
16).

The professional tried to ‘find a balance’ between expert driven goal setting and
parent driven goals and child’s interests. There were times when some parents felt that
professionals shared goals via reports and that the parent was informed of goals. Some
parents were not aware or didn’t know the goals for their child. There was the possibility
that professionals were also unclear, as goals were not detailed explicitly:

'We would make our own kind of observations and try to work out our goals from that'
(Professional 9).

Stage 5: Transitioning Stage

This stage refers to the ending of the relationship, moving on and transitioning
from EI professionals to those in school services as the child enters primary education.
For some parents transitioning from EI was fraught with angst and fear,

'Feeling of being cut off’ (Parent 3)
'Losing a comfort blanket’ (Parent 4)
Professionals acknowledged that it was a challenging time for parents as strong bonds and relationships had been formed between families and professionals. Positivity was also illuminated through the data in relation to the transition from EI, with some participants looking forward to the future. Transitioning also involved moving to another professional within EI, for example, changing professional when a child reached three years created the feelings of ‘lost’ and a parent recalled ‘crying’ when her child was transferred to another professional because they entered preschool education. Some very smooth transitions happened where professionals worked jointly with the child and their family before the transition. However, there were also feelings of uncertainty, anxiety and conflict, which arose for all, involved. Families became familiar with the system and the professional they were working with and then it changed. Some professionals also found it difficult to let a child go when they were moving to another therapist within the service. Planning for this stage within the team featured mainly for professionals as they planned for the transition for the child from the team to primary education. They prepared children through a school readiness programme, planning meetings for schools to help school staff facilitate a child’s smooth transition to education. Parents were also leaving the team and there was little reference to preparing the child’s family for the transition.

**Discussion**

This study discovered a trajectory of relationship development for the child with developmental disabilities, their family and the professionals within the EI relationship. This trajectory was found within a team setting, based in a country, where family-centred practice was the underlying philosophy. Theories of informal personal relationships by (Altman and Taylor, 1973; Kelly et al, 1983; Knapp and Vangelisti, 2005) and models of professional partnerships within disability (Fialka et al, 2012; Miller, 1994) support his trajectory. The pivotal role relationships play in EI disability services is well supported (Carpenter, 2005; Shonkoff and Fisher, 2013).

The intimacy of the *Initiating Stage* in an EI relationship links theories of both personal and professional relationships together (Knapp and Vangelisti, 2005; Fialka et al, 2012). Families share details, allowing their lives to be explored by professionals. This is the beginning stage of supporting parents as advocates for their children with developmental disabilities by arming them with information, encouragement, and optimism (Miller, 1994). Professionals helping families feel prepared and knowing what
to expect, and sharing information will facilitate the development of trust at this stage (Paige-Smith and Rix, 2011). Yung (2010) stresses that professionals and families need to have high quality conversations.

In EI, the Experimenting Stage is a deeper one than that in personal relationships proposed by Knapp and Vangelisti (2005) and is linked to the Co-operating Phase identified by Fialka et al (2012). Uncertainties continue at this stage and all participants further explore and share their expectations, establish boundaries and share roles and responsibilities. Family-centered practice reflects an enabling model of helping, where the skills of families to care for their child with special needs are fostered (Dunst and Trivette, 1996). However, from the data it is unclear if the decision-making process was based on parents’ wishes or on their levels of interaction or engagement in the relationship. This study also found that professionals expected parents to interact in a particular way during intervention. For example, to actively engage in therapy sessions and carry out home activities. Other studies also found that professionals expected parents to take a lead role in their child’s intervention, even if this was not the parent’s wish (Espezel and Canam, 2003; MacKean et al, 2005). Hence, parents may be compromised by their experience of EI. Professional expectation of parent engagement is also highlighted by Matthews and Rix (2013) and Bridle and Mann (2000) highlight that parents are forced to compromise if they wish to engage with services and in turn this can create difficulties with their relationship with their child.

To facilitate the Integrating Stage of the EI relationship it is important to understand how families and professionals want to engage together. Parents and children want to engage, but how they engage may be different. During this stage, professionals can gain a deeper understanding of a child’s interests, skills, interaction style and motivation. Professionals also gain a deeper understanding of a parent’s roles, motivation, involvement, and interaction style. Parents may have different commitments outside the family routine, which may impact their flexibility (Carpenter, 2008; Turnbull et al, 2007). This study highlights that the parents’ level of interaction may be dependent on their levels of motivation, acceptance, familiarity, personality, confidence, and dependency. Previous studies highlight that difficult times or the emotional stance of parents can influence their level of interaction (Rolland, 1994; Turnbull et al, 2005). As Miller (1994) noted when parents are armed with knowledge they can determine their own level of
interaction. Hence, parents learn from the earlier relationship stages what to expect and how they can be involved.

Closeness is key to all relationships (Lee et al, 1990) and is key in the Integrating Stage. People communicate to become closer to one another, to feel less isolated. It could be perceived that the Team Around the Family meetings, used by the professionals in this study, are for the professionals to plan and share information. They perceived these meetings as ‘fundamental’. In turn, the professionals develop closeness. This raises the question if parents knew what was involved and if time was allocated for them to be involved would they too see the Team Around the Family meeting as fundamental to the relationship? Therefore, using the information developed from the Initiation and Experimenting Stages, the Integrating Stage can facilitate and implement interest-based child learning opportunities within the context of their everyday activities (Dunst et al, 2010). At this stage of the trajectory, this would allow for children, parents and professionals to collaboratively devise a plan that reflects the child’s and families’ priorities and strengths along with measurable, obtainable goals (Bruder, 2010).

The Intensifying Stage in EI includes frequency of contact, which is also a feature of both Fialka et al (2012) and Knapp and Vangelisti (2005) models. Edelman (2004) stresses that the impact of EI is dependent on practitioner expertise and on the quality and continuity of the personal relationship between the service provider and the family. Familiarity fosters anticipation of somebody’s reaction and interaction and one adapts their interaction to suit the situation and the partner in the conversation. Altman and Taylor (1973) and Guerrero et al’s (2011) support this view whereby individuals mutually influence each other and that the interpersonal communication is dependent on who is in the relationship. In practice, limited therapy time and limited frequency of contact due to organisational factors results in lack of continuity and impacts on meeting needs. Furthermore, professionals with increasing caseloads and administration duties may lack the time necessary to become familiar with each other and develop synchronicity and collaborative ways of working. Within family-centered practice one of the outcomes is empowerment of parents and children (Dunst, 1995) and if empowered they will not feel overly dependent on professionals (Andrews and Andrews, 1986).

Furthermore, progressing through the developmental trajectory will allow for all participants to reach the Transitioning Stage feeling empowered, looking forward to the future and ready for another journey with a new team and onto the next phase of the
child’s life. The Transitioning Stage within this study equates with the last component, transition, of the developmental systems model (Guralnick, 2001). Due to the developmental trajectory of the relationship within EI, the relationship ends, in X country, when the child reaches 6 years of age or when he/she enters the primary education system. According to Guerrero et al (2011) close relationships are irreplaceable, provide fulfillment and emotional attachment. Rous (2008) developed a set of recommendations for transition for young children with developmental disabilities. Fialka (2006) suggests that in preparation for the ‘goodbye’ a checklist for the personal dimensions of taking leave should exist alongside the professional checklists. As families and professionals in EI are interdependent participants, they share resources, influence thoughts and behaviours, grow and learn over time and meet each other’s needs (Kelly et al, 1983). This study recognises the interpersonal and professional relationships that exist in EI.

Although this research was conducted in a rigorous manner supporting the trustworthiness of the trajectory of relationship development, it was based on one EI team in a particular cultural environment. The team involved in the study was keen to be involved and the team leader selected the participants. The authors acknowledge that the research was carried out in one setting, however suggest that the setting could be viewed as common in relation to the service user group and team relationships. Therefore, the findings of this study could prove to be transferable into other similar settings.

**Conclusion**

The role of relationships between professionals, children and their parents in EI is paramount. The EI relationship is a complex interdependent one which requires a roadmap of explicit stages, which can facilitate all involved in the relationship to work together. This study provides this roadmap in the form of a developmental relationship trajectory. While this model is presented as a linear process, the participants in the relationship may be at different stages of the model or children and parents may be at different stages with different professionals. This trajectory is a generic model, and may be used as a tool with potential transferability to other EI programmes. It adds to the literature on relationship development in the context of EI. This trajectory is all-inclusive, combining the views of children, parents and professionals. Equipped with the knowledge of the relationship stages combined with an awareness of what stage each
participant is at in the relationship will let the EI relationship journey begin, progress and end smoothly. Further studies giving young children with developmental disabilities a voice, alongside parents and professionals, is required to develop research within the field of EI. Further research is required to test this theory of relationship development within other EI teams in the country and also within other teams internationally.
Figure 4: A Trajectory of Relationship Stages in Early Intervention
Table 1: Family Sample

<table>
<thead>
<tr>
<th>Family Representative</th>
<th>Child Gender</th>
<th>Age (years)</th>
<th>Length of time with EI (years)</th>
<th>Referral Age</th>
<th>Diagnosis</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>5 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 2</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 3</td>
<td>Male</td>
<td>4</td>
<td>4</td>
<td>5 months</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Child 4</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Mainstream Preschool</td>
</tr>
<tr>
<td>Child 5</td>
<td>Male</td>
<td>3</td>
<td>3</td>
<td>4 months</td>
<td>Down syndrome</td>
<td>Not yet</td>
</tr>
<tr>
<td>Parent 1</td>
<td>Male</td>
<td>4</td>
<td>2</td>
<td>2 years</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Parent 2</td>
<td>Male</td>
<td>4</td>
<td>4</td>
<td>3 months</td>
<td>Physical and intellectual disability</td>
<td>Special Preschool</td>
</tr>
<tr>
<td>Parent 3</td>
<td>Male</td>
<td>5</td>
<td>5</td>
<td>6 months</td>
<td>Down syndrome</td>
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**Key Points**

Families and professionals involved in EI practice will benefit from viewing their relationship from a developmental perspective.

Both interpersonal and professional relationships are evident in EI practice.

The trajectory of relationship development emerging from this study can be used as a tool to support EI practice.

Understanding the key factors, within each relationship stage, may support positive relationships between professionals, children and their families, thus positively influencing the outcome of EI practice.

Estimated percentage of contribution to the published paper:

First Author: 70%

Last Author: 30%

Nature of first author’s contribution:

The first author:

- Led the writing of the paper and contributed substantially to the development of the paper.
- Drafted the paper and revised drafts based on the critical revision of the other authors.
- Provided final approval of the version to publish.
Exploring the facilitation of young children with disabilities in research about their early intervention service

Abstract
While participatory research approaches are being developed and applied within speech and language therapy practice it is not clear that all children are afforded the opportunity to participate in such activities. This study aimed to explore the involvement of young children, aged between two and four years, with developmental disabilities in the research process, focusing on early intervention disability services. Eight young children took part in this qualitative research. Clark and Moss’s (2011) framework for listening was used to structure the multi-method data collection process. The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging data. Findings suggest that the use of an asset based approach to participation in research, focusing on participants strengths through a variety of data collection tools, used by a skilled facilitator, supported by parental expertise enabled the children to be part of the data collection process. The research highlights that speech and language therapists can facilitate the inclusion of children with disabilities in research activities about their early intervention service they receive. As members of early intervention teams speech and language therapists need to promote their skills in facilitating the active engagement of children with developmental disabilities in research. Thus making their participation in early intervention research, a reality with potential to promote holistic practice.

Keywords
participation, qualitative research, early intervention team, young children, disabilities.
I Introduction

Article 3 of the United Nations Convention on the Rights of the Child established the principle that all children should enjoy the "freedom to seek, receive and impart information and ideas of all kinds" (Office of the United Nations High Commissioner for Human Rights, 1989). Nevertheless, children, including those with developmental disabilities, were virtually excluded as active participants in the research process and were rarely asked to tell their own stories (Grover, 2004). While, the National Federation of Voluntary Bodies (2008) states that the presumption should be of capacity rather than incapacity when involving a person with disabilities in a research process, children with disabilities may experience a double disadvantage because they are young and they have a disability (Dickins, 2004). Gallacher and Gallagher (2008) argue that it is not sufficient to carry out research on or about children and that it is no longer enough to simply reposition children as subjects – rather than objects – of research. Researchers must research for and with children and engage them as participants in the research process (Punch, 2002). It is recognised that children have different experiences and knowledge to adults (Christensen and James, 2008; James and Prout, 1997) and that we cannot rely on adult proxies to give valid accounts of children’s experiences (Beresford, 1997; Markham and Dean, 2006; Markham et al., 2009). Hence, participation of children in research is essential, supporting the view of children as competent social actors, with their own agency and voice, acknowledging children as experts of their childhood (Carter, 2009).

By promoting and facilitating children’s participation in research we are advancing childhood research, adding to research generally (Tisdall, 2012) and responding to our ethical responsibility to explore ways to make children’s participation a reality (Merrick, 2011). In this article, the authors share the results of a research study, which explored the involvement of young children with developmental disabilities in research through the application of a variety of tools. We argue that the SLT as a member of an early intervention (EI) team has a unique role and skill set to facilitate children with disabilities to participate together with their parents, in research.

1 Involving Children with Disabilities in Research

Research is gradually emerging involving school-aged children with speech, language and communication needs (SLCN), (Lyons et al., 2013; Markham, 2011; Merrick and Roulstone, 2011) and young children with SLCN (Press et al., 2011; Roulstone et al.,
2013). Although, leading researchers in the field promote the facilitation of children with disabilities in research (Franklin and Sloper, 2006; Sloper and Beresford, 2006; Tisdall, 2012; Whitehurst, 2006), there is a scarcity of research involving young children and school aged children with developmental disabilities. Within the field of disabilities, research is also developing to facilitate the participation of school-aged children with disabilities (Beresford et al., 2004; Mitchell and Sloper, 2011; Porter et al., 2011) with one research study involving young children with developmental disabilities (Paige-Smith and Rix, 2011). Rabiee et al. (2005) suggest that the exclusion of children with developmental disabilities, in research, may be related to the lack of appropriate data collection methods to facilitate their inclusion. In studies to date, multiple data sources have been used to record and represent the children’s everyday lives, including Baby Cam (Press et al., 2011), observations, interviews and KiddyCam (Roulstone et al., 2013), narrative observations and photographs of daily events (Paige-Smith and Rix, 2011). Research including young children with developmental disabilities is warranted both internationally and in the country where the research took place. Research focusing on data collection methods to support their inclusion is necessary to progress this agenda forward.

Dickins (2004) recognises that listening to and consulting with young disabled children, with complex needs, requires the listener to use communication techniques and interpretation skills. Participation of a heterogeneous group of young children with developmental disabilities requires the researcher to use an open and flexible approach in the use of different research tools to aid communication (Franklin and Sloper, 2009; Kelly, 2007; Mitchell and Sloper, 2011; Paige-Smith and Rix, 2011). Although we cannot rely on adult proxy reports of children’s experiences alone (Markham et al., 2009), it is important to recognise that parents are adept interpreters of their child’s signals (Press et al., 2011) and that the skills of speakers and listeners influence successful communication (McCormack et al., 2010). In family-centred practices, the family is recognised as the expert on the needs of the child (Trute, 2007). Recognising parents’ expertise in early intervention and responding to parents’ needs and wishes is important for building relationships with parents (King et al., 1998; McWilliam et al., 1998; O’Neil and Palisano, 2000). Therefore, the roles played by the parents and the researcher, in the research process, need to be valued and supported.
2 **Context of Study**

Designed to support family patterns of interaction that best promote children’s development, EI services have long-term benefits for children and their families (Guralnick, 2005). For children with disabilities and their families, access to effective EI services, within the first five years of life, is critical to the child’s development (Guralnick, 2011). Within the context of the current study, EI services for children with disabilities are provided by multidisciplinary teams to children from birth to 5 years who are experiencing significant difficulties in two or more areas of their development (Carroll, Murphy and Sixsmith, 2013). The way that teams function varies across the country. Teams typically comprise of families, parents and children with disabilities, and a variety of professionals, including Occupational Therapists, Physiotherapists, Speech and Language Therapists (SLT), Nurses, Psychologists, Social Workers, Family Support Workers and in some teams, a Team Leader.

The country’s EI services, underpinned by the bio psychosocial model, must be family centred, integrated and inclusive (Health Service Executive, 2011). The bio psychosocial model proposes that health and wellness are caused by a complex interaction of biological, psychological, and sociocultural factors. This model provides a framework for EI team interventions. The focus of integrated EI services is on the child in the context of their family and considers the influence of the family on the child’s development (Dunst et al., 2007). This family-centred approach is also advocated in SLT service delivery (McLeod and Threats, 2008). An approach to intervention that is both family-centred and strengths-based helps families feel more confident and comfortable in supporting their children’s development (Wilcox, 2001). The American Speech-Language-Hearing Association (ASHA) (2008) highlight that EI services should be ‘developmentally supportive and promote children’s participation in their natural environments’ (p.3). For children with disabilities, participation in these activities is dependent on their skills within communication, motor, social and emotional developmental domains (Wilcox and Woods, 2011). Blackman (2003) emphasises the key role played by families as a success factor of interventions. The Health Service (2011) stress that services must be accountable, evidence based and evaluate outcomes. Facilitating a level of independent participation is an important outcome for children receiving EI (Wilcox and Woods, 2011). In keeping with EI philosophy, research is shifting to focus on enhancing young children’s participation and notably their
communicative participation (Ragavendra, 2013). Hearing the voice of children is vital in order to understand their experiences (Department of Health and Children, 2000; Government of United Kingdom, 2014) and their voices must inform practice (Whitehurst, 2006).

3 Aims of the Study

This research study aimed to answer two research questions.

1. Can young children with developmental disabilities be facilitated to engage in research?
2. If so, how can their engagement in research be supported?

II Methods

An asset based methodological approach was used in this study. The researcher’s objectives were to interact with young children with disabilities in ways that respected their particular competence (Thomas and O’Kane, 2000) and their unique and valued view of the world (Greene and Hill, 2005); to view the children as active members of their early intervention team and to add the children’s voices and engage them in the research process. Initially, the researcher took a leadership role and following a process of co-construction (Mason and Urquhart, 2001), the children’s interactions led the data collection activities. The researcher was a SLT by profession and at the time of research had over 13 years clinical experience working in EI and with children with disabilities, was a sign language user and skilled in the nuances of communication facilitation. These skills included active listening, being resourceful, respectful of the child and their style of communication, open, sensitive, and flexible.

1 Participants

A purposeful sampling strategy was used to select potential child participants from two non-government organisations (NGO) who were receiving EI services. The gatekeepers, who were managers within the organisations were asked to select: children with complex needs attending an EI team, and ranging in age from 2 to 5 years. Eight children were recruited; all attended EI team services for children with developmental disabilities in their local areas. The details of each participant are outlined in Table 1. Following the selection and recruitment procedure:
1. The researcher contacted the parents of the children identified through the selection process.

2. The parent provided consent for the researcher to meet with their child for the research.

3. The child assented to participate in an interaction with the researcher. The approach to the interaction was based on the child’s level of ability.

Data Collection

Clark and Moss’s (2011) Framework for Listening was used to guide the data collection process because it views children as ‘beings not becomings’ (Quortrup et al., 1994), and listens to children’s voices. The multi-method process involved interactions with each child, use of a Microsoft SenseCam (Hodges et al., 2006), SenseCam images, pictures, Talking Mats (Murphy, 1997), and observations. Multiple interactions also allowed the needs of the child to be respected (Irwin and Johnson, 2005) and strengthened the trustworthiness of the data (Dockett and Perry, 2007). The participants were all individuals with heterogeneous experiences and diverse interests and needs. Prior to the initial interaction, the researcher and the primary caregiver had a telephone conversation, on how best to facilitate their child’s participation to engage in the interaction. Each interaction involved the child, researcher and one or both parents, was audio recorded and took place in the child’s home. The parents’ role was one to support the child and the researcher during their interactions. Thus, supporting the view that the parent and researcher worked in partnership and also to ensure that the research was carried out to the appropriate ethical standards. The researcher engaged in active listening, and took field notes following each interview. A Total Communication approach was used, where non-verbal communication such as body language, facial expression, signing, gestures and pictures were valued as much as spoken language (Fargas-Malet et al., 2010).

At the end of the first interaction, the researcher gave the parent/s a SenseCam for the child to wear over the subsequent few days. There was one SenseCam available for the study; subsequently five children were selected, based on nearest travel distance from the researcher, to use the SenseCam. The SenseCam, developed by Microsoft Research UK, is a passive wearable camera, fitted with a wide-angle (fish-eye) lens, which results in nearly everything in front of the camera being photographed. It takes
photographs automatically and the images provide a visual account of daily tasks and activities from the child’s perspective. It offers a novel route to the collection of observational data. The use of the SenseCam provided the children with a means to share their lives from their perspective (Wang, 2006). The researcher collected the camera and a record sheet (noting the date and length of time the child wore the camera) prior to the second interaction. SenseCam Image software was used to process all the SenseCam images and the images of toys, people, places, and activities from the child’s world were printed. During the second interaction, with the five children who used the SenseCam, the researcher used Talking Mats (Murphy, 1997), along with the print outs of SenseCam images and other pictures based on the child’s preferences. The tools were varied and reflective in accordance with the research question and the individual abilities and preferences of the children.

3 Data Analysis

An interpretative framework shaped the interpretation of the data (Grover, 2004). The interactions were analysed using a constant comparative approach. Transcripts were coded to identify themes directly from the interactions. The SenseCam images were analysed using content analysis in order to reduce and make sense of the volume of qualitative material (Patton, 2002). The images were grouped into events, for example, mealtime, playtime, watching TV, people, by the researcher to form a pictorial diary of the child’s experiences. This analytical method involved the researcher adopting an outsider perspective by personally interpreting the photographs, examining and describing them as thoroughly as possible. Punch (2002) suggests that the researcher needs to be critically reflective in analysing different types of data. An interpretative framework facilitated the identification of themes in the data.

4 Rigour

The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging themes. In flexible designs such as this Patton (2002) advocates the use of an audit trail, therefore the researcher kept a reflective diary which included thoughts, feelings, biases that may have influenced all aspects of the research process and attempts made to manage them (Davis et al., 2000; Driessnack, 2006). The parents were present during all interactions with their children (as
a requirement of the research) and facilitated the researcher in her interactions with the children and verified the accuracy of the researcher’s observations and interpretations. The second author acted as peer checker of the data, by viewing the images, which supported the trustworthiness of the data collection process and data analysis.

5 Ethical considerations

The research underwent two independent reviews and received full ethical approval from two University research ethics committees. The parents were fully informed of the research and knew that they had the right to withdraw their child at any stage. Their confidentiality was assured and pseudonyms were used to provide confidentiality. The researcher wanted to facilitate the participation of the children who attended the EI services in this research and allow them to have a voice and to include those for whom obstacles may make participation difficult. Stancliffe (1999) argued that when someone is unable to communicate their own views, a well-informed guess may be preferable than no information. The National Federation of Voluntary Bodies (2008) states that where children do not have the capacity to consent a guardian (usually parent) appointed must give consent. All parents provided their written consent for their child to take part in the research. The parents knew that they might be probed to give supportive evidence to statements made by their child during the interviews. However, there should also be an opportunity for the child to express assent. In accordance with (Ireland and Holloway, 1996; Scott, Wishart and Bowyer, 2006), the agreement of the children to take part in the research was also requested. The researcher checked at the beginning of each interaction that the child was willing to participate. The age and level of ability of the child dictated how the child’s own assent and participation could be achieved (Ireland and Holloway, 1996; Scott et al., 2006). The researcher looked for verbal and non-verbal signals of the child’s willingness to partake or withdraw.

III Findings

The research demonstrated that the young children with disabilities could participate in the research process about their early intervention service. The children’s engagement was facilitated successfully through the use of a number of strategies during the process of data collection. It emerged that a variety of data collection tools were needed, together
with parent knowledge and skills and researcher knowledge and skills. The findings are reported under these headings.

1 Variety of data collection tools

The tools that supported the children in this study were the use of the SenseCam and Talking Mats. The SenseCam was used as a recorder of the child’s everyday experiences and the contexts they experienced. Five children wore the SenseCam for an average of five hours over a three-day period. During the study, Child 6 did not want to wear the SenseCam around her neck, and used it as a ‘handbag’ and wanted to take pictures herself. Her mother responded to her communicative signals and facilitated her to wear the camera by stitching the camera to her vest. She wore the camera and communicated to her mother when she did not want to wear it and her mother responded by taking the vest off. Child 6 moved outside during the first interaction and the researcher followed the child’s lead and the interaction continued outside. Thereby allowing her to be an active participant in the research process.

Child 7 wore the SenseCam during an EI therapy session and also during his EI group interventions. This provided images and observations of his interactions with his therapists and demonstrated his participation during intervention. The SenseCam images included a playdoh activity showing him rolling playdoh with his hands, then rolling playdoh with a roller and then placing a shape in the playdoh and then the final product. For Child 7, the SenseCam allowed us view his interest in the outside world with images of his pets consistently being captured on his visits outside. His siblings and his mother were also very important people in his life. For Child 8, the images showed us his interest in Thomas the Tank Engine programmes on TV.

When using Talking Mats (Murphy, 1997), the children chose the images of their world and used non-verbal expressions such as smiling or verbally commented. The child and their parent viewed them and validated their importance in the child’s life. Of the five children who used the SenseCam, Talking Mats were used as a tool with three of the children when looking at the photos. Child 5 looked at the SenseCam images on the researcher’s laptop and named and pointed to the ones he liked. Child 2 looked, and pointed and named the pictures.
2 Parents’ Knowledge and Skills to Support Engagement

The child interacted with the researcher and participated in the research. The parents supported their child’s interactions when it was needed, between the researcher and the child, and the parents on occasion directed the interactions.

‘I am going to do music with him now. I have a few cds that get him up. There is an Irish dancing cd and he goes mad for that.’ (Mother of Child 1 interaction 1).

Child 5’s mother showed the researcher his activities and carried out their therapy routine and involved the researcher to take turns in the Mr. Potato Head activity.

‘Here are some of his routines, that’s kind of a list of all the ones we’ve built up and then I kind of have them in pockets so we might do a song, ...we’ve Mr. Potato head and the new thing then is the pictures with the words.’ (Mother of Child 5 Interaction 1).

Parents influenced the interactions in EI by contributing knowledge about their child. The parents shared how their child interacted in EI.

‘He would push away or wriggle off my lap or turn away. If he really doesn’t want something done he would let you know alright’ (Parent of Child 1 Interaction 1)

‘People who will actually play with him and sit down with him. He responds to them much more’ (Parent of Child 2 Interaction 1)

Within the interactions in the home it was clear that a parent influenced and effected change in their child particularly in relation to using home opportunities to include treatment goals. When an investment in structure and routine was attached to EI, it facilitated interaction.

‘Looking back it was great they (professionals) really got them into the routine. It (therapy sessions) became very familiar to them. The hello song at the beginning.’ (Mother of Child 4 Interaction 1).

When the researcher and his mother were observing Child 5 holding on to a toy, his mother commented that ‘he wouldn’t have done that a year ago’ (Child 5 Interaction 1). Accordingly, involvement in EI enabled developmental progress.

‘The words are coming great. The last time then she (SLT) gave me these ones (mother showed the researcher cards) with just the words and he is getting it. He has strengthened no end’ (Child 4 Interaction 1)
He is completely different (to when he was two). Even in the last 2 months he has come on (Child 1 Interaction 1).

3 Researcher Knowledge and Skills to Support Engagement

During the interactions the researcher verbalised what the child was doing and how they responded when the response was not verbal, for example, when the child signed and/or vocalised the researcher said ‘signed car and said da’. This allowed for more accurate transcription of the audio recording. The researcher, being a SLT and using a Total Communication approach, could read a lot of the children’s signals and signs. The researcher also asked the parents during the interactions to verify the accuracy of her interpretations of unclear signs, signals, gestures, vocalisations and words. The researcher followed the child’s lead in all the interactions. During the interviews, all forms of communication were viewed as equal.

The researcher observed Child 2, during interaction 1, playing a game with marbles and he allowed the researcher to take turns and play hide and seek with them. Marbles were of interest to this child. The child’s motivation also influenced activities, and the materials used made a difference. The researcher read the child’s non-verbal communication to alert her as to when had how to take her next turn. The researcher and Child 1, during interaction 2, played with playdoh. The child opened the playdoh boxes, squeezed the playdoh and rolled it out into a snake. The task was completed under the direction of his mother. Also during this interaction, the researcher noted that his mother commented on good sitting, commented saying ‘open’, ‘squeeze’ and made noises to go with the activity, named colours, named verbs ‘pull’, ‘push’, and used short phrases ‘good open’, ‘take some out’, ‘lid off’, ‘we scoop’, ‘in the box’, ‘lid on’, ‘s’, ‘small snake’, ‘big snake’, and changed her intonation patterns and stressed different words. His mother noted that:

‘You have to be patient. You have to go slowly. Face to face contact. (Child 1 Interaction 2)

All eight children involved in the study communicated non-verbally when, they did not want to take part, were no longer interested in an activity and when they were finished interacting. They interacted by moving away or turning away from the researcher, pushing a toy or pictures away, not wanting to wear the SenseCam or wanting to leave the room. The researcher responded to the children’s communicative attempts by following the child’s lead and either changing the activity or stopping the interview.
Initially the process was researcher led, followed by a period of co-construction and finally child led. The researcher adapted the data collection methods according to each child.

IV Discussion

This research demonstrated that young children with disabilities could participate in research about their EI service. The research demonstrated that, although engaging these children with developmental disabilities in the research is difficult and complex, it is possible. EI services strive for inclusion and to be accountable (Health Service Executive, 2011). This research shows that the young children involved in these services were included in adding to research about EI services. Young children with disabilities are central to EI services. The ideology of EI services is participation of all children with disabilities in their everyday activities. Within this research, the children were viewed as competent social actors and given the opportunity to take part in research about EI. Similar to other research findings (Beresford et al., 2004; Franklin and Sloper, 2009; Kelly, 2007), a range of data collection techniques, skills and support was required to engage this heterogeneous group of young children to participate in the research. Research with children with developmental disabilities is difficult and is compounded by the complexity of impairment and by the complex variety of children. Hence, for the children in the study, their level of participation in activities varied and was dependent on their abilities and on the context of the activity, a finding similar to those found by Paige-Smith and Rix (2011). This research also found that the people, that is, parents and the researcher were key factors in the children’s engagement. This study provides evidence that a multi-method process allowed the children in this study to give a picture of their skills, needs and interests, identified what motivated them, and identified their capacity to make decisions and how they interacted in their home context.

Within the research, the parents played an important role in their child’s participation. The children in the study were engaged in the process with the support of their parents. Firstly, the parents consented to their children being involved in the study. The parents acknowledged their child’s capacity to take part (Federation of Voluntary Bodies, 2008). Secondly, the parents were a factor in the success of their child’s engagement in the research process. This is similar to the opinion that parent involvement in EI is a key factor to successful intervention (Blackman, 2003). Similar to
Trute’s (2007) view that parents should be regarded as partners with professionals in family-centred practices, the parents and the researcher were partners in the research process. The researcher perceived the parents from a position of equal expertise (Carpenter et al., 2004) and did not rely on them to act as proxies for the children (Markham et al., 2009). Rather than acting as proxies, they enabled their child’s inclusion and their participation in the research. Without the active commitment of the parents in the research process the use of the SenseCam (Hodges et al., 2006) as a tool for data collection would not have been positive. The parents provided the opportunities for their children to wear the SenseCam in their home settings. Thirdly, during the interactions with the children in their homes, the parents verified their child’s communication skills, their interests and demonstrated how interventions were supported within the home context. The parents made activities available to their child and integrated therapy interventions into home activities. Thus supporting Axelsson et al. (2013) suggestion that child-focused activities are more involving than routines. Lastly, the parents acted as interpreters when it was required, verifying the accuracy of the researcher’s interpretations of their child’s communicative signals. Thus supporting the reliability of the researcher’s interpretations.

The data collection tools used in the study facilitated the young children to participate in the research process. At the time of the research, the SenseCam (Hodges et al., 2006) had not been previously used with young children with disabilities. This research demonstrates that it is a useful research tool to use with this heterogeneous group of children. The SenseCam facilitated auto photography, where the world inhabited by the children was captured while, at the same time, reflecting the worlds they live in (Erdner and Magnusson, 2011). The SenseCam allowed the researcher to gain a more comprehensive picture of the children’s worlds obtaining data that traditional interactions could never have provided. The use of photography is supported by previous research (Press et al., 2011; Roulstone et al., 2013) and this research adds to the evidence base to include young children with disabilities. The use of Talking Mats (Murphy, 1997) also facilitated the children’s engagement in the research and provided a prop to use pictures and images taken by the SenseCam in the interactions. In order to engage these children in research activities, the researcher and the parents needed to be flexible and respond to the child’s individual capabilities.
Consulting with young children with disabilities requires the listener to use communicative techniques and interpretative skills (Dickins, 2004), which can have a substantial influence on communication (McCormack et al., 2010). This research suggests that the techniques and the skills of the researcher were an integral factor in the successful engagement of the children with disabilities in this research. The researcher was a speech and language therapist, with a professional qualification in the nuances of communication facilitation (ASHA, 2008). The authors argue that the researcher was not only a competent researcher but also had clinical competence to actively engage with the children in ways that another researcher may not. The researcher’s specialist expertise and experience in working with children with disabilities facilitated the interactions and allowed the interactions to flow as the researcher understood sign language and made consistent attempts to interpret the child’s communicative intentions, which is supported by McCormack et al. (2010) and Dickins (2004).

An important outcome of EI for a child with a disability is independent participation (Wilcox and Woods, 2011). This independence to participate in research can be hindered by a number of factors such as communicative competence. This research provides an example of children with disabilities displaying communicative participation in research. Speech and language therapists have a role to ensure that communication is conceptualised as a skill that is central to participation across all activities and routines in EI (Wilcox and Woods, 2011). While all professionals within EI have skills to work with these children, SLTs have clinical competencies to help interpret and report children's views (Wilcox and Woods, 2011). SLTs can facilitate children in research and support researcher colleagues, in research about EI. SLTs can help colleagues to understand how each child communicates, shows their likes and dislikes, makes choices and to interpret a child’s communicative signals. This knowledge is also important for planning family-based interventions (Dunst, 2001; McWilliam, 2010). SLTs together with their EI colleagues need to consider the young children, with whom they are working, as potential research participants and need to consider ways to facilitate participation.

The strengths of the study are that it involved multiple interactions allowing the needs of the child to be respected (Irwin and Johnson, 2005) and strengthened the trustworthiness of the data (Dockett and Perry, 2007). The researcher was reflexive by considering her role as a researcher and the power relations in the research process.
(Davis et al., 2000; Edmond, 2006). The researcher’s clinical qualifications and clinical experience together with the parents’ expertise helped ensure reliability of the data. The second author also facilitated peer checking of the data adding to the rigour of the research process (Patton, 2002). However, the research could be criticised for being non-standardised and that the analysis of the findings are the researcher’s interpretations and may not take account the child’s own insights. The study was limited by the time that was allotted to collect the data with only eight children taking part in the study, and five wearing the SenseCam. The practice of auto photography could be seen as passive participation, however in this research the photographs were used to facilitate active participation. There is opportunity to extend the use of the SenseCam to ensure that the images are representative of the child’s life. The positive outcome of the study may have also been attributable to the children’s motivation and that of their parents to facilitate their child in the research.

In conclusion, the importance of facilitating research with children rather than on children is increasingly recognised and promoted. Systems can make this participation in research activities a reality through the use of; an asset based methodological approach, a variety of data collection tools, with the support of parents and an interviewer skilled in the nuances of communication facilitation. Enabling young children with disabilities to have a voice in research has the potential to positively influence the services they receive facilitating a more truly holistic approach to EI practice.
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Appendices


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Stancliffe RJ. (1999) Proxy respondents and the reliability of the Quality of Life


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</tr>
</tbody>
</table>

Table 1: Child Sample
Appendix D

Chronology of the Thesis
2009  Research proposal written and background reading commenced to establish background and rationale for the study.

Ethical Approval Applications made to three independent Research Ethics Committees and approval granted.

2010  Conducted pilot study to engage young children with disabilities in the research and a protocol to support their inclusion devised.

Literature review commenced.

2011  Access to commence recruitment of EI teams via Disability Managers.

Recruitment process of five EI teams from urban and rural geographical areas commenced. Following recruitment process one team accepted the invitation to partake.

2012  Recruitment of participants (children, parents and professionals) from one urban EI team who agreed to take part. Data collected, data analysis commenced, literature review continued, theoretical sampling and constant comparative approach conducted.

April: Paper titled ‘The Progression of Early Intervention Disability Services in Ireland’ submitted to Infants and Young Children (in Appendix A).

August: Paper titled ‘The Progression of Early Intervention Disability Services in Ireland’ accepted by Infants and Young Children.

2013  January: Paper titled ‘The Progression of Early Intervention Disability Services in Ireland’ published in Infants and Young Children.

April to May: Expert Panel Process as part of data analysis process.

Ongoing data analysis, theoretical sensitivity and writing of thesis draft.

2014  Presentation to participants and dissemination leaflet sent to all parents of the EI service involved in the study. Ongoing writing of thesis.


February: Paper titled ‘Exploring the Participation of Young Children with Disabilities in Research about Their Early Intervention Service’ accepted by to Child Language Teaching and Therapy (in Appendix C).

April: Paper titled ‘Exploring the Participation of Young Children with Disabilities in Research about Their Early Intervention Service’ published online.

## Appendices

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</thead>
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Re: Understanding early intervention in Ireland: a conceptual evaluation
developed from case studies.

Dear Manager

Thank you very much for agreeing to facilitate me in making the connections with the relevant people in early intervention services in YOUR AREA. As you are aware, I am a lecturer at the National University of Ireland Galway and a speech and language therapist. I am studying for a PhD part-time at NUI Galway. I am hoping to carry out a research study, which aims:

- To explore the participants’ experiences of their early intervention service
- To identify what makes the early intervention service work
- To identify what makes the service not work
- To identify factors that can be used for all early intervention services in Ireland to enable services to be of the highest quality.

The research is hoping to focus on the early intervention teams in your area. I have received ethical approval from the relevant committees. I have also received Garda Clearance. I am aware that the Early Intervention Teams in YOUR AREA include other organisations. I hope that the approvals with suffice. I attach the information contained in my ethics applications. If there is anything else I need to do please let me know.

For each team face to face interviews will be carried out with five team members and five parents. Five children (aged between 2 & 5 yrs.) will also be invited to be involved with their parent’s permission. I am keen to hear the stories of the children, parents and professionals who are involved with these services.
I am hoping to carry out the interviews in early 2012. Therefore, I need to recruit participants in the coming months. I would be delighted to come and meet the relevant people involved with these services to explain the study in more detail and answer any questions that they may have.

Thanking you

Clare Carroll (nee O'Shaughnessy)
Researcher
NUI Galway
2011 STUDY INFORMATION

**TITLE:** Understanding early intervention services in Ireland: a conceptual evaluation developed from case studies.

**Aims of the proposed study**

To identify and explore factors which facilitate and inhibit Early Intervention (EI) services from the stakeholders’ perspective

*The Study objectives are:*

1. To determine conceptual constructs which frame a possible best practice model for Ireland.
2. To understand the integration processes within EI services through an exploration of the experience of parents/carers, team professionals and children.
3. To explore and evaluate the participation and contribution of children with disabilities to the research process.

**Brief Plan of Investigation**

A grounded theory approach within an in-depth qualitative case study (Checkland, 2007) design is proposed. The research will focus on participants from five EI teams from two local health office (LHO) areas in Ireland. The research will look at each team as a case to learn about the phenomenon and to identify factors and processes that facilitate quality EI provision. The teams will be from a rural LHO area and an urban LHO area in Ireland. The study will take place within these areas. The interviews with participants will take place in a place of convenience to them; for example, work setting, home or other.

In the first instance each team will be explored as a unique case. Subsequently the cases within each particular LHO area can be compared and contrasted. This will then allow for similarities and differences to be compared and contrasted between the LHO areas. This will then in turn provide a picture of the case of EI services nationally. Within each
case the selected service users (parents and children with disabilities) and team professionals can be approached.

For inclusion all participants will be involved in one of the selected EI teams when the study commences and up to six months in the immediate past and be willing to participate. They will have English as their first language as resources will not allow for the recruitment of interpreters. 40-50 family participants and 10-20 team professionals will be included (after Morse, 2000). Child participants will be aged between 2 and 5/6 years and parents and team professionals will be adult age. For each team face to face interviews will be carried out with four team members, five parents and five children (aged between 2 & 5/6 yrs.; with their parent’s permission).

Permission to contact the EI teams for the study will involve in the first instance discussions with the early intervention project officer/disability coordinator/manager. Following this the researcher will contact and meet with the gatekeeper to discuss the selection plan for all participants.

**Child Participation**

Children’s involvement is vital in order to understand their experiences and to maximise their participation and that of their families (National Children’s Strategy, 2000). The Mosaic approach (Clark & Moss, 2001) will facilitate a deep understanding of the complexities of children’s everyday lives. It will allow me to listen to the children and allow them to evaluate the EI service and allow their views to become embedded in early years practice. With this understanding opportunities exist to integrate and coordinate activities at all levels of the system. Methods of data collection with children will be in accordance with best practice guidelines (National Disability Authority, 2006).

Following the selection and recruitment of the children by the gate keeper:

1. The researcher will contact the parents of the children identified through the selection process.
2. The parent will be asked for consent for the researcher to meet with their child for the research.
3. The child will then assent to participate in an interaction with the researcher. The approach to the interaction will be based on the child’s level of ability. I want to facilitate the participation of the children who attend the EI services in this research and allow them to have a voice and to include those for whom obstacles may make participation difficult. Stancliffe (1999 as cited in D’Eath et al, 2005) states that: “a well-informed guess may be preferable to no information in cases where the person is unable to communicate her/his own views”. The age and level and type of disability of the child will dictate how the child’s own assent and participation can be achieved. The National Federation of Voluntary Bodies (2008) states that the presumption should be one of capacity rather than incapacity. They also state that where children do not have the capacity a guardian (usually parent) appointed must give consent. However, there should also be an opportunity for the child to express assent. In all instances of research with children, where parental consent is obtained, the agreement of the children to take part in the research should also be requested (Ireland & Holloway, 1996; Scott, Wishart, & Bowyer, 2006).

Within this study parents, advocates or supporters may act as proxies responding on behalf of the child. I will check at the beginning of each session and throughout the session that the child is willing to participate. The investigator will be alert and sensitive to the child’s behaviours throughout the process.

Analysis
The design will be iterative; the collection of data from each case is followed by a review of theoretical ideas to support the emerging data from the research field, gained through interview and observation methods. This means that not only the voice and perspective of all those involved in the teams i.e. parents, children and professionals will be considered, but also of the relevant group participants and the interactions between them. This will allow for similarities and differences to be compared and contrasted. This will then be framed within a review of international best practice to identify key constructs for a best practice model for the Irish context.
All interviews will be analysed using a constant comparative approach. QSR Nvivo data collection and management software will be used. This will allow for building a conceptual framework through the course of the study (Miles & Hubermann, 1994). Transcripts will be coded to identify themes directly from the interviews, in line with a grounded theory approach and following Strauss and Corbin (1990). The three case layers of analysis reflect the conceptual design of the case studies. These case layers include: individual participant case study within the EI team combines to make up the service case study; the EI teams combine to make a LHO area case study; the LHO areas combine to provide a perception of the national EI service.

Ethical Considerations

A particular difficulty is the participation of young children with disability and their role in assent. I will check at the beginning and during each session that the children are willing to participate. Due to the range of ages and abilities of the children each child’s participation will be assessed on an individual basis in consultation with parents. I have 15 years clinical experience of working as a SLT with this client group, nine of which were in the context of EI services. I am experienced in communicating with children with significant communication using Lamh (Augmentative Sign Language System for children with disabilities), communication boards and other systems of communication such as PECS (Picture Exchange Communication System) and observing children’s communication both verbally and non-verbally. I will use these skills along with play, photographs, and observation together with their parents. I am highly aware of the individuality of each case and ways to best facilitate children’s participation to engage and interact will be discussed at length with each child’s parents. I will be looking for verbal and nonverbal signs of the child’s willingness to partake or withdraw, for example, refusal techniques might include: declining to stay in the room, or falling asleep. The child’s parents will be present at all times and able to withdraw their child if they wish to at any point in the process. The extent to which proxy responses accurately reflect the views of the child with special needs are disputed and the subject of some debate. The proxy will be well briefed and understand that they may be probed to give supportive evidence to statements. The key to successful data collection with people with an
intellectual disability is flexibility and sensitivity to the requirements of the individual. Therefore, a person known to the child with special needs may be the best interviewer as a greater level of communication and trust may already exist.

As with any research study issues of rigour and trust are important. The major methods for ensuring rigour are intricately linked with the notion of reliability and validity (Morse, 2000). The data collection methods with disabled children have been piloted with children in 2010. I will need to be reflexive by considering my stance as a researcher and the power relations in the research process (Emond, 2006; Goodenough et al., 2003). In flexible designs such as this Patton (2002) advocates the use of an audit trail, therefore I will keep a reflective diary which will include thoughts, feelings, biases that might influence all aspects of the research process and how I attempted to manage them (Davis et al., 2000; Driessnack, 2006)

Parents and professionals will be fully informed of the research and will be advised that they have the right to withdraw at any stage and anonymity and confidentiality will be assured. Through the interviews sensitive issues may arise for parents, children and professionals when communicating their experiences. The EI team responsible for the care of the child and family will be the first point of contact for post-interview support should such arise.

The importance of confidentiality is stressed in research governance guidelines but confidentiality may not be sustained if the child reveals information that the interviewer feels should be passed on in the child’s best interests such as child protection (Coad & Lewis, 2004).

All participants will be given unique identifiers to ensure anonymity. All recordings and transcripts of interviews and paper format documents will be stored in a locked filing cabinet in the Speech and Language Therapy Department at NUIG. Electronic data will be stored on a password protected computer. In compliance with NUIG regulations, data will be stored for five years before being destroyed.
| Appendix F | Information Letter to Gatekeeper |
Dear X

Thank you for agreeing to act as the gatekeeper for my PhD study. As you are aware the relevant Research Ethics Committees approved the study. I need your help in recruiting professionals, parents and children involved with your early intervention teams. The following is information that will help you to select the participants.

**For selecting the children the criteria includes:**
Currently attending an early intervention team.
Range of length of time involved in team: new (greater than 6 months)/ involved for some time/ready for discharge
Aged between 2 and 5 years.

**For selecting the parents the criteria includes:**
Currently attending an early intervention with their child.
Range of length of time involved in team: new (greater than 6 months)/ involved for some time/ready for discharge
Their child has not already been selected to take part.

**For selecting the professionals the criteria includes:**
Currently working on an early intervention team.
The recruitment process is highlighted below for each early intervention team.
Step 1: The early intervention co-ordinator will identify 5 children, 5 parents and all professionals (who meet the sampling criteria)

↓

Step 2: The families and professionals selected will receive an information leaflet and covering letter sent by the EI co-ordinator after the 6th February 2012.

↓

Step 3: The families and professionals may contact the EI co-ordinator directly. Otherwise the EI co-ordinator will contact the families and professionals by phone to ask their permission to give their contact details to the researcher by the 24th February 2012.

↓

Step 4: If a family does not give permission, the early intervention co-ordinator will select another family that is similar in terms of the sampling criteria for the child/parent that was selected.

↓

Step 5: The EI co-ordinator will contact the researcher and provide details of the families and professionals who agreed to participate. It is important to note that up until this point all data will be held within the service.

↓

Step 6: The researcher will then contact the families and professionals directly.

I really appreciate your help with the recruitment process and do contact me if you have any queried on Y. The covering letters and information leaflets are in the post. I will forward on more letters and leaflets as required.

Thanking you

Clare Carroll
Researcher, NUI Galway
| Appendix G | Information Letter for Families for Child Participants |
Dear Parent

My name is Clare Carroll and I am a speech and language therapist and a lecturer. I currently lecture in the Discipline of Speech and Language Therapy at NUI Galway. Prior to this I worked as a senior speech and language therapist with the HSE in Mullingar. I am studying for a PhD part-time at NUI Galway.

The X Early Intervention Service is keen to understand more about its services. They want to hear the stories of the children, parents and professionals who are involved with their services. The National University of Ireland Galway, together with your Y organisation, hopes to carry out a research project during 2012.

As your child is involved with Y Early Intervention Services, Ms X is forwarding this information to you on my behalf. Attached is an information letter on the research project for you to read. It states the purposes of the research and how it will be carried out and how you may be involved if you so wish. Your child’s experience of the service he/she is receiving will support future developments for the service. I look forward to the possibility of meeting you and your child and hearing your child’s story.

Thanking you

Clare Carroll
Researcher
NUI Galway

6th February 2012
THANK YOU

Thank you for taking the time to read this information leaflet and I look forward to the possibility of meeting with you and your child.

Clare Carroll

091 495384
c.carroll@nuigalway.ie
WHO IS DOING THE STUDY?
My name is Clare Carroll and I am a lecturer and a speech and language therapist from the National University of Ireland, Galway.

WHAT IS THE STUDY ABOUT?
The study is looking at different parents’, children’s and professionals’ experiences of early intervention services to get an understanding of how they work and what makes them work. The study is focusing on early intervention teams in Y. It is an opportunity for your child to share his/her story and views to support future developments.

WHO WILL BE ASKED TO TAKE PART?
Five children (between 2 and 5 years old), five parents and all team professionals involved with the X early intervention teams are invited to take part in the study. Your child was selected by Ms. X on my behalf to take part. I will only contact you if you give Ms. X permission to pass your contact details on to me. If you would like your child to be involved, you will be required to give me permission to interview your child.

IF YOU ARE INTERESTED IN TAKING PART WHAT WILL IT INVOLVE?
I hope to meet you and your child two or three times to have a conversation about your child’s early intervention experiences. The conversations will take place in a place convenient for you and will last about one hour for each visit.

We will chat about how best to involve your child as you know your child best. We may use pictures, objects, gestures, Lamh sign language and/or other methods which are appropriate for your child. It might be useful to observe your child during an early intervention therapy session. We will discuss this together.

With your written permission, the interviews and interactions will be tape-recorded to make sure that accurate information is recorded. This recording will be typed out word for word in an interview transcript. A person from X service will be available following the interviews if the need arises where you need to talk to someone.

IF YOU ARE INTERESTED IN TAKING PART WHAT DO YOU DO NEXT?
You and your child’s participation are voluntary and if you decide not to become involved your care and service will not change in any way. If you are interested you can ring Ms. X on xxxx. Otherwise she will be in contact with you to see if you are interested in taking part. She will then pass your contact details on to me and I will then ring you to arrange to meet. You and your child can change your minds and withdraw from the study at any stage.

DOING THE STUDY THE RIGHT WAY
I will tell people what I found out in the study when it is finished, although your names are never used when this happens. No-one else will know who has taken part in the study. I will send a copy of the findings to you. All information will be stored anonymously and securely in my office in NUI Galway.

If you are unsure about getting involved or have any questions please ring me on 091 495384 and I will answer your questions.
| Appendix H | Information Letter for Families for Parent Participants |
6th February 2012

Dear Parent

My name is Clare Carroll and I am a speech and language therapist and a lecturer. I currently lecture in the Discipline of Speech and Language Therapy at NUI Galway. Prior to this I worked as a senior speech and language therapist with the HSE in Mullingar. I am studying for a PhD part-time at NUI Galway.

The Y Early Intervention Service is keen to understand more about its services. They want to hear the stories of the children, parents and professionals who are involved with their services. The National University of Ireland Galway, together with your Y Organisation, hopes to carry out a research project during 2012.

As you are involved with Y Early Intervention Services, Ms X is forwarding this information to you on my behalf. Attached is an information letter on the research project for you to read. It states the purposes of the research and how it will be carried out and how you may be involved if you so wish. Your experience of the service you are receiving will provide support for future developments of the service. I look forward to the possibility of meeting you and hearing your story.

Thanking you

[Signature]

Clare Carroll
Researcher
NUI Galway
Thank you for taking the time to read this information leaflet and I look forward to the possibility of meeting with you.

C l a r e  C a r r o l l
WHO IS DOING THE STUDY?

My name is Clare Carroll and I am a lecturer and a speech and language therapist from the National University of Ireland, Galway.

WHAT IS THE STUDY ABOUT?

The study is looking at different parents’, children’s and professionals’ experiences of early intervention services to get an understanding of how they work and what makes them work. The study is focusing on teams in X. It is an opportunity to share your story and your views about early intervention to support future developments.

WHO WILL BE ASKED TO TAKE PART?

Five children (between 2 and 5 years old), five parents and all team professionals involved with the X early intervention teams are invited to take part in the study. You were selected by Ms. X on my behalf to take part. I will only contact you if you give Ms. X permission to pass your contact details on to me.

IF YOU ARE INTERESTED IN TAKING PART WHAT WILL IT INVOLVE?

I hope to meet you to have a conversation about your early intervention experiences. The conversation will take place in a place convenient for you and will last about one hour.

With your written permission, the interviews and interactions will be tape-recorded to make sure that accurate information is recorded. This recording will then be typed out word for word in an interview transcript.

A person from Y will be available following the interview if the need arises where you need to talk to someone.

IF YOU ARE INTERESTED IN TAKING PART WHAT DO YOU DO NEXT?

You participation is voluntary and if you decide not to become involved your care and service will not change in any way. If you are interested please ring Ms X on xxxxxx. Otherwise she will be in contact with you to see if you are interested in taking part. She will then pass your contact details on to me and I will then ring you to arrange to meet. You can change your mind and withdraw from the study at any stage.

DOING THE STUDY THE RIGHT WAY

I will tell people what I found out in the study when it is finished, although your name will never be used when this happens. No-one else will know who has taken part in the study. I will send a copy of the findings to you. All information will be stored anonymously and securely in my office in NUI Galway.

If you are unsure about getting involved or have any questions please ring me on 091 495384 and I will answer your questions.
| Appendix I | Information Letter for Professionals |
6th February 2012

Dear Team Professional

My name is Clare Carroll and I am a speech and language therapist and a lecturer. I currently lecture in the Discipline of Speech and Language Therapy at NUI Galway. Prior to this I worked as a senior speech and language therapist with the HSE in Mullingar. I am studying for a PhD part-time at NUI Galway.

The Y Early Intervention Service is keen to understand more about its services. They want to hear the stories of the children, parents and professionals who are involved with their services. The National University of Ireland Galway, together with your Y Organisation, hopes to carry out a research project during 2012.

As you are involved with Y Early Intervention Services, Ms X is forwarding this information to you on my behalf. Attached is an information letter on the research project for you to read. It states the purposes of the research, how it will be carried out and how you may be involved if you so wish. Your experience of where the early intervention services have come from and where they are now will support future developments of the service. I look forward to the possibility of meeting you and hearing your views.

Thanking you

Clare Carroll
Researcher
NUI Galway
A research project will be carried out which aims to explore early intervention services to gain an understanding of how they work. The research is focusing on teams in two areas in Ireland.

This research aims:

- To explore your experiences of your early intervention service
- To identify what makes your early intervention service work
- To identify what makes your service not work
- To identify factors that can be used for all early intervention services in Ireland to enable services to be of the highest quality.

A child, their family and a group of health professionals make up an early intervention team. This range of people will be invited to take part in this study. *Face to face interviews* will be carried out with *team members and parents*. Children will also be invited to be involved with their parent’s permission. Children will be involved in different ways such as by watching them with their parents and team members, interviewing and through talking to their parents about how they spend their time, what do they like/not like about early intervention. The interviews with parents and children will be carried out in a place convenient for you and will last about one hour. More than one meeting may be needed with the children. With your written permission, the interviews will be tape-recorded to make sure that accurate information is recorded. This recording is typed out word for word in an interview transcript. A contact person will be available for parents following the interviews if the need arises where they need to talk to someone.

All information you provide is *completely confidential* and will *adhere to legislation on data protection*. Your name will not appear on any report resulting from this project, however, with your permission, anonymous quotations may be used. There will be an opportunity for you to read your interview transcript and clarify that the information is accurate.
A number of professionals, parents and children will be selected and subsequently the team’s secretary may make contact with you. As you will have noted not all of you will be contacted to take part (a selection), however if you would like to be included please contact ……… on the number below.

Your participation is voluntary. If you decide to take part you will help to inform our understanding of early intervention services and help provide recommendations to improve the service. If you decide to take part and then change your mind you can withdraw from the project at any stage. If you decide not to become involved your care and service will not change in any way.

Following the research a report will be written which will include all contributions. A copy of the findings will be sent to all who participate.

Thank you for taking the time to read this information.
Appendices

Appendix J  Protocol to Include Child with Disabilities in Research
Interview Protocol for Child Interviews

1. Phone interview guide with parents to arrange a meeting

The researcher explains the purpose of the research and confirms their interest in taking part.

Tell me about (name of child)?
Where do you live?
What are his activities for the next month?
Any EI appointments over the next month? (In order to establish those that may wear the SenseCam)

Directions to home.
The researcher explains the provisional plan for the interviews.

2. Interview guide with parents and children

The researcher explains to parents the purpose of the research and the provisional plan for the meetings. The parents sign the consent form to take part at the face-to-face interview. The researcher will engage in ‘active’ listening, which shows the interviewee that close attention is being paid to what they say; and also tries to keep the interviewee focused on the subject, as unobtrusively as possible.

Tell me more about (name of child)?
Family, interests, likes/dislikes, support system.

Tell me about his daily routine/ weekly routine/ monthly routine.
Where does he go, with whom, what does he do.

Tell me about his involvement with the EI?
Where does he go, who does he, what does he do, what is the plan for him i.e. goals

Tell me about his communication skills.
Expressing his needs and wants, interactions, how and why s/he communicates and with whom e.g. family, team.

Clark and Moss’s (2001) Framework for listening will be used to frame the data collection process. There are six components to the framework; multi-method process;
participatory; reflexive; adaptable; focussed on children’s lived experiences; embedded in practice.

1. *Multi-method process*

The researcher will be aware of the individuality of each case. The ways to best facilitate the child’s participation to engage and interact will be discussed at length with each child’s parents. Each child will be seen on two or three separate occasions. This will support the building of rapport; discussion with parents of the child’s communication skills and communication style of the child; observation; and interviewing. While talking to the parents, the researcher will be making observations of the child and interacting with the child as appropriate.

Language use will include a range of question types and a range of materials will be used. Methods to facilitate the child’s participation will be applied in practice. These methods may include pictures and/or photos and/or gestures and/or Lamh sign language of objects, people, events, feelings or experiences. Talking Mats, an augmentative and alternative communication tool will also be used as an aid to facilitate interaction as required. Observations, play, toys and puppets could also be used.

Four of the selected sample of children will wear a SenseCam for one week. It is a passive wearable camera, developed by Microsoft Research UK and has not previously been used with children with disabilities. It is fitted with a wide-angle (fish-eye) lens, which results in nearly everything in front of the camera being photographed. It takes photographs automatically and the images are a visual account of daily tasks and activities from the child’s perspective. It offers a novel route to the collection of observational data. The parents will be given a record form to log when the child wore the camera, how long it was worn for and to note any comments they have.

2. **Participatory**

- Watch child to see what they do and like
- Child actively co-con structs the interview
- Child active not passive
- Develop understanding of the activity and responses of the child in context
- Purpose is exploratory
3. Reflexive

- Active listening
- Recording, gathering documentation
- Awareness of my own reflexivity and theoretical approach
- Renegotiating roles
- Constantly check that my understanding matched the intended meaning of the child’s response

The researcher views disability within the social model of disability and views children within the sociological understanding of childhood. She believes in the competency of children. As a qualified speech and language therapist with 14 years experience of working with children with disabilities, her goal is to facilitate the children to communicate their experiences. The researcher will be aware of her assumptions and experiences and their impact on the research process.

4. Adaptable

Methodological approach will be varied and reflective in accordance with the research question and the individual abilities and preferences of the children.

Reflect on the heterogeneity of participants, individuality of participants and the diversity of participants

5. Focused on children’s lived experiences

Children are viewed as active members of the team. They are active members in their daily lives. The research takes place in their own homes with them doing their usual everyday activities. Focusing on their abilities rather than their disabilities.

6. Embedded in practice

Children are viewed as active members of the team. Where possible the children will wear the camera during therapy sessions and intervention groups.
Appendix K  Topic Guide for Parent Interviews
# Understanding Early Intervention Services in Ireland: A Conceptual Evaluation

## Appendices

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<th>How did you become involved with the early intervention team?</th>
<th>What is your experience of the team?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background, access, location.</strong></td>
<td>Assessment, treatment, planning, coordination of care, monitoring, partnership, detection and identification of issues</td>
</tr>
<tr>
<td><strong>What is your understanding of early intervention?</strong></td>
<td><strong>Who is involved?</strong></td>
</tr>
<tr>
<td>What assumptions do you make / take for granted about EI?</td>
<td>How does it happen?</td>
</tr>
<tr>
<td>What perceptions do you have about the process / how it functions?</td>
<td>When are you involved with?</td>
</tr>
<tr>
<td><strong>Who is involved?</strong></td>
<td>Why does it happen?</td>
</tr>
<tr>
<td><strong>How does it happen?</strong></td>
<td>Positive experiences and Negative experiences</td>
</tr>
<tr>
<td><strong>When are you involved with?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Why does it happen?</strong></td>
<td></td>
</tr>
</tbody>
</table>

## What influences/effects/helps the way the team works with your child?

- Personal qualities of members
- Commitment of staff
- Communication within the team
- Opportunities for creative working
- Working relationships
- Common values
- Conflict

<table>
<thead>
<tr>
<th>What influences/effects/helps the way the team works with your child?</th>
<th>What changes if any would you recommend to the way the team works?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What enables the team?</strong></td>
<td><strong>How would you prefer the service to work?</strong></td>
</tr>
<tr>
<td><strong>What challenges occur?</strong></td>
<td><strong>What needs to be considered for best practice in/ an ideal model of EI?</strong></td>
</tr>
<tr>
<td><strong>What concerns have you?</strong></td>
<td><strong>What outcomes do you want for your child?</strong></td>
</tr>
<tr>
<td><strong>Who is responsible for EI? What roles do people have?</strong></td>
<td></td>
</tr>
</tbody>
</table>
Appendix L  Topic Guide for Professional Interviews
<table>
<thead>
<tr>
<th>How did you become involved with the early intervention team?</th>
<th>What is your experience of the team?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background, time, professional role</td>
<td>Access, Assessment, treatment, planning, coordination of care, monitoring, partnership, detection and identification of issues</td>
</tr>
<tr>
<td>What is your understanding of early intervention?</td>
<td>Who is involved?</td>
</tr>
<tr>
<td>Definition, function, process, aspirations, roles.</td>
<td>How does it happen?</td>
</tr>
<tr>
<td>What expectations do you have of EI for your clients and families and for professionals?</td>
<td>When are you involved?</td>
</tr>
<tr>
<td></td>
<td>Why does it happen?</td>
</tr>
<tr>
<td></td>
<td>Positive experiences and Negative experiences</td>
</tr>
<tr>
<td></td>
<td>What influences/effects/helps the way the team works?</td>
</tr>
<tr>
<td>Personal qualities of members, commitment of staff,</td>
<td>What changes if any would you recommend to the way the team works?</td>
</tr>
<tr>
<td>communication within the team, opportunities for creative working, working relationships, common values, conflict</td>
<td>How would you prefer the service to work?</td>
</tr>
<tr>
<td>What enables the team?</td>
<td>What needs to be considered for best practice in/ an ideal model of EI?</td>
</tr>
<tr>
<td>What challenges occur?</td>
<td>What outcomes do you want for the team?</td>
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<tr>
<td>Who is responsible for EI?</td>
<td></td>
</tr>
<tr>
<td>What roles do people have?</td>
<td></td>
</tr>
<tr>
<td>Appendix M</td>
<td>Expert Panel Process</td>
</tr>
</tbody>
</table>
Expert Panel Process (April to May 2013)

1) The researcher randomly selected 26 codes from the open coding process. Each panel member received an email with an attachment, which included the full list of open codes. The selected codes were highlighted. Each member also received the statements from study participants linked to each code. Each member looked through their selected codes and the linked statements while asking the following questions.

- Does it make sense?
- Do the statements fit under the right headings?
- Is the process rigorous? Is the process clear?

2) The researcher provided detailed information from the axial coding phase. Each member looked through the data and asked the following questions.

- Does it make sense?
- How credible is the researcher’s interpretation?

3) The panel met in May 2013 at a convenient time in Aras Moyola and discussed the data analysis process. Members of the panel commented that the results were very interesting and that the process was clear and that they felt that the researcher’s interpretations were accurate.
<table>
<thead>
<tr>
<th>Appendix N</th>
<th>Consent Form for Adult Participants</th>
</tr>
</thead>
</table>

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CONSENT FORM

FOR

Research project titled “Understanding early intervention services in Ireland: a conceptual evaluation developed from case studies”

I_____________________________________ have read the information leaflet (Print name) regarding the above named project and I understand its content. I understand my role in the project and consent for to take part. I have had the opportunity to ask questions. I consent to the interviews being tape-recorded and for anonymous quotations to be used from my interview in the research report. I understand that I can withdraw my consent at any time during the research.

Signed: _____________________________________________

Print Name: ___________________________________________

Parent/Carer/Guardian/Professional _________________________

Witness: ______________________________________________

Print Name: ___________________________________________

Date: _________________________________________________
| Appendix O1 | Consent Form for Families for Child Participants |
CONSENT FORM
FOR
Research project titled “Understanding early intervention services in Ireland: a conceptual evaluation developed from case studies”

I_____________________________________ have read the information leaflet regarding the above named project and I understand its content. I understand our role and my child’s role in the project and consent for __________________________ to take part and I have had the opportunity to ask questions. I consent to the interviews being tape recorded and for anonymous quotations to be used from my child’s interviews in the research report. I understand that I can withdraw my consent at any time during the research.

Signed: ________________________________
Print Name: ________________________________
Relationship with Child: Parent/carer/guardian

Witness: ________________________________
Print Name: ________________________________
Date: ________________________________

(Child’s name)
Appendix O2  Consent Form for Families for Child Consent
CONSENT FORM

FOR

Research project titled “Understanding early intervention services in Ireland: a conceptual evaluation developed from case studies

Signed: ________________________________

Print Name: ____________________________________________________________

Witness: _______________________________________________________________

Relationship to Client: Carer/Spouse/Parent (delete as appropriate) __________

Date: ____________________________________________________________________
<p>| Appendix P | Open Codes: Through the analysis process 285 codes emerged from the open coding phase |</p>
<table>
<thead>
<tr>
<th>Phase 1 - Open Codes (285 Codes Developed)</th>
<th>Code Definitions for Consistency (rules for inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to accept</td>
<td>Reference to parents ability to accept advice and information</td>
<td>10</td>
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<tr>
<td>Accepting disability</td>
<td>Reference to accepting the disability</td>
<td>5</td>
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<tr>
<td>Accepting feedback</td>
<td>Reference to ability to accept feedback and criticism</td>
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<td>0</td>
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<tr>
<td>Accepting level of ability</td>
<td>Reference to accepting level of ability and realistic expectations of level of achievement</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Accepting service level</td>
<td>Reference to putting up with or being compliant with service provision and what is on offer</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Acknowledging disability</td>
<td>References referring to acknowledging the disability and taking it into consideration in assessment and interventions</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Acknowledging parents</td>
<td>Reference to professionals acknowledging parents and their opinions and views. The parents feel listened to.</td>
<td>13</td>
<td>32</td>
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<tr>
<td>Activity in the home</td>
<td>Reference to child playing activity in home</td>
<td>9</td>
<td>74</td>
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<td>Phase 1 - Open Codes (285 Codes Developed)</td>
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<tr>
<td>Adaptability and flexibility</td>
<td>Reference to making changes to accommodate others i.e. other professionals, parents, self, being flexible</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td>Amusing</td>
<td>Reference to amusing</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Reference to anxiety and worry in relation to self, involvement with families, team, therapy, intervention</td>
<td>18</td>
<td>68</td>
</tr>
<tr>
<td>Appreciation</td>
<td>References to parents’ appreciation for services and intervention</td>
<td>5</td>
<td>7</td>
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<tr>
<td>Approaches to intervention</td>
<td>References relating to named approaches e.g. family centred, social model. Defining and describing EI and the service delivery provided</td>
<td>17</td>
<td>64</td>
</tr>
<tr>
<td>Assessment of child</td>
<td>References to assessment of child and reasons for assessment and purpose of assessment</td>
<td>14</td>
<td>31</td>
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<tr>
<td>Assessment of need influences</td>
<td>Reference to influences on Assessment of Need</td>
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<tr>
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<tr>
<td>Assessment outcome</td>
<td>Reference to what happens after assessment</td>
<td>13</td>
<td>29</td>
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<tr>
<td>Assessment procedure</td>
<td>References related to assessment within the team of child and family</td>
<td>17</td>
<td>65</td>
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<td>Assumed collaboration</td>
<td>Reference to assumptions or perceptions that collaboration is happening</td>
<td>5</td>
<td>10</td>
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<tr>
<td>Assuming</td>
<td>Reference to professionals making assumptions about what parents think and about who is involved with families</td>
<td>22</td>
<td>53</td>
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<td>Attachment</td>
<td>Reference to feeling attached and close to each other</td>
<td>3</td>
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<td>Authority</td>
<td>References to decision making and dictating what a team member should do or a professional should do</td>
<td>9</td>
<td>17</td>
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<tr>
<td>Awareness</td>
<td>Reference to parents’ awareness of what is happening</td>
<td>17</td>
<td>35</td>
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<tr>
<td>Awkwardness</td>
<td>References to feeling awkward interacting with families or professionals</td>
<td>4</td>
<td>7</td>
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<tr>
<td>Phase 1 - Open Codes (285 Codes Developed)</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
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<tr>
<td>Bad days</td>
<td>Reference to bad days and feeling down</td>
<td>8</td>
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<tr>
<td>Being different</td>
<td>Reference to differences, uniqueness and linked to individuality</td>
<td>5</td>
<td>16</td>
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<tr>
<td>Biggest Change</td>
<td>Reference to big changes linked to the transition with over six years</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Blame</td>
<td>Reference to blame game and whose fault it is. Possibly linked to conflict and parent expectations and motivation</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Boundaries</td>
<td>Reference to boundaries professional v personal. May link with roles within the team</td>
<td>22</td>
<td>106</td>
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<tr>
<td>Building relationships</td>
<td>Reference to building relationships with families</td>
<td>15</td>
<td>47</td>
</tr>
<tr>
<td>Child difficulties</td>
<td>Reference to child difficulties, impairments.</td>
<td>21</td>
<td>103</td>
</tr>
<tr>
<td>Child needs</td>
<td>relates to statements about child needs in terms of service, therapy,</td>
<td>23</td>
<td>87</td>
</tr>
<tr>
<td>Child's decision</td>
<td>Reference to child's decision making</td>
<td>15</td>
<td>37</td>
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</tbody>
</table>
## Phase 1 - Open Codes (285 Codes Developed)

<table>
<thead>
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<tbody>
<tr>
<td>Reference to child's personality</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Reference to child recognising</td>
<td>6</td>
<td>29</td>
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<tr>
<td>Reference to child's current skills</td>
<td>15</td>
<td>105</td>
</tr>
<tr>
<td>References to working together</td>
<td>21</td>
<td>65</td>
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<tr>
<td>Reference to ways to communicate and interact with the child</td>
<td>16</td>
<td>142</td>
</tr>
<tr>
<td>Reference to child communicating and interacting with parent during activities</td>
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<td>177</td>
</tr>
<tr>
<td>Reference to child interacting and communicating with professionals during sessions or in other activities</td>
<td>19</td>
<td>79</td>
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<tr>
<td>Reference to the importance of communication. Linked to sharing information and interacting with families and interacting with</td>
<td>5</td>
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<tr>
<td>Phase 1 - Open Codes (285 Codes Developed)</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
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<tr>
<td></td>
<td>professionals</td>
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<td>Conflict by misinterpretation</td>
<td>Reference to professionals misreading information</td>
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<tr>
<td>Conflict with assessment</td>
<td>Reference to issues and struggles arising from assessment</td>
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</tr>
<tr>
<td>Conflict with management</td>
<td>Reference to conflict or issues that arise with management and leadership of staff</td>
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<tr>
<td>Conflict with meeting needs</td>
<td>Reference to clashes caused by trying to meet needs</td>
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<tr>
<td>Conflict with role</td>
<td>Reference to conflict with role description</td>
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<td>Conflict with scheduling</td>
<td>Reference to struggles with scheduling, how scheduling causes a struggle or disagreement</td>
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<tr>
<td>Phase 1 - Open Codes (285 Codes Developed)</td>
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<td>Confusion</td>
<td>Reference to confusion and uncertainty around what parents are expected to do, unclear instructions</td>
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<tr>
<td>Consistency</td>
<td>Reference to being consistent in delivering a service, continuity of care</td>
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<tr>
<td>Contentment</td>
<td>Reference to feeling content and happy</td>
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<td>Continuous learning</td>
<td>Reference to continuous learning or still learning</td>
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<tr>
<td>Continuous professional development</td>
<td>Reference to any courses, reading e.t.c. that professionals have done to expand their knowledge</td>
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<tr>
<td>Continuous structure</td>
<td>Reference to ongoing structure and routines for child</td>
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<td>Coping</td>
<td>Reference to coping with disability, child, changes</td>
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<tr>
<td>Coordinating</td>
<td>References related to team coordinator role in terms of job</td>
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<tr>
<td>leadership</td>
<td>description, need for role,</td>
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<tr>
<td>Cover or relief</td>
<td>Reference to cover when a professional is off</td>
<td>7</td>
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<tr>
<td>Creating awareness or insight</td>
<td>References related to enhancing the awareness of parents’ knowledge and insight</td>
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<tr>
<td>Creating expectations</td>
<td>Reference to professionals setting up parents’ expectations, too high or too low</td>
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</tr>
<tr>
<td>Credit</td>
<td>Reference to praise and credit of professionals, parents, courses</td>
<td>19</td>
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<td>Dealing with conflict</td>
<td>Reference to dealing with differences of opinion and conflict</td>
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<td>Defiance</td>
<td>Reference to standing up and defying authority. Linked to conflict</td>
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<td>Dependency</td>
<td>Reference to fostering parents’ dependency or feeling dependent</td>
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<td>Devastated</td>
<td>Reference to feeling devastated</td>
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<td>Reference to child developing and making progress.</td>
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<td>Reference to times in families lives when it is difficult or hard</td>
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<td>Reference to being told not to worry</td>
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<td>5</td>
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<tr>
<td>References related to schooling</td>
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<tr>
<td>References to assessment requirements for entry, assessment needs.</td>
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</tr>
<tr>
<td>References to planning for school and finding the school and what is involved</td>
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</tr>
<tr>
<td>Reference to differences between the two services, disorders, demands</td>
<td>5</td>
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<tr>
<td>Empowering</td>
<td>Reference to empowering families, professionals giving parents the abilities to interact, communicate, help their child</td>
<td>11</td>
</tr>
<tr>
<td>Engaging with other services</td>
<td>Reference to parents engaging with private services and other interventions. Services outside the organisation that they may be attending. Having other options to consider</td>
<td>13</td>
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<td>Enjoying therapy</td>
<td>Reference to children enjoying interventions and responding positively</td>
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<td>Evolving</td>
<td>Reference to people evolving and changing</td>
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<td>Expectations for child</td>
<td>Reference to expectations of progress, development of child</td>
<td>18</td>
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<tr>
<td>Expectations for school</td>
<td>Reference to what parents are expecting or want for education</td>
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<td>Expectations of professionals</td>
<td>References related to what professionals expect of parents</td>
<td>16</td>
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<tr>
<td>Expectations of service</td>
<td>Reference to what professionals and parents expect from particular professionals</td>
<td>22</td>
</tr>
<tr>
<td>Expectations of therapy</td>
<td>Reference to expectations of attending therapy. More general expectations than specific to child or parent</td>
<td>12</td>
</tr>
<tr>
<td>Expense</td>
<td>Reference to costs of equipment and expenses</td>
<td>10</td>
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<tr>
<td>Expert driven</td>
<td>Professionals make decisions without consulting with families</td>
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<tr>
<td>Familiarity</td>
<td>References to being familiar and comfortable in situations and developing familiarity with people and places</td>
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</tr>
<tr>
<td>Family benefits</td>
<td>Reference to other benefits from the therapy and service interactions for the rest of the family not just the child with the disability</td>
<td>11</td>
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<tr>
<td>Family support</td>
<td>Reference to families supporting themselves and extended family</td>
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<tr>
<td>Fear</td>
<td>Reference to fear of moving into new role and being accepted and</td>
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<tr>
<td>Feedback</td>
<td>Reference to feedback received or given</td>
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</tr>
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<td>Feeling guilty</td>
<td>Reference to parents feeling guilty</td>
<td>6</td>
</tr>
<tr>
<td>Feeling part of the team</td>
<td>Reference to feeling part of the team and to feeling acknowledgement from fellow professionals. Feeling accepted on the team. This acknowledgement will help building of relationships and the sharing of information</td>
<td>9</td>
</tr>
<tr>
<td>Feeling prepared</td>
<td>References to parents feeling prepared for future activities, events, situations</td>
<td>8</td>
</tr>
<tr>
<td>Feeling secure</td>
<td>References to feeling secure with the intervention being provided</td>
<td>3</td>
</tr>
<tr>
<td>Fighting</td>
<td>Fighting for service</td>
<td>9</td>
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<tr>
<td>Finding the balance</td>
<td>Reference to balance, equilibrium</td>
<td>12</td>
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<td>First impressions</td>
<td>Reference to first impressions of intervention or team or professionals</td>
<td>8</td>
</tr>
<tr>
<td>Freedom</td>
<td>Reference to freedom to do things and make changes</td>
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**Code Isolation**

*Interviews\Child 1 Visit 1* - § 2 references coded [0.14% Coverage]

I don’t feel involved in his goals.
I will be left

*Interviews\Child 3 Visit 1* - § 1 reference coded [0.10% Coverage]

Like she was on her own you see like because you’d go off your head like.

*Interviews\Child 5 Visit 1* - § 4 references coded [0.68% Coverage]

So some mornings if I’m the one doing it, well I want to do it but I feel a bit lonely if I’m out in the kitchen doing the work and somebody else is doing it for him.

Trying to get that emotional thing, and then you’re on your own again.

Because you’re on your own doing the planning you know.

Because parents have to do it on our own

*Interviews\Parent 3* - § 1 reference coded [0.06% Coverage]

Because it can be a lonely place originally.

*Interviews\Prof 1* - § 1 reference coded [0.25% Coverage]

The days of thinking that you are going to do the job yourself is like totally crazy you know.

*Interviews\Prof 10* - § 2 references coded [0.40% Coverage]

I know, but I suppose it is Freudian in a way, I suppose in the fact that the psychology is very interesting, but anyway it is Freudian in a way in that I do feel I’m the only social worker in the team, annoys me sometimes.

Because I just would love someone else could help sometimes, right

*Interviews\Prof 11* - § 4 references coded [0.42% Coverage]

But I had a huge feeling of just being isolated really.

So we found we’ve kind of moved away from getting involved with OT and PT at very early age I think we (SLT) kind of work a lot more in isolation and we are working separate from that,
But there’s very few situations where I see kids on my own really. I think sometimes we go off and we do our own little things. We might do it as individuals but I don’t think as a team. While like I might have my own assessment, my own just kind of like the department assessment and physios would have theirs and speech therapists would have their version. So we’d all make our own notes.

I prefer that they do their own section and that’s why I’ve let it run. SLTs do their own.

Code Isolation

It is possible that I will be distanced a little bit.

Again you’re very much working on your own when you’re out in the home environment,

And I became very aware of my own vulnerability working in isolation with a family

But also you have nearly somebody to support you in there, sort of going into residential area often you’d now go in with a physio doing stuff, not just on your own.

I suppose when I was initially here everything was done in isolation and I was doing it on my own.

Because I spent so long out in the trenches on my own fighting things.

Which is their own OT assessment.
CODE EMPOWERING

Interviews\Child 4> - § 2 references coded [0.67% Coverage]
It made me really look at myself and how I deal with him. Sometimes I might go on my own agenda instead of taking the time and standing back and listening to him. Looking back on yourself on the video wasn’t easy.

Interviews\Child 5 Visit 1> - § 3 references coded [0.82% Coverage]
And I think it’s a great help with the speech therapist too because the parent then click into what they’re doing, really clued in
Men find it hard to do this funny talk. No it’s not funny talk, it’s simple, down to earth children talk. I think men don’t find it, maybe the modern, I’d say my brother in law would find all that stuff interesting but it doesn’t come naturally to him. It’s a woman thing.

Parent 2> - § 7 references coded [1.31% Coverage]
Oh the points of reference. So we use points of reference throughout the day and gradually I remember we talk, and I was thinking, how are we going to incorporate them into our day but we’re actually doing it anyway. And we wouldn’t have known, even I see everybody’s kids now and they’re slouching in their buggies and I’m going, fix them.
Yeah or people if they’re feeding a baby too fast now, I’m thinking, oh no.
A bit of information is a dangerous thing.
The team leader definitely. I don’t think if I had taken respite care or if I hadn’t let other people in, he wouldn’t have fed for anybody else. He wouldn’t, I was getting to the stage where if my husband was feeding him I’d have to check after feeding him, is he doing it right? Is he doing it right?

Interviews\Parent 3> - § 8 references coded [1.27% Coverage]
And then to have to go and say how am I going to help him now and the good thing about those actually is it kind of, it makes you realise yeah, I’m doing it, I’m all right, I’m doing the right thing and that’s huge. It’s like, I’m on the right road I’m doing the best I can do. And that’s a huge thing,
CODE EMPOWERING

You’re aware of those slight differences. I mean me, I speak very quickly as you can see but even when we did the Hanen course, they videoed us and you could see how you are and then I’ve slowed down with my son. And I have also slowed down with my daughter, so it’s benefitted her as well.

Like things, an example of it there now when my daughter was reading first. I would kind of jump in with, if she was struggling with a word I would jump in with the word. But after doing Hanen, I stopped.

I learnt that for him but I was doing it with her.

Now having said that I suppose we’ve learned a lot in the

We’ve a lot of skills now. So we will keep it up ourselves like obviously but

Interviews\Parent 4\> - § 1 reference coded [0.66% Coverage]

I’ve video tapes of sessions because certain things you wouldn’t see, wouldn’t be aware of yourself until you see it on video and they say to you, because I’ve an awful bad habit of if my daughter says something I go, yeah ah ha, you know, kind of, and they say no

Repeat what she says. So you wouldn’t realise it until you see it on the video. It’s very good.

Interviews\Parent 5 (Mother & Father)> - § 3 references coded [3.28% Coverage]

Whereas before I would never have heard it. We listen now to

So this course has been very good in making you kind of stop and slow down.

We’re wording, we’re stressing everything to her, before look at the froggie, now look at the green froggie.

That’s all from the course really.

Yeah more looking at ourselves and the way we were with her every day, like we’d be talking away but you’d never take any notice of what we’re saying so whereas now you kind of, you stretch things more and repeat more.

So we’re finding that very good

We’re picking up now bits from them. By just watching them.

Like the speech therapists are constantly signing so you kind of pick up the ones that are relevant to you.
CODE EMPOWERING

We’re doing more signs since that course I think. Yeah, certain ones you’d always do, breakfast and certain ones around routines I suppose.

Interviews \ Prof 15> - § 2 references coded [1.09% Coverage]

So I enable the child. I enable the parent to facilitate the child hence they’re the people to do it and then you enable the family to move on.

So yeah I do but I mean as I said I do think it’s great they have support when they need it or whatever but there must be a point where they feel that they’re empowered, yeah. And they tap into it as needed to empower them.

So I think you have to keep just enabling them, the family, to the same kind of way.

It should be all about that no matter what way you’re doing it, if you’re supporting them at the time or whatever.

Interviews \ Prof 17> - § 1 reference coded [0.11% Coverage]

Sometimes you can say things but sometimes you’ve to wait your time which I find hard.

Interviews \ Prof 5> - § 4 references coded [1.37% Coverage]

Would be very much the behaviour again and looking at how to work with your child and work with their behaviours and set them up for success and use the rules and everything and parents are very well clued into that.

Give her the medical stuff and have her to read it and just say look, have a look at all that, come back to me and if there’s anything you need explaining I’ll explain it.

So it’s again just giving them that empowerment again and respect really also.

So using the word with their disability and with their learning disability all the time and we can build on it and further develop them.

And I’m going, yes, yes because then they’re actually making the decision to move on. I’m not making it for them you know. And I’m saying yeah, I’m delighted you said that. And then once you start moving it on you move it on and you’re down the ladder in no time.
It really would be a lot with the family again but I think again going back to are they deciding, they decide within intervention once they become familiar how it works I suppose, the system.

And again having them feel secure that they can say I want this from you, that they feel they can ask you, they too have a voice within the therapy session; say this is something I really want to target.

We run an awful lot of training to support family awareness as well and understanding. Because it really is their understanding about (a) their child has a disability, the impact on the family, the impact on them, their role within this therapeutic setting, their role as therapist assistant we'll say as well as being mum and carrying out exercises at home and being on board with us and their role only evolves in time once they’ve kind of built up that rapport with you.

And I think coming in and hopefully experiencing a very open communication style within EI, a very parent and family service that they feel equipped to expect that from other services, you know, on their journey and they feel confident and feel that they’ve had so much support here that they feel well they can request that support, that that’s what's expected.

They feel empowered.

And the level of support. I suppose again that they feel empowered, that they've been equipped with so much skills here also that they’d have the confidence to keep going themselves as well. Yeah it is such a long journey for them.

We feel empowered, I suppose try and empower the family to understand that and this is why we’re focusing on, regardless of whether he has A, B, C or D, whatever that tells us we’re going to look at the skillset he has now and where we can bring him with that.

If we can set them up within this short time span that they understand our roles, that they feel empowered and feel they’ve been given, I suppose empowered they too can do it. They can do it and they can make it. As you say one parent said they’ll be fine, and they will be fine but it’s believing that you’ve had such support and feel empowered that you can do it and knowing who to ask then because you’re now empowered with awareness of what such and such a role is, this problem arises, I
CODE EMPOWERING

know who to ask, I need to go to speak to an SLT, I need to go and address this with so and so. That they know that.

and while we’ve supported them so much we’ve also supported them to make those connections, that they then can keep going and have that strength and when they go to school that they can, they have those other parents that they know are familiar with, empower them as well and if things arise they feel they can ask or make demands if they need to.

Interviews\\Prof 9> - § 1 reference coded [0.38% Coverage]

It needs to be kind of a mixture of all the different types. I suppose it’s our job to keep kind of educating parents on what therapy involves because if they feel they’re getting the message that one to one is the best well then we need to continuously show them why training is important, looking at the research and what is actually working.
| Appendix R | Axial Codes: The researcher distilled the open codes during axial coding and 15 categories emerged. |
## Phase 2 – Axial Codes

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<td>Child Influence</td>
<td>Refers to the influence and power that the child has in the relationship</td>
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<td>Refers to the expectations and outcomes a person expects to receive in the relationship. This is based on a person's past relational experiences, and personal observations of other people's relationships. People will be satisfied when their outcomes meet or exceed their comparison levels.</td>
<td>29</td>
<td>542</td>
</tr>
<tr>
<td>Costs and Rewards</td>
<td>People are motivated to be in relationships that provide them with high level of rewards and low level of costs</td>
<td>12</td>
<td>37</td>
</tr>
<tr>
<td>Dependence</td>
<td>Refers to families having more to lose from termination of the relationship. How parents perceive the quality of alternatives impacts on dependence</td>
<td>29</td>
<td>272</td>
</tr>
<tr>
<td>Disabling</td>
<td>Refers to how influence can cause hesitation or 'chilling effect' and cause fear</td>
<td>29</td>
<td>217</td>
</tr>
<tr>
<td>Phase 2 – Axial Codes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
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<tr>
<td>----------------------</td>
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<td>-----------------------</td>
</tr>
<tr>
<td>Enabling</td>
<td>Refers to the use of influence for success and for learning to help child development and growth</td>
<td>31</td>
<td>333</td>
</tr>
<tr>
<td>Imbalance</td>
<td>Refers to influence being a manipulator and creating imbalances in the relationships and conflicts</td>
<td>29</td>
<td>395</td>
</tr>
<tr>
<td>Interaction Process</td>
<td>Refers to the interactions between the team members and others. Incorporates influence, dependency, enablers, disabling</td>
<td>31</td>
<td>907</td>
</tr>
<tr>
<td>Investment</td>
<td>Refers to resources that are attached to the relationship and help predict commitment. They would decline in value or be lost if the relationship were to end. Can be intrinsic in terms of time and effort. Extrinsic in terms of resources or benefits, identity and being part of a group.</td>
<td>23</td>
<td>160</td>
</tr>
<tr>
<td>Other Services and Factors</td>
<td>Other services that participants engage with such as education and the impact of changes in the organisation</td>
<td>18</td>
<td>115</td>
</tr>
<tr>
<td>Phase 2 – Axial Codes  (15 Codes Developed)</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
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</tr>
<tr>
<td>Parent Influence</td>
<td>Refers to the influence parents have to effect change in their child</td>
<td>32</td>
<td>750</td>
</tr>
<tr>
<td>People in the Relationship</td>
<td>Refers to who the players are and their profiles, that is what do they look like?</td>
<td>32</td>
<td>908</td>
</tr>
<tr>
<td>Professional Influence</td>
<td>Refers to the influence the professional has to effect change in children and families</td>
<td>30</td>
<td>492</td>
</tr>
<tr>
<td>Relationship Stages</td>
<td>Refers to the team process and stages of relationship formation</td>
<td>32</td>
<td>1427</td>
</tr>
<tr>
<td>Appendix S</td>
<td>Selective Codes: The categories were further distilled to four emergent themes. Through constant comparative analysis, reading and interpretation the central phenomenon of synergistic interdependent relationships in EI was illuminated from the data</td>
<td></td>
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</tr>
</tbody>
</table>
### Dynamic Interdependent Relationships in Early Intervention

- **Consequences**
  - **Desired Consequences:** Refers to the consequences of the relationship that are desired and favourable. High level of desired consequences indicate satisfaction with the relationship.
  - **Enabling:** Refers to the influencers and drivers enabling success for learning to help child development and growth.

<table>
<thead>
<tr>
<th>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</th>
<th>Code Definitions for Consistency (rules for inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dynamic Interdependent Relationships in Early Intervention</strong></td>
<td>Refers to the early intervention relationship between families and professionals being a dynamic and interdependent one. The people involved and the influence they have drives the relationship forward. Their driving forces are restrained by a number of factors in the relationship and need to be considered throughout the dynamic relationship stages. Covariance exists between the drivers and the restraining factors. There are consequences to the relationship, both desired and undesired outcomes.</td>
<td>33</td>
<td>9380</td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td><em>Refers to outcomes of the relationship. These may be positive or negative consequences.</em></td>
<td>32</td>
<td>2810</td>
</tr>
<tr>
<td><strong>Desired Consequences</strong></td>
<td>Refers to the consequences of the relationship that are desired and favourable. High level of desired consequences indicate satisfaction with the relationship</td>
<td>32</td>
<td>1375</td>
</tr>
<tr>
<td><strong>Enabling</strong></td>
<td>Refers to the influencers and drivers enabling success for learning to help child development and growth.</td>
<td>31</td>
<td>333</td>
</tr>
<tr>
<td>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
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<td>Units of Meaning Coded</td>
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</tr>
<tr>
<td>Rewards</td>
<td>Refers to benefits or outcomes of the relationship. People are motivated to be in a relationship when rewards are high</td>
<td>32</td>
<td>1042</td>
</tr>
<tr>
<td>Undesired Consequences</td>
<td>Refers to the negative outcomes of the relationship. Low level of negative consequences is required to maintain motivation in the relationship.</td>
<td>31</td>
<td>1435</td>
</tr>
<tr>
<td>Costs</td>
<td>Refers to negative consequences or losses from the relationship. People are motivated to be in relationships that provide them with low level of costs.</td>
<td>31</td>
<td>823</td>
</tr>
<tr>
<td>Disabling</td>
<td>Refers to how the influencers can cause hesitation or 'chilling effect' and cause fear</td>
<td>29</td>
<td>217</td>
</tr>
<tr>
<td>Imbalance</td>
<td>Refers to the influencers in the relationship manipulating and creating imbalances in the relationships and creating conflicts</td>
<td>29</td>
<td>395</td>
</tr>
<tr>
<td>Driving Factors</td>
<td>Refers to the driving factors in the relationship, relationship enhancers, influences the restraining factors in the relationship.</td>
<td>32</td>
<td>2501</td>
</tr>
<tr>
<td>Therapeutic Relationship</td>
<td>This refers to the microsystem of the relationship. The people who are involved in the therapeutic triangle, their profiles and how they</td>
<td>32</td>
<td>2501</td>
</tr>
<tr>
<td>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
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<tr>
<td>-----------------------------------------------------------</td>
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</tr>
<tr>
<td>Child Influence</td>
<td>Relates to the influence and power that the child has in the relationship</td>
<td>29</td>
<td>244</td>
</tr>
<tr>
<td>Parent Influence</td>
<td>Refers to the influence parents have to effect change in their children and their influence in the relationship</td>
<td>32</td>
<td>669</td>
</tr>
<tr>
<td>People Profiles</td>
<td>Refers to who are the players in the picture and what are their profiles. What do they look like?</td>
<td>32</td>
<td>1086</td>
</tr>
<tr>
<td>Professional Influence</td>
<td>Refers to the influence the professional has to effect change in children and families</td>
<td>29</td>
<td>502</td>
</tr>
<tr>
<td><strong>Restraining Factors</strong></td>
<td>Refers to factors that impact on the relationship and influence the driving factors in the relationship.</td>
<td>33</td>
<td>3887</td>
</tr>
<tr>
<td>Relationship Stages</td>
<td>Refers to the stages of relationship formation within the team process. Could be perceived as the chronosystem of the relationship</td>
<td>33</td>
<td>1669</td>
</tr>
<tr>
<td>Initiating Stage</td>
<td>Refers to getting involved in the team and initiation of the process</td>
<td>27</td>
<td>339</td>
</tr>
<tr>
<td>Experimenting Stage</td>
<td>Refers to the start of developing the relationship, getting started</td>
<td>27</td>
<td>245</td>
</tr>
<tr>
<td>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
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<td>------------------------</td>
</tr>
<tr>
<td>Integrating Stage</td>
<td>Refers to the development of a relational identity; parents and professionals see themselves as part of a team and they disclose and share information openly</td>
<td>28</td>
<td>425</td>
</tr>
<tr>
<td>Intensifying stage</td>
<td>Refers to progressing the relationship to a closer one. Connections and trust have emerged from the experimentation phase. Deepen the level of closeness. Called the affective exchange stage. Openness and disclosure</td>
<td>31</td>
<td>522</td>
</tr>
<tr>
<td>Transitioning Stage</td>
<td>Refers to the ending of the relationship and moving on</td>
<td>25</td>
<td>138</td>
</tr>
<tr>
<td>Investment</td>
<td>Refers to resources that are attached to the relationship and help predict commitment. They would decline in value or be lost if the relationship were to end. Can be intrinsic in terms of time and effort, extrinsic in terms of resources or benefits, identity and being part of a group</td>
<td>32</td>
<td>443</td>
</tr>
<tr>
<td>Intervention</td>
<td>Refers to the benefits from being involved in the relationship</td>
<td>28</td>
<td>198</td>
</tr>
<tr>
<td>Motivation</td>
<td>Refers to intrinsic motivation and may be linked to reasons to work in EI</td>
<td>12</td>
<td>34</td>
</tr>
</tbody>
</table>
### Phase 3 – Selective Coding: Core Category Mapped to 4 Themes

<table>
<thead>
<tr>
<th>Code Definitions for Consistency (rules for inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team Factors</td>
<td>Refers to the factors that help the professionals feel part of the team</td>
<td>5</td>
</tr>
<tr>
<td><strong>Dependence</strong></td>
<td>Refers to families having more to lose from termination of the relationship. How parents perceive the quality of alternatives impacts on this</td>
<td>25</td>
</tr>
<tr>
<td><strong>Alternative Services</strong></td>
<td>Refers to the types of alternatives that people perceive they have outside the current relationship (Thibaut &amp; Kelley, 1959)</td>
<td>18</td>
</tr>
<tr>
<td>Engaging with other services</td>
<td>Refers to parents engaging with private and other interventions. Services outside the organisation that they may be attending. Having other options to consider</td>
<td>13</td>
</tr>
<tr>
<td>Fighting</td>
<td>Refers to fighting for services</td>
<td>9</td>
</tr>
<tr>
<td><strong>Comparison</strong></td>
<td>Refers to the expectations that of the kinds of outcomes the a person expects to receive in the relationship. This is based on a person's past relational experiences, and personal observations of other people's relationships. People will be satisfied when their outcomes meet or exceed their comparison levels</td>
<td>30</td>
</tr>
<tr>
<td>Anticipations</td>
<td>Refers to the expectations of therapy, service, professionals have of parents, hopes for the child and for school</td>
<td>29</td>
</tr>
<tr>
<td>Appraisal</td>
<td>Refers to parents making judgements based on past relational</td>
<td>27</td>
</tr>
<tr>
<td>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Observations</td>
<td>This refers to perceptions of the relationship based on perceptions of roles, organisation, child, early intervention.</td>
<td>23</td>
</tr>
<tr>
<td>Interaction Process</td>
<td><strong>Refers to the interactions between the team members and with others.</strong>&lt;br&gt;<strong>Incorporates influence, dependency, enablers, disabling</strong></td>
<td>32</td>
</tr>
<tr>
<td>Avenues</td>
<td>Refers to how people interact with each other, what methods are in place to facilitate interaction</td>
<td>24</td>
</tr>
<tr>
<td>Key Factors</td>
<td>Refers to the key factors that are important for the interaction between all in the relationship</td>
<td>26</td>
</tr>
<tr>
<td>With Whom</td>
<td>Refers to who interacts with whom in the relationship</td>
<td>32</td>
</tr>
<tr>
<td><strong>Macro level Context</strong></td>
<td><strong>This refers to the context for the therapeutic relationship and is linked to macro level influences within Bronfenbrenner’s Ecological Model</strong></td>
<td>25</td>
</tr>
<tr>
<td><strong>Other services and Organisational</strong></td>
<td><strong>Refers to macro level influences on the relationship. Refers to the changes that are evolving. This is also linked to influence as a disabler and imbalance as it is</strong></td>
<td>18</td>
</tr>
<tr>
<td>Phase 3 – Selective Coding: Core Category Mapped to 4 Themes</td>
<td>Code Definitions for Consistency (rules for inclusion)</td>
<td>Interviews Coded</td>
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<td>-----------------------------------------------------------</td>
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<tr>
<td>factors</td>
<td>management and government forcing the changes. Some perceptions are positive meaning an enabler</td>
<td></td>
</tr>
<tr>
<td>Organisational change process</td>
<td>Refers to changes in service or organisation</td>
<td>13</td>
</tr>
<tr>
<td>Education</td>
<td>Refers to schooling</td>
<td>14</td>
</tr>
<tr>
<td>Education Requirements</td>
<td>Refers to assessment requirements for entry, assessment needs.</td>
<td>8</td>
</tr>
<tr>
<td>Educational Future</td>
<td>Refers to planning for school, finding the school and what is involved</td>
<td>10</td>
</tr>
</tbody>
</table>
### Appendices

<table>
<thead>
<tr>
<th>Appendix T</th>
<th>Examples of Memos</th>
</tr>
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</table>

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Name: building relationships

Frequency of contact helps build closer relationships and subsequently professionals know their needs better. Linked to prioritising between parents and professional goals and expectations. Linked possible to negotiating and finding the balance. Is knowing dependent on relationship? Is relationship dependent on frequency of contact?

Link with lack of continuity and impact on meeting needs

‘If I was seeing her once every 3 or 6 months we would not have been able to tease out some of those things along the way’

Relationships between professionals and working together for long periods has developed familiarity with therapy activities and goals and facilitates the link between therapies and home. The professionals feel confident that the home support will provide the opportunities for parents to carry out the therapy goals and that the trust is there that the therapist feels confident about how the home support monitor the child's performance.

Understanding parents is important. Understanding parent roles, motivation, involvement, and interaction style. Understanding that the parents’ level of interaction is dependent on their level of motivation, acceptance, familiarity, personality, confidence, and dependency. Difficult times or emotional stance of parents can play a part on their level of interaction. Understanding that parents can be up and down, have other commitments, and may lack flexibility due to these commitments. Parents decide their own level of interaction, do they know what to expect, how they can be involved. Some parents depend on professionals and expect cure or fix, other parents understand that they must do and reinforce at home, other parents believe that they must lead the intervention for their child and seek other options, and others are subservient. Some assume teacher role and make materials and are highly motivated and possibly put pressure on themselves. Everyone has expectations of themselves and strive for their own goals and ambitions. Some are content and others strive for more. Parents are people and have expectations of their own roles and are using a service and have expectations and desires about a service. What do parents expect of themselves? How do they want to be involved? How parents interact in therapy can cause challenges for
professionals. How professionals interact can cause challenges to parents. Expectations of parents for therapy and education Expectations of professionals for parents.

**Example of ANALYTICAL MEMO**

The team is working in ways and has done independently to the organisation and to the geographical area. One way that has been leading it and trying to coordinate it in terms of the area is the intake forum and now there are other issues e.g. senior management and the organisation and its management putting pressure on the team in terms of making changes. So where the autonomy of the team is possibly at risk now and this uncertainty and change is impacting on it. Interacting with the model outing pressure on the model that has been established and set up within the team and within this niche within this organisation that has been let to evolve and develop and now maybe they are being now to put requirements on the team and I think that this is coming from local and national levels. It is the impact of the national policies impacting on the organisation, which then impacts on the team. Not sure how the individual line managers where they impact on the professional piece. How will that impact on the individual professionals.

It looks like it is very family centred in where the family is the centre the family is taken into consideration. The professionals have interactions with the parents with the siblings and with the children and with the grandparents (involved in training). Huge family involvement. Members of families are not alienated in the provision of care. References made to the journey. I need to think about the trajectory of the disability? The journey? Trajectory of illness? Is there a trajectory of disability and lifelong journey? I suppose a lot of the professionals and the parents that I have interviewed are considering the journey. They are thinking of the first few years of life and I am not sure if some of the professionals are thinking about the journey to beyond that 0-6 is the start and it should be positive and it should be setting them up for future interactions with services. I am not sure how the parents perceive that. One of the parents who was very knowledgeable about the changes that are afoot and was concerned about progressing into school age and leaving the organisation. Therapy care pathways in terms of the children who continue to need more and use
the organisation as it is and then there are other children who don’t now fit the model that the organisation present with moderate and severe disabilities. The children who are mild disability go back to the community so they leave. Because they have a diagnosis of Down syndrome they get into the service but they may not have a mod/severe disability. It is inconsistent and then this leads to uncertainty, as there are different pathways of care. No size fits all. Where do the interaction models fit and I do perceive it to be a responsive model of care rather than one that is paternalistic. It would look that way. It would look like those that are on the tertiary team I am considering the psychologist and the dietician and the medical professionals, doctors that are more on the periphery. They are coming from more medical model however I do think that when they are more within the team functioning dietician directly involved and psychologist this may change.
Appendix U

Factsheet for Family Participants
A Trajectory of Relationship Development for Early Intervention Practice

Each early intervention service is unique with interactions involving different people in different places. Families and professionals engage in a relationship to help the child with special needs meet their full potential. This means that the relationship is key to successful early intervention. Relationships between children, their parents and the professionals are complex and are dependent on a lot of different factors. A road map of explicit relationship stages is needed to facilitate all involved in the relationship to work together.

In 2012, 5 children (aged between 2 years and 5 years), 6 parents and 17 professionals shared their experiences of your early intervention service. A roadmap in the form of a developmental relationship trajectory emerged. This roadmap is shown below.

The people in this study recognised that interpersonal and professional relationships exist in early intervention. They also highlighted the importance of transitions also emerged.

The study highlighted that the early intervention relationship journey can begin, progress and end smoothly with

- Knowledge of the relationship stages
- Awareness of what stage each participant is at in the relationship
- Each partner taking personal accountability within the relationship.
| Appendix V | Presentation to EI Team and Professionals and Organisation Managers |
Your key contribution to:

A Model of Relationship Development for Early Intervention Practice

Clare Carroll
PhD Supervisor: Dr. Jane Sissmith
School of Health Sciences, NUI Galway

Celebrating your Contribution!

- Firstly, thank you so much to the children, the parents and the professionals who took part
- Thank you for sharing
  - your time
  - your experiences
  - your interest in research in EI to inform practice
- Thank you to Deirdre…

Aims of the study
- To understand an early intervention service from the stakeholders’ perspectives.
- To build a conceptual framework of constructs to facilitate early intervention services.

Study objectives
- To explore the stakeholders’ accounts of their experiences with their early intervention (EI) team.
- To identify and explore factors which facilitate and inhibit EI services from the stakeholders’ perspectives.
- To illuminate the processes within EI.
- To explore and evaluate the participation and contribution of children with disabilities to the research process.
- To determine conceptual constructs which frame a possible best practice model for Ireland.
A Trajectory of Relationship Development for Early Intervention Practice

Sharing Research Findings on 26/11/2014

A grounded theory approach within an in-depth qualitative case study design (Strauss & Corbin, 1990; Stake, 1995)

Parents
- 6 parents
- semi structured interviews

Professionals
- 17 HCPs
- semi structured interviews
- Observations of a team meeting and team assessment

Children
- Main Approach (Clark & Venn, 2001)
- 5 children
- Multiple interviews
- Respondents take images of the child's world
- Parents present at all times
- Discussion with parents
- Observation

Sharing Research Findings on 26/11/2014

Synaesthetic Interdependent Relationships in Early Intervention
Relationships are key!

- The EI relationship is a complex interdependent one which requires a roadmap of explicit stages, which can facilitate all involved in the relationship to work together.
- This study:
  - Provides this roadmap in the form of a developmental relationship trajectory.
  - Identifies a generic model, with transferability to other EI programs.
  - Identifies the importance of transitions in EI.
  - Includes the views of children, parents and professionals.

So.....

EI relationship journey can begin, progress and end smoothly

A Trajectory of Relationship Development for Early Intervention

1. Referral
2. Getting started
3. Sharing information
4. Support
5. Transitioning

Initiating Stage | Experimenting Stage | Integrating Stage | Intensifying Stage | Transitioning Stage

Sharing Research Findings on 26/11/2014
Sharing of research findings to date


Conferences


<table>
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<tr>
<th>Appendix W</th>
<th>Executive Summary for Organisation</th>
</tr>
</thead>
</table>

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Executive Summary

Background
In Ireland radical change is taking place in the provision of early services for children with special educational needs and disabilities (Government of Ireland, 2014). The guiding principles that inform all children’s and young people’s services are: children’s rights, family-oriented, equality, evidence informed and outcomes focused (Government of Ireland, 2014). The Health Service Executive (HSE) currently aims to ‘provide integrated services that meet the highest standards’ for those using disability services (HSE, 2015, p. 8). In September 2015, the United Nations (UN) General Assembly adopted new Sustainable Development Goals as part of the ‘Transforming our World: the 2030 Agenda for Sustainable Development’ (United Nations, 2015). The Sustainable Development Goals validate the work of early childhood professionals around the globe and set core actions for EI services to achieve, for example, Sustainable Development Goal 4 aims ‘to ensure equitable and inclusive quality education for early childhood development and to ensure lifelong learning’ (United Nations, 2015, p. 19).

Study
With the policy and legislative contexts driving change, early intervention services need to be informed by evidence from the perspectives of all who use them underpinned by concepts which are grounded in praxis. This study aimed to gain an understanding of the processes that facilitate integrated EI services for children with disabilities by including multiple perspectives in the Irish context. Because of the heterogeneity of EI service provision and the lack of research generally to support EI practice in Ireland, qualitative exploration was required. Data were collected from multiple perspectives within one early intervention disability service. In total, 31 indepth interviews with young children with disabilities, parents and professionals were undertaken and data were collected and interpreted in a coherent, systematic and rigourous way.
Outcome
A conceptual model, shown below, represents the study findings. This model can inform best practice early intervention services in Ireland. The concepts, which are integral to the model, can support the implementation and evaluation of best practice EI services.

The conceptual model acknowledges that:

1. Synergistic interdependent relationships exist in the early intervention context.

2. Key factors exist to support and hinder early intervention practice in order to support positive outcomes for the child and their family. For example:
   a. Understand how rewarding and enabling the service is to all involved in the relationship.
   b. Consider the goal of the partnership as one where the rewards exceed the costs.
   c. Balance the system influences and the people influences within the relationship.
3. Relationship Stages: The application of the relationship trajectory as a tool, within Irish family-oriented practice, would facilitate an understanding of each individual participant’s motivation to participate and a shared understanding that it is a developmental journey from initiation to transition (Carroll & Sixsmith, 2016a).

4. Listening to young children with disabilities has the potential to positively influence the services they receive. The knowledge and skills of the Speech and Language Therapist in early intervention can be recognised to support other team members to make their communicative participation a reality (Carroll & Sixsmith, 2016b).

The conceptual model can support:

1. Training for EI professionals and families to support family-oriented practice and shared decision making.

2. The development of strategic and operational plans to support national policies.

3. The development of quality indicators for practice to support measurable goals for EI services in Ireland.

4. The development of national guidelines for EI to allow a common framework to scaffold the complexity of EI practice across Ireland and support the progression of involving families in the delivery of services.
References

Carroll, C., Murphy, G., & Sixsmith, J. (2013). The Progression of Early Intervention Disability Services in Ireland. *Infants and Young Children, 26*(1), 1-88. doi: 10.1097/IYC.0b013e3182736ce6


