

**A qualitative case study exploring service users' and
providers' experiences of continuity of care when
transitioning from Early Intervention Teams -
The case of Autism Spectrum Disorder.**

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A thesis submitted for the degree of Master of Arts

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List of Abbreviations

AONO	Assessment of Need Officer
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
AT	Autism Therapist
CASP	Critical Appraisal Skills Programme
CFD	Community Facilitator for Disabilities
CICTF	Chronic Illness and Care Trajectory Framework
DA	Discourse Analysis
EI	Early Intervention
EIT	Early Intervention Team
EITM	Early Intervention Team Manager
FSW	Family Support Worker
GT	Grounded Theory
HSCT	Health and Social Care transition
HSE	Health Service Executive
IPE	Interprofessional education
IT	Institute of Technology
MCHB	The Maternal and Child Health Bureau
NA	Narrative Analysis
NDA	National Disability Authority
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapist
P	Parent
PACT	Preclinical Autism Consortium for Therapeutics
PCCC	Primary, Community and Continuing Care
PCCCT	Primary, Community and Continuing Care Team
PDS	Progressing Disability Services for Children and Young Adults
PT	Physiotherapist
SADT	School Age Disability Team
SAI	Sociological Association of Ireland
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech and Language Therapist
TRACK	The transition of care from Child and Adolescent Mental Health Services to Adult Mental Health Services
WHO	World Health Organization

Declaration

This work is submitted to fulfil the requirements of the degree of Master of Arts at Sligo Institute of Technology. No part of this thesis has been previously submitted at this or at any other third-level institution. Apart from due acknowledgements, it is entirely my own work.

Signed: _____

Date: _____

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Preface

In June 2017, I graduated from National University of Ireland: Galway as a Speech and Language Therapist. During my time there, I developed a love for research, in particular qualitative research. In the summer following graduation, an opportunity arose in IT Sligo to conduct a research master's degree which resonated with me. Firstly, it involved qualitative research and, secondly, it was related to health and social care. I, very fortunately, was offered the opportunity, which I gratefully accepted. Alongside the research commitments associated with this thesis, I have also been working as a community-based speech and language therapist (SLT) in the Health Service Executive (HSE). I provide therapy services to children with a variety of communication impairments. Some of these clients present with Autism Spectrum Disorder (ASD). This involves liaison with many other health and social care professionals, e.g. occupational therapists, clinical psychologists, public health nurses, community paediatricians and general practitioners.

In line with international guidelines, an inter-disciplinary team-based approach to care is seen as the highest standard of care for the child with ASD and their family. In line with international trends, HSE policies emphasise co-ordination of services and communication amongst health and social care professionals in an effort to create an integrated and seamless model of health care delivery and positive continuity of care experience for service users with ASD and their caregivers. However, even with these policies in place many professional and organisational contingencies continue to challenge this idealised model of health and social care delivery. The result is that the service users and caregivers I work with continue to voice concerns about fragmented care and informational and management continuity of care.

I thought that this master's opportunity would enhance my knowledge of inter-professionalism and continuity of care. I hoped that the inclusion of the service users' perspectives would increase my knowledge of the difficulties faced and provide me with practical ideas to best support them. I believed it would also allow me to build on my qualitative research skills and provide me with an opportunity to work in a multidisciplinary research team with social scientists, academic health and social care professionals and other primary care professionals. I began the Master's programme in September 2017.

Abstract

A qualitative case study exploring service users' and providers' experiences of continuity of care when transition from Early Intervention Teams - The case of Autism Spectrum Disorder.

Gráinne Quinn.

Seamless and continuous care across transitions are the gold standard for an individual with Autism Spectrum Disorder (ASD) when moving through services, agencies or organisations. However, little is known about the experience of continuity of care in this context. The aim of this study was to explore service users' and providers' perspectives of continuity of care when children with ASD transition from Early Intervention Teams (EITs) to Primary, Community and Continuing Care Teams. Key concepts of the Chronic Illness and Care Trajectory Framework were utilised as a 'conceptual lens' to explore participants' perspectives on this. The model highlights the concept of the 'journey' through health and social care services, the 'work' that is required to manage this transition and the 'social-organisational context' influencing this work.

Semi-structured interviews were completed with caregivers of children with ASD who had transitioned services within 12 months of the study (n=5). Service providers were also interviewed (n=14) to contextualise service users' accounts and explore solutions to problematic experiences.

Parents' expectations of this transition are dissimilar to their experiences, leading to emotional and 'work' consequences. Participants report that they are not '*known*' in EIT (*relational continuity*) which heightens the need for effective information transfer (*informational continuity*) when transitioning. Caregivers report that they are burdened by the responsibility of communicating key details regarding their children's complex trajectories to new service providers. The context and approaches to care vary significantly when the child transitions services (*management continuity*). Service providers concur that information sharing practices need to be more streamlined to ensure a smoother transition.

Results of this study highlight the 'work' involved in continuity of care when transitioning and propose solutions to improve experienced continuity of care. The findings offer novel insights into continuity of care experiences associated with health and social care transitions for caregivers of children with ASD.

Chapter 1: Introduction

1.1 Introduction and overview of chapter

This chapter outlines the background and rationale for the present study exploring caregivers' of children with ASD and their service providers' perspectives on the experience of continuity of care associated with the transition from a single Early Intervention Team (EIT) to the Primary Community and Continuing Care Teams (PCCCTs) located in the North West of Ireland. This chapter presents:

- The background to the study
- Rationale for the study
- The aim and objectives of the study
- An overview and structure of the remainder of the thesis.

1.2 Background to the study

1.2.1 Continuity of Care

Continuity of care is recognized as an important feature of all health care services including primary care services (Haggerty, Freeman and Adair, 2003; Gulliford, Naithani and Morgan, 2006). It is recognised as a fundamental feature of care as it is shown to improve quality of care outcomes for service users (Al-Azri, 2008). It is a common goal for policymakers and health care providers to improve individuals' experiences of continuity of care as it is associated with better service user safety (e.g. avoiding practices which lead to negative outcomes of care; van Servellen, Cook, Render, and Woods, 2000), higher service user satisfaction (Saultz, 2004; van Servellen, Fongwa and D'Errico, 2006) as well as more effective and efficient care provision (Wierdsma, Mulder, De Vries, and Sytéma, 2009; Russell, Rosati, Rosenfeld, and Marren, 2011).

Continuity of care refers to how a service user's health care is connected over time and incorporates three main domains: relational, informational and management continuity (Guthrie, Saultz, Freeman and Haggerty, 2008). Relationship continuity refers to an ongoing therapeutic relationship during various episodes of care. This ongoing relationship results in an accumulated knowledge of the service user and their care, which allows future care to be consistent with the service user's needs (Haggerty et al., 2003). Informational continuity refers to the availability of clinical and biographical information on past events and personal

circumstances across interactions with the health and social care services. This information can then be used to make current care appropriate for each service user (Haggerty et al., 2003). Management continuity refers to the consistent and coherent approach to the management of health conditions over time. It involves coordinating and personalising care and can be thought of as the ‘seamlessness’ of care which can involve crossing boundaries of care systems (Haggerty et al., 2003). Continuity of care is described as being of high importance for frequent users of health and social care services, including those with complex needs and developmental disabilities (Guthrie et al., 2008). Continuity of care is context-specific and therefore it is important to explore individuals’ differing interpretations of it in a variety of health and social care contexts (Liao, Zeng, Xu and Yang, 2018).

1.2.2 Service provision for children with disabilities in Ireland

In the last 20 years, there have been many changes in service provision for young children with disabilities in Ireland. This began with the Primary Care Strategy (2001) which developed first-level contact for assessment, diagnosis, treatment and rehabilitation of various disabilities in a primary care setting (Health Service Executive [HSE], 2001). In 2006, A Vision for Change (HSE, 2006) was launched which aimed to reform mental health services in Ireland. Within this policy it was noted that autism spectrum disorder (ASD) was no longer considered to be a mental illness or disorder, and therefore the care of children or adults with a diagnosis of ASD was transferred from mental health services to primary care services. Both of these policies acknowledged that services for children with disabilities should be child centred, comprehensive, coordinated and integrated. Yet today, disability services for young children vary in nature and equity according to the region and the service-providing agency (HSE, 2010). In order to address the equity and consistency of children's disability services, the HSE advocated that services for children with disabilities needed to be reconfigured (HSE, 2010) and initiated a national programme called “*Progressing Disability Services for Children and Young People (PDS)*”.

The PDS programme (HSE, 2011), which was launched in 2011, aims to implement new and more coordinated structures for disability services, which include the provision of services through ‘*children’s disability network teams*’. The services provided are to be timely and accessible for children with disabilities and their families and provide a singular clear pathway for assessment and intervention. On full establishment of this policy, children’s disability network teams (working with children aged 0-18) will be in operation. These disability network teams will provide interdisciplinary working as a cornerstone of this child-

and family-centred model of service delivery. Interdisciplinary working involves a number of professionals working together with the child and family to conduct joint assessments and to develop joint goals. The team of professionals meets regularly to complete service-planning activities related to the child (Australian Capital Territory, 2014). This policy highlights how care for the child with a disability and their family will be client-centred, coordinated with clear pathways and seamless transitions which are respondent to the voice of the service user (HSE, 2011).

Many parts of the country, however, are still undergoing a process of modernisation and restructuring to meet the objectives of PDS. At present, some parts of Ireland operate under this children's disability network teams (0-18 years) model with coordinated, client-centred, interdisciplinary early intervention and school age disability teams. On the other hand, some areas operate an early intervention service where the child 0-6 years is cared for and then transitioned to a separate primary, community and continuing care service (6-18 years). These services still operate using a predominately multi/uni-disciplinary model of care. A multidisciplinary team is composed of members from more than one discipline. Team members work independently and interact formally. Appropriate experts from different professions handle different aspects of a service users case independently. In contrast to inter-disciplinary care, the service users difficulties are subdivided and treated in parallel, with each provider responsible only for his or her own area (Australian Capital Territory, 2014). This in turn has potentially significant implications for experiences of continuity of care. In fact, these transitions can in turn lead to an experience of 'forced' or 'involuntary' discontinuity of care when the child transitions service organisational boundaries. This can have many potential negative implications for the quality of care received by service users.

1.2.3 Service provision for children with disabilities in the North West of Ireland

The disability services in the North West of Ireland are currently being restructured and modernised under PDS. There was no deadline in place at the time of writing this thesis to indicate when the areas' modernisation to a children's disability network team will be completed. At present, children who have or are at risk of having physical and sensory disabilities, intellectual disabilities, mental health concerns and ASD, and who are up to the age of 6 years are referred to HSE based, multi/inter-disciplinary Early Intervention Teams (EITs) (Carroll, Murphy and Sixsmith, 2013). These teams comprise a range of disciplines that may include physiotherapists, occupational therapists, psychologists, speech and language therapists, nurses, social workers, family support workers and paediatricians. An

interdisciplinary collaboration is recommended for individuals with disabilities as it involves the combination of the strengths of multiple disciplines with the aim to maximise client outcomes (Brodhead, 2015). Interdisciplinary collaboration is related to increased educational outcomes and increased treatment fidelity for children (Kelly and Tincani, 2013). The EITs in the North West of Ireland aim to run an interdisciplinary team service for their service users, yet due to staff shortages and large caseloads this is not always possible. When the child reaches 6 years of age or begins primary school education (whichever comes first), service provision ceases with EIT and is transferred to Primary, Community and Continuing Care Teams (PCCCTs) (Carroll et al., 2013).

1.2.4 Autism Spectrum Disorder (ASD) and service provision for children

ASD is a highly prevalent, lifelong neurodevelopmental disorder (Kuhlthau, Delahaye, Erickson-Warfield, Shui, Crossman and van der Weerd, 2016). It is characterised by difficulties with communication, social language and interaction skills, restricted interests, and repetitive behaviours (American Psychiatric Association [APA], 2013). These difficulties are evident from an early age and it is recommended that children be screened for ASD between 18 and 24 months (Johnson and Myers, 2007; Guthrie, Swineford, Nottke and Wetherby, 2013). Because of the varying difficulties that children with ASD present with, there is a need for engaging with multiple health and social care services (HSE, 2018). NICE (2011), Intervention Guidelines for youth with ASD recommend that service users receive intervention through interdisciplinary teams based on their complex and multifaceted needs. In Ireland, children who are suspected of presenting with ASD are referred to Early Intervention Teams (as described above) where investigation and intervention begins. Because of the range of difficulties and the need for engagement with varying services, the care journey or trajectory of the child with ASD can transition many professional, health and social care services organisational and agency boundaries. Health and social care transitions for children with ASD can be more complex because of their varying needs. For example, many young people with ASD experience communication challenges and unusual sensory responses to environmental stimuli, which results in increased anxiety when they enter a new environment. Additionally, visiting a new service provider and/or a new office environment may therefore create obstacles for youth with ASD that are not experienced by other groups of youth with additional needs. Research has highlighted how transitions can adversely impact the health and well-being of individuals with ASD and that of their caregivers if there is limited or no continuity of care (Lamb, Hall, Kelvin and Van Beinum, 2008; Singh, 2009). Hence, the optimum is to ensure

smooth transitions for children with ASD (Singh, 2009). The modernisation of team based services gives rise to new interpretations of continuity of care e.g. relationship, team and cross-boundary models.

1.3 Rationale for the present study

There is a paucity of research focusing on the experiences of continuity of care for families of young children with ASD as they transition through health and social care services. Also, despite the growth of empirical work in the field of continuity of care research, qualitative methodologies focusing on service users' experiences of continuity and drawing on social scientific theory are scarce (Alegria, Pecosolido, Santos and Vera, 1997; Philipsen and Stevens, 1997; Freeman, Shepperd, Robinson, Enrich and Richards, 2001; Gallagher, MacFarlane, Murphy et al., 2012). This is despite international recommendations for further research focusing on the concept of the service user's 'journey' or 'trajectory' through and across the health care system, particularly in the case of chronic conditions such as is the case with ASD (Freeman et al., 2001).

This study was designed to explore service users' and service providers' perspectives on experienced continuity of care associated with the transition from EIT to PCCCT. It is envisaged that results obtained from this research and the ensuing discussion will inform and shape policy and service developments in relation to continuity of care and provision of disability services in Ireland and contribute to further research ideas in areas of disability care.

1.4 Outline and structure of the thesis

The remainder of this thesis is set out in five chapters. *Chapter 2* presents a synthesis and critique of the literature reviewed in relation to continuity of care and health and social care transitions for children with ASD. *Chapter 3* describes the methodological approach and methods undertaken in the study. In *Chapter 4* key findings from the study are outlined. *Chapter 5* contains a general discussion about the results presented in this thesis and their contribution to the literature. These findings are interpreted in the context of previous research. Prior to the conclusion of the thesis, the chapter addresses the strengths and limitations of the study. Finally, *Chapter 6* provides key conclusion, recommendations for policy, daily practice and future research.

Chapter 2: Literature Review

2.1 Introduction and overview of chapter

The purpose of this chapter is to present an overview of the international and national literature pertaining to service users' and providers' perspectives of continuity of care in the case of young children with ASD and their caregivers and in the specific context of transitioning from Early Intervention health and social care services/teams to 'follow-on' services provided by primary care, community-based services and/or school-age disability teams.

The chapter will begin by presenting an overview of the search strategy and comprehensive review process completed by the researcher. Following on from this, the review will be presented thematically in four key subsections pertaining to the research question of the present thesis.

Section 1 of the review will present an overview of Autism Spectrum Disorder in relation to primary signs and symptoms of the disorder as well as the complex multidisciplinary, diagnostic and intervention process associated with ASD. In line with the specific focus of the present thesis, literature describing the complexity of care journeys or 'trajectories' associated with ASD in the early years (i.e. 0-8 years) and the many health and social care *transitions* that occur within these trajectories will be examined.

In Section 2 of the review an attempt will be made to define the complex concept of health and social care transitions (HSCTs). The policy initiative referred to as 'transition planning' will also be briefly discussed, in particular its potential for ensuring a positive experience of seamless 'continuity of care' for those with complex health and social care conditions, including ASD. Key theories concerning health and social care transitions will be summarised. In particular, the utility, potential and relevance of such theories for framing research about continuity of care experiences in the case of children with ASD undergoing HSCTs will be discussed and critiqued.

Section 3 of the review will present a brief summary of key definitions and models of 'continuity of care', a quality of care outcome impacted by the process of health and social care transitioning.

Finally, *Section 4* will summarise, synthesise and critique the limited empirical literature concerning caregivers' and service providers' views on the experience of HSCTs for children and youth with ASD, and the associated impacts of HSCTs on experiences of continuity of care.

The chapter will conclude by providing a summary and synthesis of the key content of the chapter, highlighting significant knowledge gaps in relation to our understanding of continuity of care experiences for young children with ASD and their caregivers when transitioning from early intervention services to 'follow-on' health and social care services and teams.

2.2 Search strategy

The literature for this chapter was collated over a period of 18 months: from September 2017 to March 2019. Literature was collected and sourced both systematically and unsystematically. Electronic databases including, Academic Search Complete, PubMed, the Cumulative Index to Nursing and Allied Health Literature and Science Direct were searched to find literature relevant to this review. Other articles were obtained through reviewing bibliographies of relevant articles. The terms (and synonyms) used for the literature review searches are outlined and briefly defined in appendix A and B. The Critical Appraisal Skills Programme tools (CASP; CASP, 2017) were used to critically appraise and review the quality of studies for inclusion in this review. A sample of this tool can be found in appendix C.

2.3 Introduction to Autism Spectrum Disorder

2.3.1 What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterised by a variety of impairments including social communication and interaction difficulties, restricted and repetitive patterns of behaviour and/or interests, resistance to change and significant impairments that adversely affect daily functioning (Kogan, Bloomberg and Schieve, 2009; APA, 2013). Individuals with ASD often present with secondary symptoms including aggression, tantrums, and self-injury (Koegel, Koegel, Ashbaugh and Bradshaw, 2014). These behaviours often develop when primary symptoms are not addressed (Koegel et al., 2014). ASD is a spectrum disorder. This means that the impairments that individuals diagnosed with ASD have can vary in level of severity and in level of support needed to function and participate in society (Koegel et al., 2014). Signs and symptoms of ASD are typically noted in the early years; however, this is not always the case. Difficulties with social deficits and atypical

behavioural patterns may not be recognised as symptoms of ASD until later in life when the child does not meet social, educational, occupational, or other important life stage norms (Koegel et al., 2014). ASD is becoming more prevalent in society. Studies suggest that much of this recent increase in prevalence is likely attributable to factors such as improved awareness, recognition and improved diagnostic practices/service availability (Schieve, Rice, Devine, et al., 2011; Blumberg, Bramlett, Kogan, et al., 2014). Epidemiological studies suggest that this increase in the diagnosis of ASD is worldwide, in every racial, ethnic, and social group (Centres for Disease Control, 2012). It has been noted that the estimated prevalence of ASD has been gradually increasing and is now thought to be approximately one percent across the lifespan (Thompson, Boltel, Falkmer and Girdler, 2018). ASD is a lifelong disability with many of the associated difficulties persisting throughout life (Lindgren and Doobay, 2011; Camarata, 2014). The presentation, severity and impact of difficulties vary with age, developmental and health status and with the presence of any additional disabilities or morbidities including, for example, cognitive impairment, attention deficits, sensory issues, depression (Lindgren and Doobay, 2011; Koegel et al., 2014). There is no medical treatment for ASD, although behavioural interventions have been found to maximise an individual's ability to function and participate in society (Dawson, Rogers, Munson, et al., 2010; Reichow, Barton, Boyd and Hume, 2012; Rogers, Estes, Lord, et al., 2012; Eapen, Crnčec and Walter, 2013).

2.3.2 Complexity of service provision for young children with ASD

In the 1960s and 1970s, the outcomes for children with ASD were poor as there were few comprehensive interventions available. Since this time hundreds of effective interventions for children with ASD have become available (Koegel, Werner, Vismara, and Koegel, 2005; Baker-Ericzen, Stahmer and Burns, 2007; Harper, Symon, and Frea, 2008; Koegel, Singh, and Koegel, 2010; Robinson, 2011). The '*wait and see*' approach and/or failing to provide intervention for the symptoms mentioned above is likely to have cumulative negative consequences for the child with ASD (National Research Council, 2001). There is a significant need for children with ASD and their caregivers to actively engage in these interventions through a variety of services, organisations and agencies. These interventions are recommended to ensure the complexity of the needs of the child and family are met in order to function and remain well in society (Lindgren and Doobay, 2011; NDA, 2015). Internationally, the needs of a child with ASD are met through a variety of services including bio-medical (e.g. paediatrician), therapeutic (e.g. speech and language therapy and occupational therapy), psychological (e.g. developmental and clinical psychology and counselling), social (e.g. social

work and social care practice) and educational (e.g. special education teachers) (Lord and Bishop, 2014).

International best practice recommends an interdisciplinary team-based early intervention programme as this increases the likelihood of improved long-term outcomes for children with ASD (NICE 2011; Lord and Bishop, 2014). International policy documents declare that services for children with ASD could be improved if providers and agencies worked in a more collaborative manner (HSE, 2006; Missouri Autism Guidelines Initiative, 2010; NICE, 2011; Cameron et al., 2012; Ministries of Health and Education, 2016). Interdisciplinary working refers to a model of working whereby multidisciplinary team members work together in assessing and delivering interventions (HSE, 2018). The provision of care for a child with ASD, along with support for caregivers, may transition many professional, organisational and agency boundaries (Mackintosh et al., 2012; American Psychiatric Association, 2013). This is evident in the early years period, which involves an extensive and complex diagnostic and early intervention process before transitioning to a new service. It is noted that there should be systematic connection and integration between the early intervention program and the next stage for the child, whether it is transition to school or to a special educational or therapeutic setting (Lord and Bishop, 2014) .

2.3.3 Service provision for young children with ASD in the Irish context

In the Irish context, a complex care pathway or journey is in place for children with a disability/suspected disability in the preschool and school-aged periods. For example, in the 0-6 year period, service provision for children in the Irish system is located in what are referred to as Early Intervention Teams (EITs) involving a variety of bio-medical, therapeutic, psychological and social services. The purpose of these EITs is to provide a team-based approach to care including multiple professionals as mentioned above in order to best support the needs of the child and family (HSE, 2018). Following this period, children with ASD are discharged from EIT services and undergo a transition to multidisciplinary, community-based primary health care teams referred to as Primary, Community and Continuing Care Teams (PCCCTs) or in some instances School Age Disability Teams (SADTs) (Carroll et al., 2013). As mentioned in the Section 1.2.2, as part of the PDS policy, SADTs are currently being phased into implementation (HSE, 2018). It is envisioned that when fully implemented SADTs will operate as interdisciplinary disability teams which will be coordinated and run seamlessly alongside EITs. It is recognised by the HSE that there is need to establish greater coordination between

agencies in an effort to support shared care, good communication and smooth transitions (HSE, 2011). Internationally, this type of ‘transition’ which occurs in the early years has been highlighted as significant for the child and his/her caregivers (Eapen et al, 2017). The preference of children with ASD for routine and their resistance to change in that routine may in part explain the significance of this transition. Section 2.4.3 below discusses this in more detail.

2.4 Definitions and constructions of health and social care ‘transitions’

In this subsection, key definitions of health and social care transitions will be presented along with an overview of key theories that have been used to frame research about health and social care transitions and/or associated experiences of continuity of care. The utility of such theories and their potential for framing the present research exploring perspectives of continuity of care in the context of young children with ASD transitioning from EIT will be discussed and critiqued.

2.4.1 Definition of the phenomenon of ‘transition’

The Cambridge Dictionary defines the concept of ‘transition’ in general terms as involving *‘a change from one form or type to another, or the process by which this [change] happens’* (cambragedictionary.org, 2019). Transition as described in this definition contains two imperative factors, “change” and “process”. Research on transitions in general has gained more attention and focus internationally over the past two decades (The European Agency, 2002). Through this increased interest and focus, the general definition of transition is changing and is being viewed in a more holistic way (The European Agency, 2002). A transition involves more than ‘change’: a transition is now described as a process. A ‘process’ describes the significant preparatory work and planning needed for a successful transition in any context (The European Agency, 2002). Schlossberg’s conceptualises transitions (in general) as *‘any event, or non-event that results in changed relationships, routines, assumptions, and roles’* (Evans, 2010). It is argued that an individual’s perception plays a key role in transitions as a transition is only a transition if it is so defined by the individual experiencing it (Evans, 2010). In order to understand the meaning that a transition has for a particular individual, the type, context, and **impact** of the transition must be considered. This has considerable implications for any research which endeavours to explore the experience of transitions in the context of health and social care and services.

2.4.2 Health and Social Care Transitions

A health and social care transition (HSCT) is defined as the purposeful, planned movement of an individual from one health care system to another (Blum, Garell and Hodgman, 1993). An optimal HSCT is described as involving an “*uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive*” transfer from one service to another (Blum et al., 1993, p. 570). HSCTs for children bring unique challenges in order to ensure they are developmentally appropriate (Blum et al., 1993). Each child’s health and social care journey is shaped by various demographic, personal and ecological factors, in addition to the specific health-related needs of the child (Reiss and Gibson, 2002; Schor, 2015; Javalkar, Johnson, Kshirsagar et al., 2016). A HSCT for a child with complex needs (such as is the case with ASD) has been described as a significantly more “*complex and dynamic phenomenon*” (Reiss and Gibson, 2002, pg.1308). In line with the general definitions of transition outlined above in section 2.4.1, a HSCT for these children is described as a *process* rather than a one-time event (American Academy of Pediatrics et al., 2011; National Health Care Transition Center, 2013). Furthermore, a HSCT for a child with additional needs and complex care needs is said to involve skills, coordination and education of the child, their family, clinicians and caregivers (Javalkar et al., 2016).

2.4.3 Planning for Health and Social Care Transitions

In recent years, the related concept of ‘*transition planning and care*’ has gained worldwide recognition for its importance, particularly in relation to children with complex health and social care needs. For example, in the United States in recent decades transition planning for these children was identified as one of the six core objectives of the Maternal and Child Health Bureau (MCHB, 2008). Consensus statements and position papers from other international health and social care associations and voluntary health care groups also echoed this focus (American Academy of Pediatrics et al., 2002; Rosen, Blum and Britto, 2003; URBIS, 2015; New Zealand Autism Spectrum Disorder Guidelines, 2016; SIGN, 2016). It was argued that because children with additional health care needs are living longer and are surviving into adult life due to medical care improvements (Perrin, Bloom and Gortmaker, 2007) such planning is paramount. The need for better transition care and planning for children with complex care needs is supported by the research literature: it demonstrates that youth with additional health care needs (including children with ASD) have more negative outcomes in areas such as health status, community living, and employment in comparison to their peers when they transition

to adulthood (Wagner, Newman and Cameto, 2005; Gorter, Stewart and Woodbury-Smith, 2011).

While there is international agreement on the importance of transition planning for people with ASD (New Zealand Autism Spectrum Disorder Guidelines, 2016; SIGN, 2016), there has been little research on the variety of transitions this population face and little movement toward achieving the goals set by international health governing bodies with regard to supporting those with ASD in times of transition. For example, in the United States between 2009 and 2010 a National Survey of Children with Special Health Care Needs was conducted. This survey included participants who had a diagnosis of ASD. The results of this showed that only 40% of youth with additional health care needs received the basic national transition planning standard when transitioning to adult services (McManus, Pollack and Cooley, 2013). In addition, many did not receive any services related to preparation for transition (McManus et al., 2013).

Despite efforts to develop clinical guidelines, recommendations and transition ‘tools’ worldwide, there has been minimal research and minimal evidence to indicate what effectively facilitates positive experiences of transition (Watson, Parr and Joyce, 2011; Bloom, Kuhlthau and Van Cleave, 2012) and the experience of continuity of care for those in such transitions. International research to date regarding ASD has almost exclusively focused on the transition to adult services. As indicated above, however, in both the international and national contexts, children with ASD and their caregivers experience much earlier HSCTs and little is known about how these transitions and the associated continuity of care are constructed and experienced.

The literature on health and social care transition preparation specific to children with ASD is therefore significantly absent or lacking. The need for integration and coordination of the variety of services involved with ASD is considered best practice and critical to ensuring a seamless continuity of care experience for the child and family (Bagnell and Santor, 2012; NICE, 2013; NDA, 2017). However, problems with coordination of services *within* teams are consistently reported within the literature in relation to service provision for young people with ASD (Liptak, Benzoni and Mruzek et al., 2008; National Disability Authority, 2012; Carroll et al., 2013; Khanlou, Haque, Mustafa, Vazquez, Mantini and Weiss, 2017).

It has been asserted that current PCCCT services within the Irish context can vary from “*robust, comprehensive and integrative to isolated, patchy and ineffective*” (HSE, 2012, p. 2). This type of variation and inconsistency in service provision has been shown to be a significant source of stress for parents both in national and international contexts (Tehee, Honan and

Havey, 2009; Ekas, Lickenbrock, and Whitman, 2010; Lovell, Moss, and Wetherell, 2012; National Disability Authority, 2012; Weiss, Robinson, Fung et al., 2013). For example, studies have consistently demonstrated that parents experience a lack of coordination of care in the context of ASD when it is delivered by multidisciplinary teams (NICE, 2011; SIGN, 2016; New Zealand Autism Spectrum Disorder Guidelines, 2016). This is characterised by a lack of coordination activities or plans (Sobotka, Francis and Vander Ploeg Booth, 2016), systemic issues and poor information sharing practices amongst professionals (Anderson, Sosnowy, Kuo and Shattuck, 2018) and geographical dispersion of members of teams and gaps in service provision (Keegan, 2016).

Whilst these findings are valuable in informing us about coordination issues, results are only relevant to the context of care provided within single health and social care teams. In other words, they do not address the experience of caregivers when children transition from one health and social care team to an entirely different one in a new and unknown physical and infrastructural context. The growing prevalence of youth with ASD has lent urgency to efforts to improve transition programmes and supports (Interagency Autism Coordinating Committee, 2013). A more in-depth understanding is required of the needs of transitioning youth with ASD and of their families' strategies to aid in the achievement of desired outcomes. It is argued that the availability and efficacy of supports and services can inform transition programme development, which may lead to improved experiences of care for service users and their caregivers (Anderson et al., 2018).

2.4.4 Key transition theories and application to health and social care transitions for children with ASD

When a theory is used in research to simultaneously convey the values of the researcher and provide a clearly articulated signpost or lens for how the research will process new knowledge, this is referred to as the 'theoretical frame' (Collins and Stockton, 2018). In this section of the review, key transition theories that offer potential for exploring and evaluating transition and continuity experiences in the context of health and social care will be summarised. Specifically, the potential of such theories for framing research about transitioning and continuity of care for children with ASD and their caregivers will be discussed and critiqued. In particular, an attempt will be made to demonstrate the utility of theory to help conceptualise the meaning of transition and the many factors impacting on the process and experience of health and social care transitions.

Following a comprehensive search of the literature, a variety of transition theories were encountered which appeared to offer potential for use as a theoretical frame for the present research namely: Sociocultural Theory (Vygotsky, 1962, 1978), Family Systems Theory (Turnbull, 2000; Turnbull, Turnbull, Erwin and Soodak, 2005), Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979, 1986), Transition Process for Young Children with Disabilities (Rous, Hallam, Harbin, McCormick and Jung, 2005) and Chronic Illness and Care Trajectory Framework (CITCF; Corbin and Strauss, 1991). Appendix D outlines a brief summary of these theories and their potential for use as theoretical frames for the present thesis. In this section of the review, three of the theories (Bronfenbrenner, 1979, 1986; Corbin and Strauss, 1991; Rous et al., 2005) thought to have most relevance and potential will be discussed and critiqued.

The Ecological Systems Theory

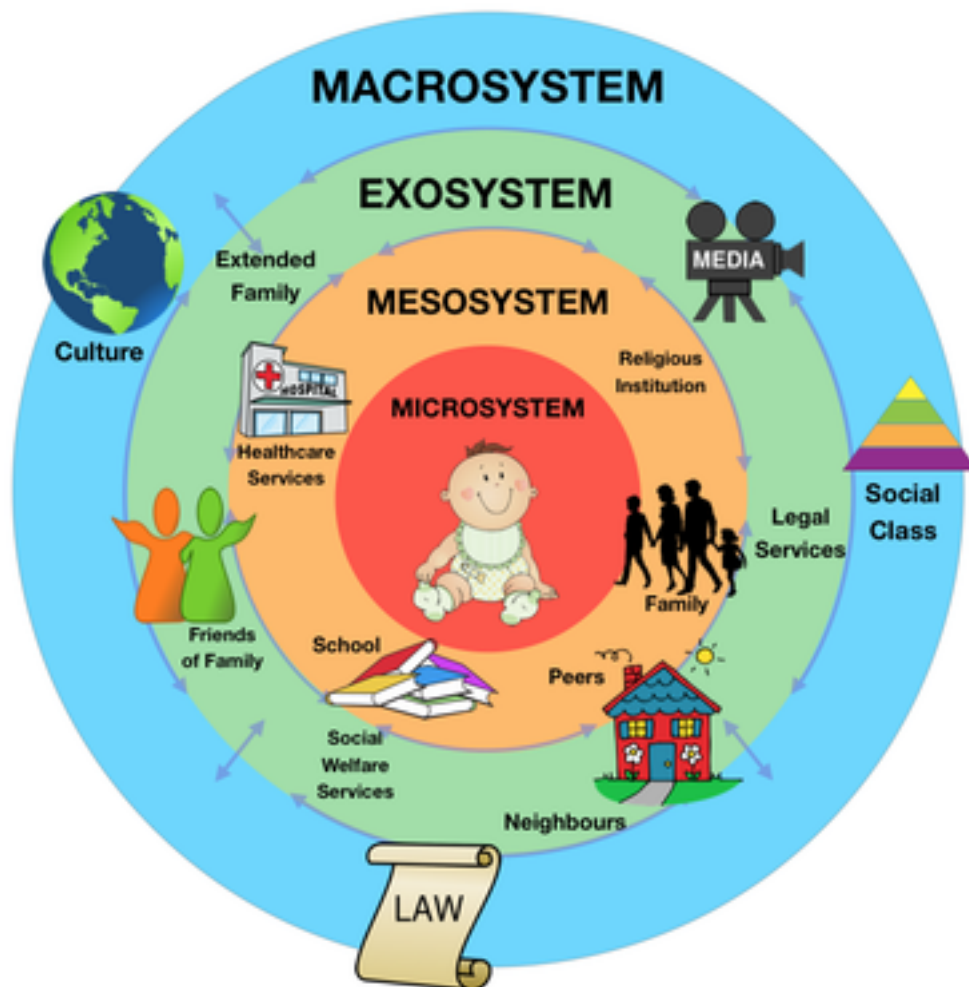
The ecological systems theory, first proposed by Bronfenbrenner in 1970, offers a comprehensive approach to the study of transitions for children (Volger, Crivello and Woodhead, 2008). In fact, Bronfenbrenner has been referred to as the father of transitions (Brooker, 2008) and his ecological theory has been utilised as a theoretical frame to explore experiences of children in a variety of contexts, for example, in educational transitions (O'Toole, 2016), identity transitions (Hollander and Haber, 2009) and to a lesser extent in health and social care transitions (Schwartz, Tuchman, Hobbie and Ginsberg, 2011).

The ecological systems framework consists of a system with four distinct environments that surround the child (See figure 2.1 below). The child is at the centre of the model, surrounded by the first environment, called the microsystem, which includes family, friends, teachers and service provider in the case of the child with ASD. The model then broadens to the next level, the mesosystem. The mesosystem describes connections between members of the microsystem and their influence on the individual at the centre, e.g. interaction and planning by service providers and parents for transitions. The theory then extends further to the exosystem. Factors belonging to the exosystem interact with an individual's immediate environment, therefore indirectly influencing an individual, e.g. service pathways/recommendations on transition. However, the exosystem does not directly involve or come into contact with an individual. The final layer of the framework; the macrosystem, encompasses the larger social system and includes economic forces, beliefs and values, and political actions impacting on the individual (Sallis and Owen, 1997; Bronfenbrenner, 2005), e.g. influencing policy such as the PDS. The ecological approach recognises the individual's

immediate experiences in context, but also captures patterns of interaction and influences between individuals, groups and institutions over time (Rimm-Kaufmann and Pianta, 2000). An individual can have complex interactions with different environments beyond the immediate setting which can indirectly influence him or her.

In applying this theory to our understanding of health and social care transitions for children with ASD, arguably one can explain the interplay between systems and how relationships and processes combine to influence the experiences of the children (Abrams, Theberge and Karan, 2005) and their families in the process of transition. However, this theory is more widely used in research about educational transitions and no empirical papers were sourced demonstrating its specific application to research concerning health and social care transitions for young children with ASD and or their caregivers.

Figure 2.1: Diagram of Bronfenbrenner (1986), The Ecological Systems Theory



The Transition Process for Young Children with Disabilities: A Conceptual Framework (Rous et al., 2005).

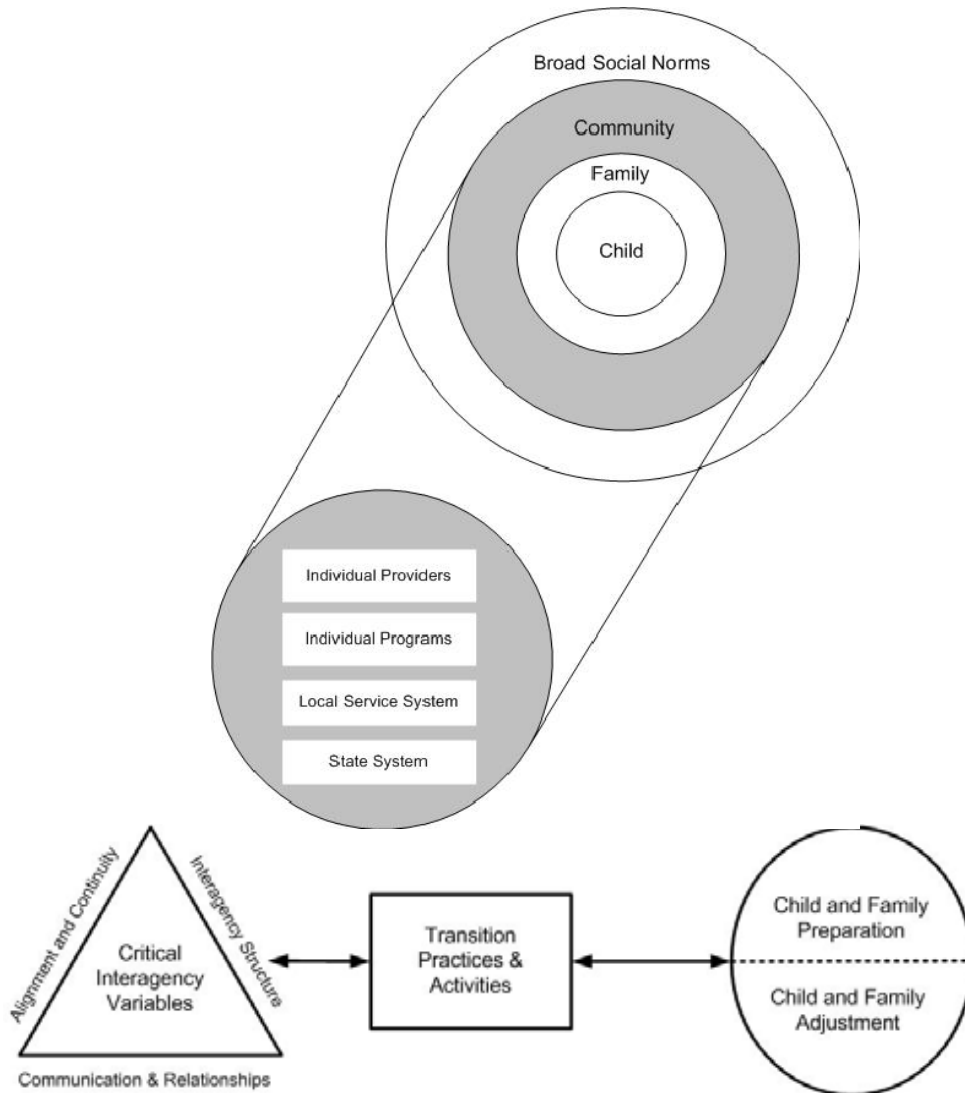
This theory is based upon a synthesis and fusion of transitions research literature, a systemic ecological orientation, and prior theoretical work on early childhood transitions (Rous et al., 2005). This framework was developed specifically to explore the experience of young children with disabilities when they transition from kindergarten to elementary school in the United States of America. The framework extends Bronfenbrenner's purist ecological theory in that it draws from two separate theoretical frameworks, ecological systems theory (described above) and organizational systems theory (see figure 2.2 below). It is argued that this fusion of theoretical influences provides a comprehensive lens to understand the complexity involved in the educational transition experiences of young children with disabilities and their families (Rous et al., 2005).

Organisational theory encompasses several different theoretical frameworks that focus on explaining and predicting the ways in which organisations and people behave. These include organisational structure, culture, systems and change (Shafritz, Ott, and Jang, 2004). It is argued that these elements influence practices and policies at a higher level which in turn influence the experiences of young children with disabilities and their families as they move through the education system (Rous et al., 2005). Level One of this framework uses specific elements from the ecological context that are shown to particularly influence the transition experiences of young children with disabilities and their families. For children with additional needs, factors related to service providers, intervention programmes, local services, and national service guidelines are factors which can be influential in transition. The second level of the conceptual model provides specific information on the transition process, which is defined as the interaction among critical interagency variables, transition practices and activities and immediate outcomes related to child and family preparation and adjustment. In turn, transitions are conceived of as interagency processes. Therefore, effective transition planning involves continuity of intervention and communication between both environments (Rous et al., 2005). Families need to be supported by both agencies through frequent collaboration and communication to facilitate their transition (Rous et al., 2005). The preparation of the child and the family for transition is also a major contribution to their success. Families should be involved early and often in the transition planning process.

This framework shows potential for exploring health and social care transitions and the resultant impact on continuity for those with ASD as it has been developed and used in research with children with developmental disabilities in transition. The framework highlights multiple aspects which impact successful educational transitions, and there is merit in the idea that these aspects influence health and social care transitions including, inter-agency collaboration,

transition planning and information exchange between caregivers and professionals. However, once again, this framework was not developed specifically to understand to health and social care transitions for children with ASD. Also, there is no reference to quality of care outcomes associated with transitions in this framework, for instance, continuity of care outcomes.

Figure 2.2: The Transition Process for Young Children with Disabilities: A Conceptual Framework (Rous et al., 2005).



The Chronic Illness and Care Trajectory Framework (CICTF)

The Chronic Illness and Care Trajectory Framework (CICTF) is a conceptual model developed by Corbin and Strauss (1991). The CICTF refers not only to the physiological process of a chronic condition (such as ASD), but to the total organisation of work that needs to occur over the course of the condition, the impact of that condition and the associated work for all people involved, including the service user, family and health and social care professionals. The

framework has its epistemological origins in interpretivism and interactionism (see section 3.2.2 – 3.2.7) and is based on a sociological perspective, which allows insight into the complexity for all involved to get the work done to manage the chronic condition. The framework includes reference to the variety of personal, interpersonal and socio-political conditions or contingencies which can all influence the management of the trajectory of one's condition (Corbin and Strauss, 1991). The many influences on the trajectory, and the concepts related to these in the CICTF, allow a researcher to observe and organise factors that shape the experience of the trajectory and their associated outcomes. It provides a health and social care services researcher with a conceptual framework to explore and understand the complexity of a condition by gaining knowledge of the relationships between variables which may not have been previously explored as whole.

The framework's utility for understanding experiences of HSCTs for those with ASD and their primary caregivers, arguably, is that it provides a lens to understand the experiences of all key participants, to be viewed not in isolation, but as an interactional experience of all participants. Whilst, the CICTF has not previously been applied to research with an ASD population undergoing a health and social care transition, arguably it has much potential in this regard. The CICTF was developed through extensive ethnographic work with people with chronic conditions and disabilities, their families and health care professionals (Corbin and Strauss, 1991). Specifically, the trajectory construct could provide a useful framework for a sociological understanding of the journey these families experience as they transition from one service or team to another. The CICTF could offer potential for illuminating the 'work' (in particular 'kin work' and 'information work', 'care trajectory' and 'organisational contingencies' – see section 3.2.7) inherent in providing a positive continuity-of-care experience for children with ASD and their caregivers. The core concepts of the CICTF are described in section 3.2.7 in chapter 3. The CICTF provides a means of analytically ordering the immense variety of events that occur as professionals and caregivers work to prepare and support the child with ASD and family as they transition from one health and social care team or service to another, and the resultant impact ('reciprocal impact') this has on 'felt' experiences of continuity of care.

2.5 What is Continuity of Care and how does it relate to the process of HSCTs?

In recent years, continuity of care has become an important issue for those involved in national health care and transition planning worldwide and in turn has become a central focus of care for many health and social care disciplines (Guthrie et al., 2008; Leleu and Minvielle, 2013). This is because continuity of care has been described as a key component of quality of care and has been found to be increasingly important for complex and vulnerable service users of health and social care systems, particularly, the elderly, those at the end of life, individuals with chronic conditions, disabilities and those who transition through multiple healthcare systems over the course of their care journeys (Price and Lau, 2013; Hirschman, Shaid, McCauley, Pauly and Naylor, 2015).

Many national health service providers have published and advocated policy documents in an effort to promote service configurations and delivery that facilitate improved experiences of continuity of care for their service users (Australian Government, 2016; National Health Service England, 2016; World Health Organization, WHO, 2018). However, a fundamental issue is that continuity of care does not appear to be defined consistently within these policies. There is a lack of clarity over what continuity of care is and which attributes of care contribute to the concept of continuity of care (Parker, Corden and Heaton, 2011; WHO, 2018;. Thus, there have been many calls to improve the consistency and clarity in defining the concept (WHO, 2018). Three systematic reviews have been conducted in recent decades which address this issue (Freeman et al., 2001, Reid, Haggerty and McKendry, 2002 and Haggerty et al., 2003). Key outcomes of these works inform us in part of the complexity of the concept.

In 2002, a highly acclaimed multidisciplinary systematic review of the literature of continuity of care (involving primary care, mental health care, nursing and condition-specific care) was carried out by Reid, Haggerty and McKendry. The review concluded that 'continuity of care' is conceived of differently in different health care sectors, e.g. primary care, mental health care, nursing and condition-specific care and in the case of different service user groups. They found that within continuity of care literature the meaning of the phrase is often presumed rather than defined, and calls for research exploring the meaning and experiences of continuity of care pertaining to specific health and social care contexts and scenarios were highlighted.

In 2003, a further review of the meaning of continuity of care across disciplines by Haggerty, Reid, Freeman, Starfield, Adair and McKendry concluded that continuity of care contains two core elements and three types of continuity that are constant across all health care domains. Interestingly, more recent literature relating to primary and acute care (e.g. Miller, Condin, McKillen et al., 2009; Price and Lau, 2013; Maarsingh, Henry, van de Ven and Deeg, 2016) shows that researchers are still using the same principles of continuity of care as defined by these two systematic reviews. The first core element of continuity of care is the experience of care by a service user with his/her service provider(s) and the second is the realisation that care extends over time beyond a specific episode of illness or disease (Haggerty et al., 2003) hence its relevant linkages to the concept of HSCTs discussed above. The work of these reviews also highlighted that there are several types of continuity referred to in the health and social care services literature. Some of these, arguably, have relevance for our discussion about HSCTs and the potential outcomes of inadequately supported and facilitated transitions. Health care services recognise **informational**, **relational** and **managements** features and have advocated their importance for ensuring high quality care (Haggerty, Roberge, Freeman and Beaulieu, 2013). For this reason, these three concepts will be described in further detail in order to describe their relevance to health and social care transitions.

Relational continuity is the ongoing service user/provider relationship which bridges past to current care and current care to future care (Haggerty et al., 2003). This ongoing relationship is highly valued in primary care settings: it is the implicit contract implying ongoing provider responsibility to the service user (Reid et al, 2002). A consistent team of health care providers gives the individual the feeling of certainty and coherence in their care (Reid, et al., 2002), something that is potentially jeopardised when a service user transitions from one team/ or set of services to follow-on services. Relational continuity is foundational for experiencing information and management continuity (Jackson, MacKean, Cooke and Lahtinen, 2017). The quality of the relationship rather than length is inherent in providing good relational continuity with service users (Ridd, Shaw and Sailsbury, 2006). Service users emphasise being treated with respect and as a person, not as a 'case number'. This is perceived as being vital in order to build good relational continuity (Jackson et al., 2017). Service users recognise that building these relationships takes time but that this sense of 'knowing' improves ones overall satisfaction with the service (Ridd et al., 2006). Service provider also emphasis that strong relationships with service users (service users 'being known') is often being key to

informed decision making of the individuals clinical management and thus improve the experience of management continuity (Ridd et al., 2006; Jackson et al., 2017).

Informational continuity is defined as the link of information between one care episode to the next and from one health care provider to the next (Reid et al., 2002). This may include information on past events and personal circumstances which can be used to make appropriate current care choices for the individual (Reid et al., 2002). Information collated can be either condition- or person-specific: this means that documented information includes specifics on the individual's health needs and/or the knowledge of the service user's values, preferences and social history (Haggerty et al., 2003). Both elements have been found to be equally important in particular within the primary care literature (Reid et al., 2002) and again modernised multioccupancy services that cross agencies and boundaries threaten informational continuity.

Management continuity is defined as the consistent, coherent and timely approach to the management of an individual's health condition that is responsive to a service user's changing needs (Haggerty et al., 2003). Management continuity is particularly important for individuals with chronic or complex diseases that require input from several health care providers, for instance, ASD (Haggerty et al., 2003). Management continuity is described as being successful when an individual feels that services are delivered complementary to each other and within in a timely manner (Haggerty et al., 2003). Individual shared management plans or protocols facilitate management continuity, yet management plans alone do not necessarily constitute good management continuity (Waibel, Vargas, Aller, Coderch, Farré and Vázquez, 2016). Relevant literature emphasises the importance of consistency of content across plans and consistent implementation of plans across organisational boundaries (Reid et al., 2002). However, practitioners need to be flexible in order to adapt to the individuals needs at a given time. In summary, management continuity requires both consistency and flexibility with care choices at different stages throughout an individual's care journey (Reid et al., 2002).

Modernisation in health and social care services to team and interdisciplinary services that cross agency and organisational boundaries gives rise to new and more contemporary definitions of continuity of care (Gallagher et al., 2012). These include team and cross-boundary continuity, longitudinal continuity and flexible continuity. They are described by Freeman and colleagues in their 2001 systematic review. Team and cross-boundary continuity is defined as "*effective communication between professionals and services and with patients*"

(Freeman et al., 2001). Longitudinal continuity constitutes care from as few professionals as possible in relation to a single health care need (Freeman et al., 2001). Flexible continuity includes being flexible and adjusting to the needs of the individual over time (Freeman et al., 2001). As described in section 2.3.2, interdisciplinary care is recommended in the case of a child with ASD. Therefore, there are potential impacts for the experience of continuity of care for this client group. As will be described in the subsequent section, however, there is a significant gap in the literature about impacts of HSCTs on this important quality of care outcome.

Continuity of care can be viewed differently by service users and service providers. Service users often assume ongoing continuity until an episode of discontinuity occurs (Haggerty et al., 2013). Episodes of discontinuity occur when there is a lack of coordination among service providers or between the service providers and the service user (Haggerty, et al., 2013). Much previous research has focused on chronological patterns of care without directly measuring the individual's experience of continuity or the attributes of care which translate to continuity of care (Reid et al., 2002; Haggerty et al., 2003). Unless research begins to focus on the mechanisms that contribute to continuity of care or the experience of continuity of care an individual receives on their care journey, it is argued that efforts to improve continuity may be misdirected or inappropriate (Reid et al., 2002; Haggerty et al., 2003).

2.6 Experience of continuity of care associated with health and social care transitions for children and youth with ASD.

The literature search did not reveal any empirical research pertaining specifically to 'continuity of care' experiences associated with health and social care transitions for children with ASD. In the absence of literature specific to the research question associated with this thesis, studies exploring experiences of HSCTs from paediatric to adult health and social care services for individuals with ASD are included. It was thought that this literature may provide important and valuable insights into experiences of continuity and transitions that will enhance the understanding of key challenges associated with other HSCTs that occur earlier in the journeys or trajectories of those with ASD. This is in line with the observation above, in section 2.5, that service users and providers often define and conceptualise continuity differently. The empirical literature is presented in two parts. Firstly, the literature on parental/ caregiver views of HSCTs is summarised and critiqued and then a synopsis of the perspectives of service providers will be presented.

2.6.1 Parental/Caregiver experiences of continuity of care associated with health and social care transitions in the case of ASD.

Whilst there was a lack of studies focussing on the interrelated experiences of continuity of care associated with HSCTs, numerous studies have investigated parents/caregivers of children with ASD and their general ‘well-being’ (The PACT Consortium, 2018). A synthesis of the literature here reveals that well-being for parents and caregivers significantly decreases at times of transition and parents often experience periods of anxiety and/or depression when in the process of transition (Taylor and Seltzer, 2011; Cheak-Zamora, Farmer, Mayfield, Clark, Marvin, Law and Law, 2014). However, it should be noted that this literature pertains to later transitions along the child’s trajectory, i.e. from paediatric to adult service, and little is known about this issue in relation to early years’ transitions.

Other researchers have in recent years begun to document caregivers’ perspectives on what leads to a successful or challenging transition experience, but again the focus here has been on the transition to adult services for youth with ASD. For example in a study by Cheak-Zomara and Teti (2015a), parent participants described the loss of relationship with service provider (relationship continuity of care) and lack of support/ preparation for transition as major barriers to experiencing successful transitions (Cheak-Zomara and Teti, 2015a). Without this information on barriers and facilitators to effective transitioning, it is impossible to effectively plan services to assist youth with ASD in their transition to adult-oriented care. This in turn negatively impacts their health, safety and independence, and their caregivers’ well-being (Binks, Barden and Burke, 2007; Golnik, Ireland and Borowsky, 2009; Stewart, 2009).

In a further two studies Cheak-Zomara and colleagues (2014; 2015b) examine parental perspectives of the transition from paediatric to adult-based ASD services and teams. Results reveal that families feel relatively unprepared for the transition process and that transition tools are rarely used by service providers. Such studies provide us with valuable insights into how caregivers perceive and experience health and social care transitions, what mechanism of supports they desire to facilitate an experience of ‘smooth’ transitions, and proposed methods of improving outcomes associated with transitions. The authors conclude that qualitative methodologies such as focus group interviews with parents/guardians can provide invaluable and in-depth information about the lived experience of transitions. This in turn can inform providers and health care managers to develop better practices to support seamless and coordinated transitions. The authors do posit that individual interviews may be more fruitful in

complementing focus group methodologies, leading to more individual reflection and comfort and ease of participation (Cheak-Zomara and Teti, 2015a).

In a study by Kuhlthau, Delahaye, Erickson-Warfield, Shui, Crossman and Van Der Weerd, (2016), 183 caregivers of children with ASD aged between 13 and 26 years were surveyed about their perspectives on health care transitions. They found that there is a significant need to address health care transition services for youth with ASD. Results indicated that families who received transition services (including transition planning meetings, transition documents and workshops) were generally satisfied with them. Yet, alarmingly, most of the participants did not receive these preparatory services and interestingly those who were not provided with transition supports and services generally desired them. They reported that many parents experienced challenges in obtaining these services: they desired more information on the transition process and on the providers who would be taking over their care services (Kuhlthau et al., 2016). While this survey provides us with valuable information about experiences of transitions for caregivers, the survey used for data collection did not undergo any psychometric testing, and so its reliability and validity are unknown. The authors also acknowledge a potential sampling bias issue: participants were selected from a well-resourced population involved in ASD advocacy. This means that the sample may reflect a best-case scenario rather than a typical representation of those impacted by transition. The authors also advocate for the need to conduct a follow-up survey with service providers to ensure encapsulation of multiple perspectives of those involved in the transition process.

2.6.2 Service Providers' experience of continuity of care associated with health and social care transitions in the case of ASD.

Three studies to date have looked at service providers' perspectives of aspects of continuity of care associated with health and social care transitions but once again the focus has been on the key transition to adult-based services (Hodgetts, Nicholas, Zwaigenbaum and McConnell, 2013; Kuhlthau, Warfield, Hurson, Delahaye and Crossman, 2015; Havlicek, Bilaver and Beldon, 2016).

Kuhlthau et al. (2015) conducted a multi-perspective interview-based study of 19 health care providers (5 doctors, 5 psychologists, 7 social workers or care coordinators, and 2 registered nurses) on the topic. This study investigated practitioners' views about best practice for supporting HSCTs in ASD. However, they did not investigate if these best-practice guidelines were adhered to, and, if so, how successful they were. Their study was restricted in exploring the perspectives of only four health care disciplines. As stated in *section 2.3.2*,

children with ASD and their caregivers often engage with multiple disciplines to meet the complexity of health and social care needs associated with ASD and its care trajectory. Results indicate that providers perceive that care coordination is paramount to implementing successful transitions and that interventions to improve care coordination and resultant continuity of care experiences are needed. In particular, results highlighted the importance of ensuring that families are provided with written medical summaries to give to service providers in adult based services to promote informational continuity of care. Kuhlthau et al.'s (2015) study, highlighted the importance of good communication between the paediatric and adult service providers to ensure care coordination. They emphasised the need for transition planning to ensure a more positive and successful transition experience. They further recommend that education and training sessions for families, service providers and children with ASD are necessary to improve coordination of care throughout transition. The authors conclude that there is a need for research which evaluates paired service provider/service users perspectives' within the same contexts to capture their experience holistically.

A study by Havlicek et al. (2016), also looked at service providers perspectives on the facilitators and barriers to smooth transition from paediatric to adult care and services for children with ASD in foster care. They found that service providers believed that the barriers to a continuous transition included lack of training on transition planning and confusion about services. These service providers emphasised that aspects of continuity of care facilitated successful transition, e.g. professional relationship building, consistent communication and information sharing. As was the case in the study by Kuhlthau et al. (2015), Havlicek and colleagues investigated what providers believed would work in terms of improving transition experiences, not what is actually carried out in practice. However, Havlicek et al.'s (2016) study included more participants (N=41 from multiple health and administrative disciplines), compounding the weight of their findings.

Another study by Hodgetts et al. (2013), looked at both parent and provider perspectives of quality of care across a variety of health and social care sectors for families of children with ASD. Hodgetts and colleagues found that this experience was both negative and positive. Families described 'on the ground' staff as positive, while at the organisational/system level their experiences are described as a "Fight". They described the system as a "a System of exclusion" and they felt that they often encountered "Restrictions of care" for their children. The opinions of service providers highlight many similarities. Service providers (146 participants of multiple health and social care disciplines) emphasised their longing to facilitate improved quality of care across sectors, yet felt that their work was heavily shaped, restricted

and influenced by broader administration and government policies. In theoretical terms, this resonates with Corbin and Strauss's (1991) concept of organisational contingency factor referred to in Table 3.3. Arguably, however, the study by Hodgetts and colleagues has several limitations. For example, families with a child with ASD of any age were asked to participate. This sampling and recruitment strategy makes investigating a specific transition at a specific point in time along a care trajectory difficult to assess. Furthermore, Hodgetts et al. (2013), did not 'pair match' families and service providers, meaning that all participants emanated from different care areas and contexts where different practices and policies may have been in place. Another limitation of this study is that the data gathered from service providers were of a quantitative nature. It could be argued that data generated from qualitative or mixed method approaches might provide richer and more contextualised information about how systemic barriers and/or supports impact quality care outcomes across sectors.

2.6.3 Parental/Caregiver experiences of continuity of care in the context of transitioning from Early Intervention services to follow-on health and social care services for young children with ASD.

The literature search did not reveal a single study focussing on the experience of caregivers when their children with ASD transition from early intervention services and teams to follow-on services for young children with ASD in the early years (0-8) (Starr, Martini and Kuo, 2014). This is a significant concern given that, arguably, children with ASD bring further unique challenges to the experience of health and social care transitions than other children. In addition to the transition challenges faced by all children with complex care needs, children with ASD often present with specific signs and symptoms which potentially make the process of transitioning more impactful. As outlined in section 2.3.1 earlier, children with ASD often find change difficult. Social communication difficulties make it harder for them to meet the social challenges of moving to a new environment, which in the case of transitioning to new health/social care teams not only involves adjusting to new physical (e.g. clinical) environments but also involves building relationships with new individuals and understanding new rules, norms and intervention patterns (Tobin, Staunton, Mandy, et al., 2012). Furthermore, a strong preference for sameness and routine can affect a child's ability to adapt to new environments associated with meeting unfamiliar health/social care providers' in unfamiliar clinic rooms (Mesibov, Shea, and Schopler, 2005).

Many children with ASD experience heightened sensory responses to environmental stimuli as well as increased anxiety associated with entering new, unfamiliar and highly

stimulating environments (Ghaziuddin, Ghaziuddin and Greden, 2002; Aylott, 2010). Similarly, many experience hypersensitivity to touch, which presents an additional challenge to health-care providers during physical examinations and diagnostic testing (Williams, 2003; Shea and Mesibov, 2005). Also of significance is the fact that the transition to another health care service may be occurring at the same time as other critical transitions for children and young children with ASD, such as the transition from preschool to primary school, or from primary level education to secondary school (Stewart, 2009; Friedman Warfield and Parish, 2013). Further pressures on children with ASD include an expectation of increased independence as they also start formal education (Plimley and Bowen, 2007). The increased demands make transitioning between different settings and stages of life particularly challenging for these children (Sterling-Turner and Jordan, 2007). The lack of empirical evidence regarding the specific difficulties faced by children with ASD and their families when they transition from health and social care service provided in the early years (e.g. 0-6) to follow-on services and teams needs to be addressed. Only one study was sourced which proved informative about the complexity of transitioning and resultant impacts on continuity of care for young children with ASD.

A single study was sourced (Pang, 2010), from the United States which explores the concept of transitioning from early intervention services (provided by a variety of health and social care services) to Kindergarten services (where health and social care disciplines work in collaboration with educational services based in educational settings). However, this is a different service configuration from that of other international settings, including that of the Irish context (see section 1.2.3 in chapter 1). Therefore, the generalisability of issues noted should be viewed with caution. The case study conducted by Pang (2010), explored and evaluated the transition of a child with ASD and his family from an EI service to a kindergarten-based service. This study found that using a practice where the family were heavily involved was useful in supporting a positive transition to a collaborative education and health and social care service configuration. In particular results indicated the benefits of transition planning meetings between the family service providers in EI and the next placement for addressing family concerns, priorities and expectations in relation to the transition. Results also emphasised the usefulness of EI professionals providing follow-up contacts to check the status of the child and the family after their transition to Kindergarten services. This resulted in the family feeling that their long-time, intimate relationship with EI personnel did not end abruptly, and that they could get ongoing support from the EI service coordinators, which reduced anxiety, worry and intimidation for caregivers (Hains, Rosenkoetter, and Fowler,

1992; Bruns and Fowler, 1999; Adams, 2003; Pang, 2008; Pang 2010). These latter points resonate with the concepts of relationship, management and cross-boundary continuity described in sections 2.5.

2.7 Impetus for the present research

This chapter presents evidence from four different yet interrelated areas. It presents the current understanding of autism spectrum disorder, health and social care transitions, continuity of care and the experience of continuity of care in health and social care transitions for children with ASD. The scarcity of research combining these strands in the literature indicate that research is needed in the following areas:

- The caregivers' perspective of experienced continuity of care associated with health and social care transitions (in particular the transition following early intervention services) in the case of young children with ASD
- The perspective of associated service providers
- The processes and outcomes of continuity of care experiences associated with early HSCTs in the case of children with ASD
- System- and organisational-level influences that shape continuity of care experiences for children with ASD when they transition from EITs to follow on services and teams

2.8 Study aim and objectives

Aim

To explore caregivers' and service providers' perspectives of experienced continuity of care following the transition from EIT services to PCCCTs in the 12 month period post transition.

Objectives

- i. To explore caregivers' perspectives on *constructions* of continuity of care in this context.
- ii. To explore caregivers' perspectives on *experiences* of various dimensions of continuity within the 12 month period following discharge from the EIT and transitioning to the PCCCT.
- iii. To explore service providers' perspectives on continuity of care in this context, to *contextualise caregivers' accounts* and *to examine potential solutions* to address any problematic experiences outlined in objective (ii).

In *Chapter 3* the methodology and methods for the present study are described.

Chapter 3: Methodology

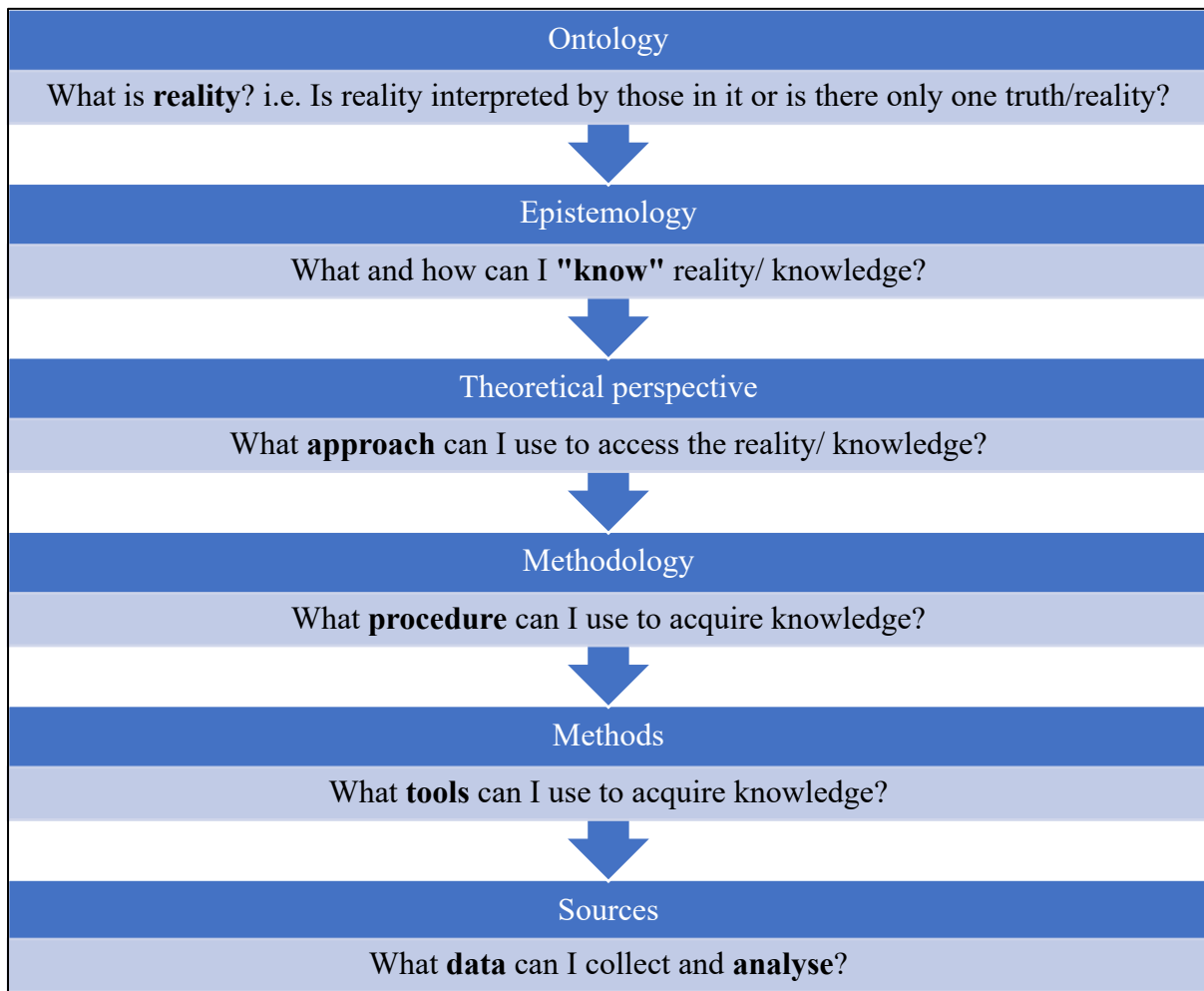
3.1 Introduction and overview of chapter

According to the literature, research is not conducted in a vacuum; research is viewed through a lens (Kivunja and Kuyini, 2017). It is conducted with a particular mindset and constructed using specific approaches and techniques (Henning, van Resburg and Smit, 2004). The lens in which research is framed is referred to as a research paradigm and the way in which research is conducted is referred to as the research methodology and methods. This chapter seeks to outline and explain the reasoning behind the choice of research paradigm for the present study, its epistemological and theoretical stances and the research methodology which guided the process. The methods used to conduct the research will also be described, including the sampling and recruitment strategy, the data generation procedures, and the data analysis process. Finally, issues of validity, reliability and ethical considerations related to this study will also be outlined.

3.2. Research paradigm and Epistemological stance

A research paradigm is described above as a ‘lens’ by which research is viewed and conducted. A research paradigm is “the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed” (Kuhn, 1962 pg. 45). According to Guba (1990), research paradigms can be characterised through their ontology, epistemology and methodology. These various concepts form relationships to each other in that ontological and epistemological positions should have a bearing on the methodology and methods selected for a research project. Figure 3.1 below describes the meanings of these key research terms.

Figure 3.1: Research “paradigm” drawing on the work of Hay (2002) and Crotty (1998).



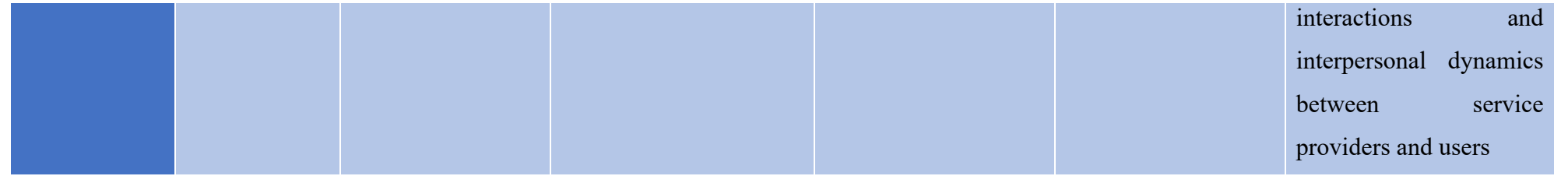
There are several possible paradigms in which research can be conducted e.g. positivism, interpretivism, critical, pragmatism and subjectivism (Creswell and Poth, 2018). Below, Table 3.1 describes these potential research paradigms and their ontological and epistemological stances and the potential for their use in the present study. Two of these paradigms are presented in health services research literature as ‘key’: positivism and interpretivism. The opposing paradigms of positivism and interpretivism and their applicability to the current study will be discussed in detail. Finally, justification for the chosen paradigm - interpretivism will be provided.

Table 3.1: Research paradigms and their applicability to the present study based upon various sources including Creswell (2014), Crotty (1998).

Paradigm	Ontology	Epistemology	Theoretical perspective	Methodology	Methods	Potential for Applicability to present study
Positivism	There is a single reality or truth	This reality can be measured using tools	Positivism	Experimental Research, Survey research	Usually Quantitative e.g. questionnaire.	The study aimed to examine a phenomenon and the meanings attached to it, not to quantitatively measure the experience as, e.g., excellent, good, fair or poor.
Interpretivist	There is no single reality of truth	Reality needs to be interpreted. It is used to discover the underlying meaning of events	Interpretivism <ul style="list-style-type: none"> • Phenomenology • Symbolic interactionism • Hermeneutics • Structural interactionism 	Ethnography, Grounded Theory, Case Study, Phenomenological Research, Discourse Analysis and others.	Usually Qualitative e.g. interviews, focus groups, observations	The objective of this research was to study the phenomenon of a single health and social care transition in depth from the perspective of the meanings that caregivers and

						service providers attach to it.
Critical	Realities are socially constructed entities	Reality and knowledge is socially constructed and is influenced by those within society	Marxism	Critical discourse analysis, Critical ethnography	Ideological review Civil actions Focus groups	The gap in existing research (as identified in Chapter 2) on this topic means that critical social theory has an inadequate base from which to challenge, contrast and question to provide a comprehensive critique.
Pragmatism	Reality is constantly renegotiated or debated	The best method is one that solves problems.	Deweyan Pragmatism	Mixed methods	Interviews, questionnaires, data mining expert review.	Pragmatism is a deconstructive paradigm. It “sidesteps the contentious issues of

						truth and reality” (Feilzer, 2010, p. 8), and “focuses instead on ‘what works’ as the truth regarding the research questions under investigation” (Tashakkori and Teddlie, 2003, p. 713). The research question under investigation aims to understand the experience; therefore this paradigm would not be appropriate
Subjectivism	Reality is what we perceive to be real	All knowledge is purely a matter of perspective	Postmodernism Structuralism	Discourse theory Archaeology Genealogy	Autoethnography, Literary analysis	The objective of this research was to study the phenomenon and the meanings attached to it, not to study the



3.2.1 Positivism

The Positivist paradigm is based on the ideas of the French philosopher, Auguste Comte (1798 – 1857). The key principle of Positivism is that only “factual” knowledge gained through observation, including measurement, is trustworthy. In positivist studies, the role of the researcher is to collect data and interpret it in an objective way. The findings of positive studies are usually observable, quantifiable and developed using statistical analysis. It has been noted that *“as a philosophy, positivism is in accordance with the empiricist view that knowledge stems from human experience. It has an atomistic, ontological view of the world as comprising discrete, observable elements and events that interact in an observable, determined and regular manner”* (Collins, 2010 pg. 38).

Crowther and Lancaster (2008) argue that, as a general rule, positivist studies usually adopt a deductive approach. The viewpoint of the researcher is independent from the study and the research concentrates on ‘facts’ to ensure that there is no ‘human interest’ within the study (Creswell and Poth, 2018). In summary, studies framed within a positivist paradigm are based purely on facts and consider the world to be external and objective.

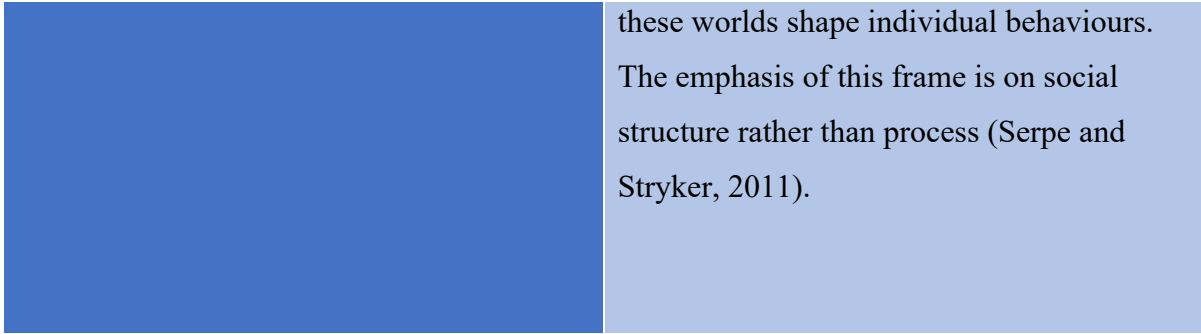
3.2.2 Interpretivism

In contrast, the interpretivist paradigm was developed based upon a critique of positivism within the field of social sciences. The key principle of interpretivist research is capturing and understanding multiple perspectives of a phenomenon that is *“lived, felt and undergone”* (Robson, 2011, p.24). Therefore, the goal of interpretivist research is to gain a rich understanding of reality (the participant’s views of the world) by obtaining and understanding participants’ “social constructions” of that reality. These social constructions are expressed through the participants’ voices, activities, beliefs and behaviour (Geertz, 1973; Klein and Myers, 1999; Creswell, 2014). Social constructions are used to identify deeper meaning and understandings in social and organisational contexts (Creswell, 2014). Interpretivist findings are based on insight gained from the participants voices, and call this the “truth” (Kumar, 2011). Interpretivism therefore has the epistemological stance that recognises the social aspect of research and other influences; in contrast to the positivist stance, it doesn’t see the world as orderly or quantifiable. In this paradigm, it is recognised that the researcher is inseparable from the research phenomenon and that these are constantly influencing each other. A number of interpretivist methodologies have been developed and are widely available. For example, unstructured observation, open interviewing, idiographic descriptions and qualitative data analysis are all presented as possible ways to capture “insider” or “emic knowledge” (Pike,

1976; Creswell, 2014). Table 3.2 below describes the major principles relating to interpretivism that were influential in framing the present research: for example, hermeneutic circle, suspicion, contextualisation, abstraction, generalisation and structural interactionism.

Table 3.2: Principles of interpretivism and their descriptions based upon the work of Klein and Myers, 1999 and Sandberg, 2005.

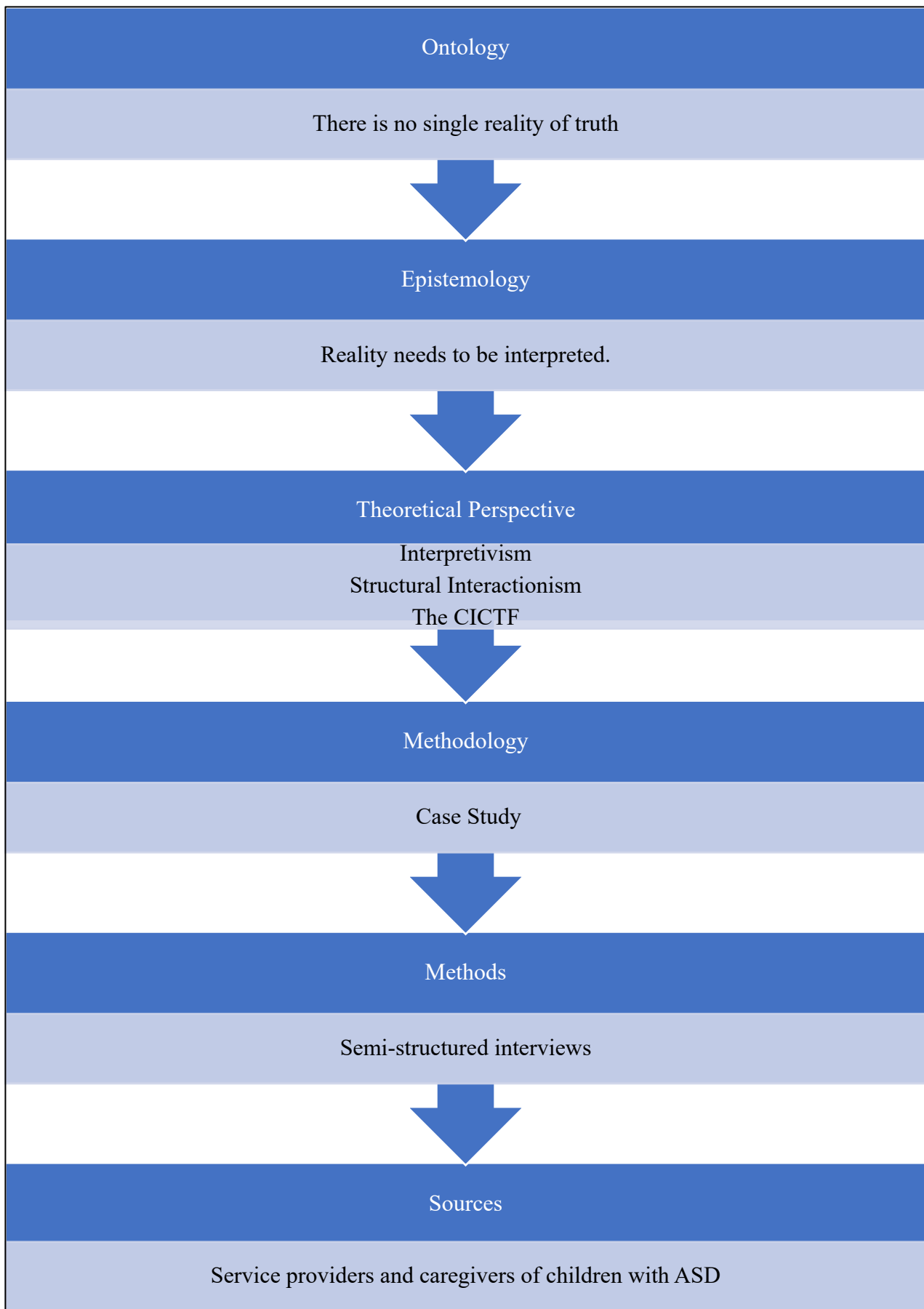
Principle	Description (Based upon Klein and Myers, 1999 and Sandberg, 2005)
Hermeneutic circle	The hermeneutic circle suggests that all human understanding is achieved by iterating between considering the interdependent meaning of parts and the whole that they form.
Suspicion	Suspicion requires critical thinking and “reading” the social world behind the words of the actors, a social world that is characterized by power structures, vested interests, and limited resources.
Contextualisation	Contextualisation requires that the subject matter be set in its social and historical context. It is noteworthy that the spirit in which this is done differs from a positivist account of history.
Abstraction and Generalisation	Even though interpretivist research is idiographic, intrinsic to interpretivist research is the attempt to relate particulars to very abstract categories. This abstraction process is sometimes called “descriptive generalization” (Lincoln and Guba, 2007).
Structural Interactionism	Is a frame of reference to better understand how individuals interact with one another to create symbolic worlds, and in return, how



these worlds shape individual behaviours.
The emphasis of this frame is on social structure rather than process (Serpe and Stryker, 2011).

Figure 3.2 below outlines an overview of the research paradigm chosen for this study, its ontological, epistemological and theoretical perspectives.

Figure 3.2: Overview of the research paradigm of the present study



3.2.3. Rationale for framing present research in the interpretivist paradigm

The present research applies the interpretivist paradigm to data collection, analysis and interpretation. Interpretivism was selected as the most appropriate research paradigm as the nature of the study, objectives, approach and techniques aligned with the key principles of the interpretivist paradigm (Creswell, 2014). The choice of this paradigm allowed for the use of approaches and techniques that facilitated achievement of the research objectives to explore perspectives of experienced continuity of care following the transition from EIT services to PCCCTs in the 12 month period post transition. In contrast, the use of positivist paradigm principles as described above would be in conflict with the nature of this study's subject matter. The study's open-ended research questions, approach to data collection and need for multiple subjective perspectives conflict with positivist beliefs in empiricism and hypotheses. The qualitative approach, as used in this study, complements interpretivism, while positivism advocates the use of quantifiable measures or statistical analysis (Neuman, 2014). Use of the critical paradigm on the other hand offers opportunity for existing perceptions and experiences to be challenged and reconstructed (Kumar, 2011), which concurs with the aim of this thesis. However, the gap in existing research on the experience of continuity of care associated with health and social care transitions for caregivers of children with ASD (as identified in Chapter 2) from both an interpretivist and positivist lens means that critical social theory has an inappropriate base from which to "challenge, contrast and question" to provide a comprehensive critique (Avgerou, 2005, pg.104-105). The rationale for the use of the interpretivist viewpoint is now elaborated on, in terms of the research topic, aim and approach.

3.2.4. Alignment of the interpretivist paradigm with research topic

The environments of EIT and PCCCT as described in chapter one and the transition between them form a complex interconnected arrangement. EITs and PCCCTs have their own policies, procedures, guidelines, directives ideas and priorities for what constitutes a successful transition. This means that what service providers from EIT and PCCCT interpret as a successful transition may differ and these interpretations or constructions may also differ from that of caregivers' perspectives. Each individual's experiences and interpretations of these experiences are shaped by their own constructions of reality. Individuals construct their own social reality (Neuman, 2014). They interact with each other, working together: this can alter their realities, leading to further activities and outcomes. For example, service users and providers work together during therapeutic interventions and the outcome of these interactions can potentially alter their overall experience of the transition. In line with the interpretivist

paradigm, communication and interaction are dependent on descriptions, narrations, symbols and diagrams that are meaningful and context-dependent (Klein and Myers, 1999; Creswell, 2014). As an example, the early pilot and sensitising work for the present research revealed how contextually dependent and meaning-laden a discharge report is (A discharge report is a clinical summary of the biographical and therapeutic information concerning the individual child. It is prepared by a health professional at the conclusion of his/her time in the service). Pilot data revealed that to one person at one point in time the discharge report may be valuable, but to another person at another point in time the report may be perceived as meaningless, or the opportunity to use them may have passed.

3.2.5. Alignment of the interpretivist paradigm with research objectives

The research question, aims and objectives outlined in chapter two also align with the principles of the interpretivist paradigm. The overall aim of the study reflects the desire to understand the environment where the research was conducted, how it emerged, the factors which influenced the context and the participants' experiences within this context. The research questions of the thesis cannot be measured or answered in isolation. The objectives of the research lend themselves to understanding the whole experience through its parts, that is, before, during and after transition—and this is in keeping with the interpretivist principle of the “**hermeneutic circle**” (Creswell, 2014). The interpretivist paradigm allows for the experience of continuity of care associated with a health and social care transition to be explored and interpreted through multiple participants' perceptions. The approach allowed for the exploration of organisational contexts of the study (i.e. EIT and PCCC) to be explored in terms of their structures and resources. This aligns with the interpretivist principle of “**suspicion**”.

3.2.6. Alignment of the interpretivist paradigm with research approach and techniques

This thesis provides analysis and interpretation of the social and organisational world in which the research participants (caregivers of children with ASD and their service providers) interact, perform their activities and create meaning in relation to continuity of care in this context. The study interprets and seeks to understand the research topic by looking beyond participants' answers into their social constructions of their environments – identifying and describing their beliefs and examining the consequences of these. As will be outlined later in the chapter, this thesis will use qualitative methods, observing and interviewing participants to understand the research topic.

3.2.7. Theoretical Framework

This study uses the theoretical framework, the Chronic Illness and Care Trajectory Framework (CICTF); it shaped the line of questioning during data collection and acted as a lens to perform analysis. Using the CICTF as a lens sought to help understand participants' perceptions of their experiences within this context. This aligns with the interpretivist paradigm's principle of "**contextualisation**", explaining reality for the study participants and how this reality emerged. The application of this theoretical lens (Corbin and Strauss, 1991; as described in chapter 2) aligns with the interpretivist paradigm's principle of "**abstraction and generalisation**" whereby social theories are applied to data discoveries (Creswell, 2014). In line with this, the CICTF, as used in this thesis, formed a basis from which to develop concepts, generate theory, draw implications and contribute insight on the experience of a health and social care transition and associated experiences of continuity of care through a new lens (Creswell, 2014). The CICTF has its basis within a theoretical perspective of interpretivism. The framework is based within a particular form of symbolic interactionism referred to as *pragmatic* or **structural interactionism** developed by Strauss (1978; 1982). Blumer's (1969) symbolic interactionism contains the schemas of action and interaction while structural interactionism adds the contextual environment. Within a structural interactionism approach the individual actor and social micro-level processes are acknowledged (as in symbolic interactionism), while at the same time organisational phenomena at the macro-structural level influencing action are also acknowledged (Gerhardt, 2000). Strauss referred to these organisational or structural factors as *conditions* or *contingencies* in his highly acclaimed co-authored book 'The Social Organisation of Medical Work' (Strauss, Fagerhaugh, Suczek, and Wiener, 1985). Therefore, structural interactionism was in line with the theoretical perspective for the present study.

The Chronic Illness and Care Trajectory Framework (CICTF) developed by Strauss and colleagues (Glaser and Strauss, 1968; Strauss et al., 1985; Corbin and Strauss, 1988) was utilised to provide an insight into the issues and influences pertaining to the transition between EIT and PCCCT. It provided a lens to view how interrelationships and contexts are shaped and managed over the trajectory of a child with ASD. This subsection includes an overview of the key concepts of the CICTF and the application of these to the present study. Finally, a justification for this theoretical framework is given, which informs the analysis and structuring of the data, in line with the case study approach. In drawing on this perspective, it was acknowledged that individuals' perspectives on continuity associated with specific health care

organisational contexts, EIT to PCCCT, would be constantly *under construction* in (inter)action amongst the range of social actors associated with these services. However, these (inter)actions would also be constantly influenced and shaped by a range of social-organisational/structural conditions or contingencies.

The CICTF is a theoretical framework which advances the idea that chronic illness progresses through a course or path that varies with the passage of time. This passage/trajectory includes the actions undertaken by the service user, the service user's family or caregivers and health care professionals in helping to manage the course of the chronic condition over time (Corbin and Strauss, 1991). Corbin and Strauss' (1988) trajectory framework is based on a sociological perspective, which allows insight into the complexity for all involved to get the work done to manage the condition. There are many conditions that influence the management of a trajectory, such as personal, interpersonal and socio-political conditions influencing daily management (Corbin and Strauss, 1988). When used as a theoretical framework for research, it enables the researcher to observe and organise factors that shape the trajectory experience. It is this process that allows the researcher to understand complexity by gaining knowledge of the relationships between multiple variables which may have been previously explored but in isolation. Hence the trajectory framework, within this study, provides a lens to understand the experiences of all key participants in the case of a lifelong developmental disorder at a particular *trajectory sequence point*, to be viewed not in isolation, but as an interactional experience of all participants. The framework is representative of complex and complicated work required to manage a lifelong conditions on a daily basis, often by service users and family, which can be largely invisible to clinicians and the medical record (Strauss, Fagerhaugh, Suczek, and Wiener, 1982; Klimmek and Wenzel, 2012).

The major unifying concept in the framework is 'trajectory' or care course: this refers to the condition progression and unites all the other concepts within the framework. These other concepts all have a relationship or influence on the illness course or its management and therefore to the core concept of the trajectory (Corbin and Strauss, 1991). These concepts are defined in Table 3.3. The concepts of "care trajectory", "trajectory sequence point", "work" and "organisational contingencies" are the major concepts that informed this study.

Table 3.3: Definitions of concepts from the CICTF

Concepts from the CICTF (Corbin and Strauss, 1991)	Description	Application to the present study
Trajectory	A Condition/Care Course	The journey of care of a child with ASD and their family experience
Trajectory Sequence Point	A point during the individual’s trajectory where it is decided that something different is to be done, e.g. transition to a new team	The point when the child and family transition from EIT to PCCCT.
Trajectory Manager	The individual who plays a central role in managing, and co-ordinating (articulating) the work required to shape and manage one’s trajectory.	The individual from EIT or PCCCT who plays a key role in managing and coordinating the work involved in the transition
Work	A set of tasks performed by individuals or groups in order to manage one or more aspects of a trajectory.	A set of tasks performed by individuals or groups in order to manage the transition from EIT to PCCCT
Information Work	This involves talk work but also record work, involving the quest for, the receiving of and passing of information from one worker to another associated with a service user’s trajectory.	This involves talk work but also record work, involving the quest for, the receiving of and passing of information from one worker to another associated with the child with ASD and his/her family.

Sentimental Work	This refers to work that is associated with managing the service user's psychosocial or <i>sentimental</i> aspects of his/her trajectory.	This refers to work that is associated with managing the child's/caregivers' psychosocial or <i>sentimental</i> aspects associated with the trajectory of the child with ASD
Patient and Kin Work	A set of tasks performed by the service user and/or the kin in order to manage one or more aspects of an illness.	Work undertaken by the family of the child with ASD to manage the transition from EIT to PCCCT.
Substitute Work	Any work that is undertaken by the service user or kin which providers were either supposed to do or service users believed they were supposed to do	Any work undertaken by the parent of child with ASD that service providers were supposed to do or it was believed they were to do
Contingencies	Unexpected events that may arise in the course of an individual's biography or trajectory that may affect work and course of illness	Unexpected events that may arise in the course of the trajectory of the child with ASD that may affect work.
Organisational Contingency Factors	The ways in which organisational structures, e.g. resources, staffing and practices, impact on the service user's trajectory	The ways in which organisational structures, e.g. resources, staffing and practices, impact on the trajectory of the child with ASD.

Reciprocal Impact	When contingencies have consequences for trajectory management, these consequences are known as reciprocal impact.	When contingencies have consequences for the management of the trajectory of the child with ASD, these consequences are known as reciprocal impact.
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The CICTF was chosen for the present study because it is consistent with the interpretivist paradigm; it encourages analysis of participants' interpretations and experiences of continuity of care and the range of organisational factors influencing these; it offers a valuable framework that facilitates a focus on the concept of the individual's journey or process from EIT to PCCCT through the health and social care system which specifically aligns with the study's aims and objectives.

3.3 Research Method and Design

In keeping with the research paradigm, a qualitative research design was chosen to conduct this research. Creswell (2013), describes how qualitative research uses the interpretivist paradigm, theoretical frameworks and the researchers' own knowledge to inform the research question through the meanings individuals or groups accord to a social or human problem.

'To study this problem qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. - (Creswell, 2013 pg. 44).

The written report or presentation at the conclusion of the research includes voices of participants, the reflexivity of the researcher, a description and interpretation of the problem and its contribution to the literature (Creswell, 2013). In recent years, the values of qualitative research have been increasingly advocated for use in health and social care related research (Kuper, Reeves and Levison 2008). Qualitative methods are employed in order to understand the "why" behind people's behaviours or actions, thus giving the researcher a way to gain an in-depth understanding of the underlying reasons, attitudes, and motivations behind the chosen research area (Kaae and Traulsen, 2015). The qualitative design of this study allowed the researcher to gain insight into the participants' views, opinions, feelings and beliefs (Hicks 2009), about their and their child's experience of the continuity of care process associated with the transition from EIT to PCCCT. As indicated in Chapter 2, quantitative caregiver perspectives on the service needs of their children with chronic conditions/disabilities have been well documented, but qualitative studies examining caregiver and youth perspectives on health and social care service needs are less frequent (Phelps, Hodgson, McCammon and

Lamson, 2009). Qualitative research has been advocated as an excellent tool for understanding the perspectives of caregivers and youth with ASD (Humphrey and Lewis, 2008; Kaehne and O'Connell, 2010). By using qualitative approaches when conducting research with families living with ASD, more complex issues can be explored (such as relationship dynamics and mixed or ambiguous attitudes; King, Law, Hanna et al., 2006; Meadan, Stoner, and Angell, 2010; Dew, Balandin, and Llewellyn, 2008; Cridland, Jones, Caputi, et al., 2014) and an emphasis can be placed on gathering rich descriptions rather than on testing a priori hypotheses (Krogh and Lindsay, 1999). As parents and caregivers of children with ASD are experts on their family challenges, strengths and what supports aid their daily lives, they need ample opportunity to share their perspectives (Phelps et al., 2009).

3.3.1 Methodological Framework

Research methodology is defined as the way to systematically solve a research problem; it is a science of studying how research is done (Kothari, 2004). Research methodology involves the various steps that are generally adopted by a researcher in studying a research problem along with the reasoning behind them (Kothari, 2004). Creswell and Poth (2018), emphasise that the explicit presentation of a study's methodological approach enhances the rigour and sophistication of the research design. There are a number of different methodological frameworks which can be used within qualitative research, e.g. narrative, phenomenological, grounded theory, ethnography and case study (Creswell and Poth, 2018). Each of these methodological frameworks has its own distinctive features and each can draw on the theoretical and epistemological principles of interpretivism to varying degrees. Case study methodology was chosen as the methodological framework for the present study. After researching and critiquing all of these frameworks, it was felt that case study methodology was consistent with the research focus and the research question.

3.3.2 Case Study Framework

Case study research has a long history across many fields and disciplines, e.g. anthropology and sociology (Thomas and Znaniecki, 1958; Hamel, Dufour and Fortain, 1993). A case study is described as the study of a case within a real life contemporary setting (Yin 2014). There are several components which define case study research (Creswell and Poth, 2018).

- Case study research examines a phenomenon of interest. In the present research, the phenomenon of interest is the health and social care transition from EIT to PCCCT and the associated continuity of care experience.

- Case study research should be bounded within certain parameters e.g. place and timeframe. In this study, this case is bounded by location within the context of a single EIT/PCCC transition in the North West of Ireland and bounded by time, within 12 months of discharge from EIT.
- Case study research presents an in-depth understanding of the case and often concludes with observations about the overall meaning or lessons learned from studying the case. This study's findings and conclusions will be discussed in the subsequent chapters of this thesis.

Case study research involves some theory development in the design phase which is different to other methodologies, e.g. ethnography and grounded theory (Corbin and Strauss, 2007), that deliberately avoid specifying any theoretical propositions. Because of this, the CICTF could be incorporated into the methodological framework. In this present research, the case study is both exploratory and descriptive in nature. It is grounded in the theoretical perspectives of the CICTF.

Finally, because the case study was used to learn about the phenomenon of continuity of care, it may be described as an instrumental rather than an intrinsic case study. This means that a description and exploration of the case itself was not the only or even the primary focus of the study but that the case was instrumental in learning about the phenomenon of transition within this context.

On the contrary, case study research does have some limitations for example: the generalisability of case study research is often critiqued (Yin, 2014). A case study involves studying the behaviour of one person, group or organisation. The behaviour of this one unit of analysis may or may not reflect that of similar entities. Case studies may be suggestive of what may be found in similar situations but further research is often recommended for validation purposes. This is one reason why case studies are often used for poorly understood problems – first qualitative inductive research is used to understand the problem before quantitative deductive research is completed for potential generalisability claims (Yin, 2014).

In summary despite its limitations, a single, exploratory and descriptive case study drawing on the theoretical framework of the CICTF formulated the methodological framework for this study.

3.4. Sampling and Recruitment

In line with ethical approval for the study, which is discussed further in Section 3.7, gatekeepers working within EIT and associated PCCCTs in North West of Ireland agreed to recruit participants for this study. The sampling and recruitment for the study will be discussed under two headings: first, Caregivers and second, Service Providers. This is in line with the multi-perspective nature of this case study.

3.4.1 Caregiver Sampling and Recruitment

Purposeful sampling of caregivers in line with case study methodology and the theoretical framework was selected as the sampling strategy for this study. Purposeful sampling is when the researcher selects individuals or sites which can purposefully inform an understanding of the central phenomenon of the study (Creswell and Poth, 2018). This involved developing a framework of variables that could potentially influence an individual's contribution to the study. Based on findings of the literature review, a range of demographic variables thought to be influential in shaping one's perspectives on continuity of care in this transitional context were drawn up, e.g. length of time known to EIT, length of diagnosis of ASD, location and number of follow-up services recommended. A list of all demographics and the rationale behind their selection can be found in Table 3.4 below.

Table 3.4: Sampling parameters considered for the caregiver sample and rationale for their inclusion

Demographic Variable	Rationale for use and consideration in the present study
No. of follow up services recommended for child with ASD	<ul style="list-style-type: none">• The number of follow-up services in PCCCT may potentially influence perspectives on continuity associated with the health and social care transition (Sanclemente-Ansó, Salazar and Bosch et al., 2015).
Length of time child/caregiver known to EIT	<ul style="list-style-type: none">• The length of time an individual is involved with the EIT may potentially influence perspectives on continuity associated with the health and social care transition (Borghans, Kleefstra, Kool and Westert, 2012).

Time since ASD diagnosis	<ul style="list-style-type: none"> The length of time an individual has had their diagnosis may potentially influence perspectives on continuity associated with the health and social care transition (Lauche, Häuser and Jung et al., 2013).
Geographical Location of child/caregiver	<ul style="list-style-type: none"> One's location may potentially influence perspectives on continuity associated with the health and social care transition (Dansereau, Masiye and Gakidou et al., 2015).

The gatekeeper had access to a database containing details about those who had been discharged from the EIT that year. The gatekeeper distributed information letters and consent forms to caregivers of children with ASD who were discharged from EIT in January 2018 and January 2019. Potential participants were given a period of two weeks to indicate their interest in partaking. They were invited to contact the gatekeeper by post or the researcher directly if they wished to participate. Caregiver recruitment took place in February 2018 and January 2019. The participant characteristics for this cohort are outlined in the table below.

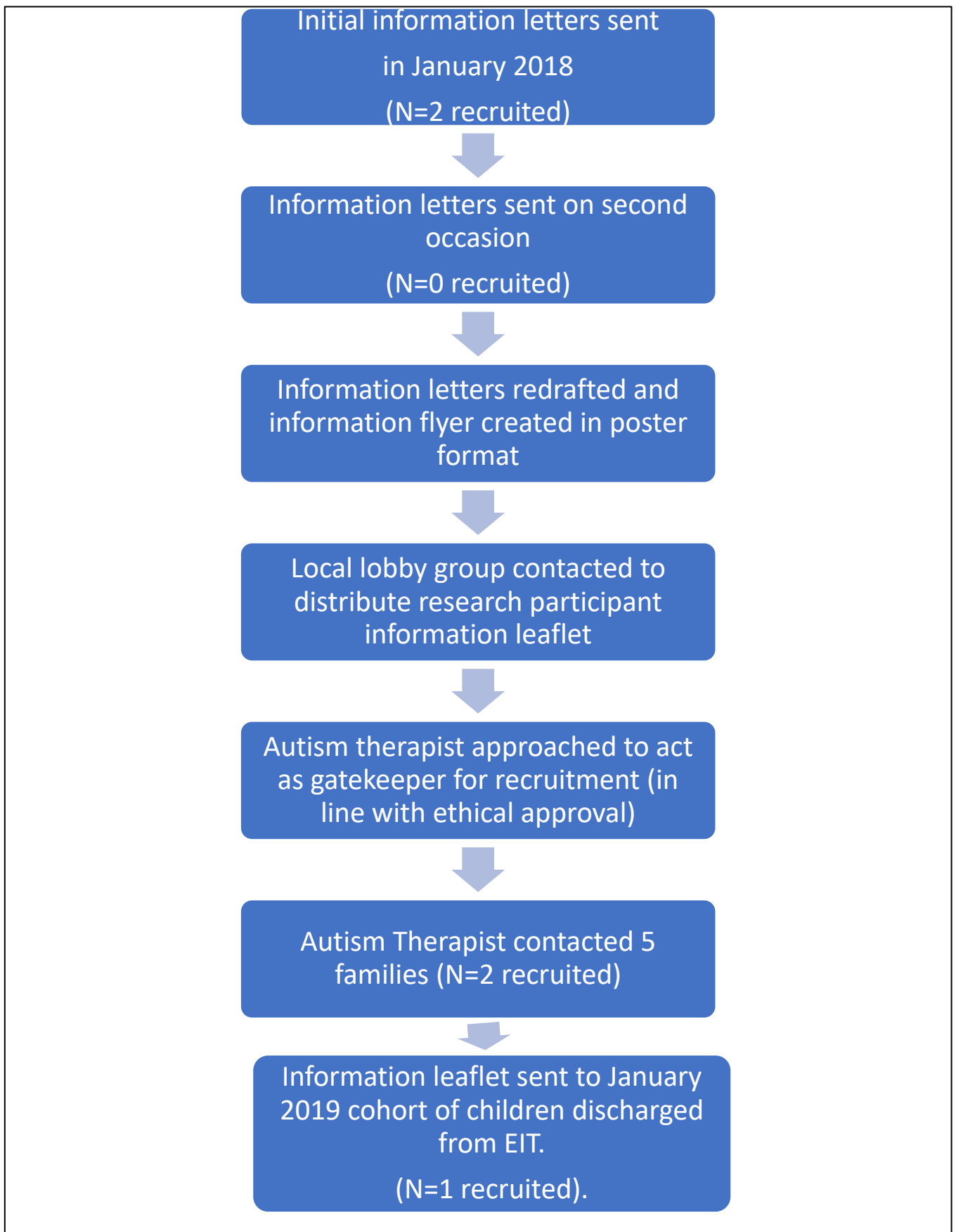
Table 3.5: Characteristics of Caregivers and their child

Participant	No. of follow up services recommended	Time know to EIT	Length of ASD diagnosis	Location
P1	5	2.8 years	1 year 5 months	Rural
P2	5	2.4 years	1 year 2 months	Rural
P3	4	2 years	1 year	Urban
P4	5	2.6 years	1 year 8 months	Urban
P5	4	2.2 years	1 year 4 months	Urban

In qualitative research, a small sample size allows for rich data collection on the topic (Patton 2015). Marshall and Rossman (2015) describe how a researcher needs to be flexible in his/her sampling approach. In the present study, difficulties were encountered in relation to recruitment of caregivers. In an attempt to recruit more caregiver participants, snowball sampling was used. Snowball sampling involves asking existing subjects to nominate further subjects known to them, so the sample increases in size (Creswell and Poth, 2018). A flow chart below highlights the number of responses from caregivers at each stage of the recruitment process. The

researcher had to explore many potential avenues to gain access to participants. In concluding each interview with caregivers, the researcher used snowball sampling asking participants if they knew others who might also be interested in partaking. Another approach involved a local parent lobbying group. The researcher shared information posters and leaflets with this group for use on their social media. Another avenue explored, in line with ethical approval, was using a different gatekeeper to access those who had been discharged from EIT. An autism therapist who had a personal relationship with these caregivers agreed to act as a gatekeeper. Below, a flowchart explains the number of caregivers recruited through each avenue. It is outlined in chronological order.

Figure 3.3: Flowchart of caregiver recruitment



3.4.2 Service Provider Sampling and Recruitment

As described in section 3.4.1, purposeful sampling of service providers was used. A framework of variables that could potentially influence an individual’s contribution to the study was created. Based on findings of the literature review, a range of demographic variables thought to be influential in shaping one’s perspectives on continuity of care in this transitional context was drawn up, e.g. profession, length of time in service, location and seniority. A list of all demographics and the rationale behind their selection can be found in Table 3.5 below.

Table 3.6: Sampling parameters considered for the service provider sample and rationale for their inclusion.

Demographic Variable	Rationale for use and consideration in the present study
Profession of service provider participant	<ul style="list-style-type: none"> • Different professional groups place different emphases on the importance of continuity of care in different contexts (Al-Azri, 2008).
Length of time in service	<ul style="list-style-type: none"> • Older providers who are more used to traditional features of Irish service delivery may have different views in relation to new service delivery structures from younger providers (McLoughlin, Armstrong, Byrne et al., 2005).
Geographical Location of provider	<ul style="list-style-type: none"> • Providers living in urban and rural areas may have different views about the trade-offs between continuity of care, travel, and access to services because of their locations (Cuddy, Keane and Murphy, 2001).
Seniority	<ul style="list-style-type: none"> • One’s position in the profession may potentially influence perspectives on continuity associated with health and social care transition.

In keeping with ethical approval, service providers who work with the families of children with ASD were recruited from both the EIT and PCCCT settings. Service providers from both settings were recruited in an attempt to capture accounts of experienced continuity of care in the transition from EIT to follow-on PCCCT services. A gatekeeper (manager of EIT) distributed information letters and consent forms by email to service providers charged with

working with children with ASD in either setting. Participants were given a period of two weeks to indicate their interest in partaking. Service provider participants were asked to contact the researcher directly if they wished to participate. Service provider recruitment took place between April 2018 and December 2018. Participant demographics for this cohort are outlined in table 3.7 below:

Table 3.7: Table of service provider participants and their characteristics

Participant Code	Occupation/ Speciality	Member of EIT/PCCCT	Seniority	Time working in service	Location
OT 1	Occupational Therapist	PCCCT	Senior	10+ years	Semi-Urban
SLT 1	Speech and Language Therapist	PCCCT	Senior	10+ years	Urban
SLT 2	Speech and Language Therapist	PCCCT	Staff Grade	Less than 1 year	Urban
SLT 3	Speech and Language Therapist	PCCCT	Staff Grade	1 year	Rural
EITM	EIT Manager/ PCCCT OT manager	Across both services	Managerial	10 + years	Across both
AT 1	Autism Therapist	EIT	n/a	10 + years	Across both
SLT 4	Speech and Language Therapist	EIT	Senior	10+ years	Urban
AT 2	Autism Therapist	PCCCT	n/a	7 years	Across both

AONO	Assessment of Need Officer	n/a	n/a	6 years	Urban
CFD	Community Facilitator for Disabilities	EIT	n/a	8 years	Across both
OT 2	Occupational Therapist	EIT	Senior	7 years	Urban
AT 3	Autism Therapist	PCCCT	n/a	5 years	Semi-Urban
FSW	Family Support Worker	Across both services	n/a	1 year	Across both
PT	Physiotherapist	Across both services	Staff Grade	3 years	Across both

3.5 Data Collection Procedures

3.5.1. Data Collection Tools

The study used semi-structured interviews as the method of data collection. Semi-structured interviews were selected as they are in keeping with the research paradigm of interpretivism and its methodology, case study research. Semi-structured interviews allow the researcher to be prepared with topics and questions to be answered (LaForest, 2009). The interviewer can change the order of the questions or the way they are worded (LaForest, 2009). The interviewer can give explanations or leave out questions that may appear redundant (LaForest, 2009). Semi-structured interviews allow for questions to be created during the interview, giving both the interviewer and the interviewee flexibility to probe for details or discuss issues (LaForest, 2009). The interviewer has a guide to follow, but is able to follow trajectories in the conversation which may be appropriate to the research question (LaForest, 2009).

Individual interviews were also chosen as this research and the information disclosed was in-depth and personal which an individual may not have wished to disclose in a group context (Yeo, Legard, Keegan and Ward, 2014). The use of individual interviews allowed for the detection or expansion of information that might not have been immediately recognised as significant by the interviewee or by the researcher (Gill, Steward, Treasure and Chadwick, 2008). Interviews with caregivers were conducted in their homes at their request and ranged in

duration from forty five minutes to one hour and twenty five minute, averaging one hour. Interviews with service providers took place in locations preferable to them including health centres or on site in IT Sligo. Interviews were audio recorded and the researcher made notes and reflections on each interview immediately after the conclusion of the interview. The development of questions for the topic guide took much thought and consideration in order to receive the highest quality of data from the interview process. Questions were initially devised based (i) on emerging themes from the literature on health and social care transitions and continuity of care and (ii) on the researcher's professional experience/knowledge of the topic and phenomenon of interest. Questions were developed using three guidelines set out by Rosenthal (2016). She states that questions should be (i) truly open-ended and neutral. This meant that during the development of questions thought had to be given to ensure that the questions did not make assumptions about the interviewee's opinion on the topic, nor offer any clues as to what the interviewer hoped the interviewee would say. Secondly, Rosenthal suggests that questions should be (ii) singular, asking about only one topic at a time. This point was followed strictly as within this research there were multiple objectives to be answered as part of the broader research question. Thirdly, she states that questions must be (iii) clear. In order to achieve this, topic guides were reviewed to ensure that there was clarity in the questions created. Topic guides were reviewed, developed and updated as part of an iterative process throughout data collection and analysis in order to adapt to new and emerging themes that were not initially anticipated by the researcher. These adaptations allowed the researcher to extract more valuable and meaningful data. To demonstrate this process a sample of the original draft topic guides used can be found in appendices E and F and later drafts of the developed and extended topic guide can be found in appendices G and H.

3.6 Data Analysis Procedures

Data analysis involves preparing, organising, reducing, condensing and representing data collected during the research (Creswell and Poth, 2018). There are multiple ways in which data in qualitative research can be analysed. Several qualitative data analysis methods which had potential for use in this study are reviewed below in Table 3.8. From this table one can see the method, a brief description, a critique and applicability in the context of the present study.

Table 3.8: Potential data analysis methods and their applicability to the study.

Method	Description	Critique	Applicability to the present study
Grounded Theory (GT)	Grounded Theory (GT) (Glaser and Strauss, 1967) is a systematic methodology that involves the development of theory through data analysis (Martin and Turner, 1986). The development of theory is conducted in a ‘bottom up’ approach (Holloway and Todres, 2003). There are three grounded theory methodologies Classic, Straussian (Strauss and Corbin, 1998) and Constructivist GT (Thornberg, 2012).	GT is often misunderstood. There is significant disagreement between grounded theorists as to what constitutes GT. Critics argue that "it is impossible to free oneself of preconceptions in the collection and analysis of data in the way Glaser and Strauss say it is necessary" (Thomas and James, 2006)	This study does not aim to develop theory, but to use theory to support both data generation and analysis.
Discourse Analysis (DA)	DA first came to prominence after a publication by Harris (1952) and it covers a number of approaches to analyse written, vocal, or sign	DA has many forms which includes but is not limited to semiotics, psycholinguistics and sociolinguistics. The choice of form must be directed by the	There are many forms of DA which exist, making selection difficult (See Potter and Wetherell, 1987; Burman and Parker, 1993; Willig, 2003).

	language use or any significant semiotic event.	research aims which can be difficult to decide early in the research process (Brown and Yule, 1983)	Using DA, requires a detailed theoretical and technological knowledge of the approach.
Content Analysis	Content Analysis was first introduced by Lasswell and Casey (1946) and is the analysis of texts of various types including writing, images, recordings and cultural artefacts. It tends to focus at a more micro level, often provides (frequency) counts (Wilkinson, 2000) and allows for quantitative analyses of initially qualitative data (Ryan and Bernard, 2000)	It is commonly used for analysis of communication such as documents and text. Content analysis is less clearly branded and the researcher should draw distinctions between "prescriptive analysis" and "open analysis" (McKeone, 1995; Patton 2015).	The themes are often quantified and the unit of analysis tends to be a word or phrase. The aims of this research project do not lend themselves to the themes being quantified and the unit of analysis are not the participants.
Narrative Analysis	Narrative Analysis (NA) emerged as a discipline from within the broader field of qualitative research in the early 20th century	Critics argue that whereas NA challenges the idea of quantitative objectivity, it is nonetheless	NA has many different manifestations of the method within a board theoretical framework (Murray, 2003).

	<p>(Riessman, 1993). NA uses field texts, such as stories, autobiography, journals, field notes, letters, conversations, interviews, family stories, photographs (and other artefacts), and life experience, as the units of analysis to research and understand the way people create meaning in their lives as narratives (Clandinin and Connelly, 2000)</p>	<p>lacking in theoretical insights of its own (Boje, 2001).</p>	
<p>Thematic Analysis</p>	<p>Thematic analysis is the most commonly used method of analysis in qualitative research analysis (Thomas and Harden, 2008; Guest, MacQueen and Namey, 2011) and is used for identifying, analysing, and reporting (themes) within data (Braun and Clarke, 2006). The method of analysis should be</p>	<p>Critics argue that reliability with this method is a concern because of the variety of interpretations that arise from the themes. Increasing reliability may occur if multiple researchers are coding simultaneously, which is possible with this form of analysis (Guest, MacQueen and Namey, 2011).</p>	<p>Thematic Analysis can be reliant on the presentation of themes supported by participant quotes as the primary form of analysis (Bazeley, 2009). Thematic analysis is in line with the methodology of the study.</p>

driven by both theoretical assumptions and the research questions. Thematic analysis provides a flexible method of data analysis and allows for researchers with various methodological backgrounds to engage in this type of analysis.

Having reviewed and critiqued several analytical methods, thematic analysis was chosen to analyse the data. Thematic analysis was selected as it is flexible and offers an accessible form of analysis (Clarke and Braun, 2013). It can be applied across a range of theoretical and epistemological approaches including interpretivism, the paradigm framing the present research. Thematic analysis allows the main features of a dataset to be summarized, and gives an in-depth description of the data (Braun and Clarke, 2006). It allows for similarities and differences across the dataset to be seen (Braun and Clarke, 2006; Miles, Huberman and Saldana, 2014). It can generate unanticipated insights not overtly seen by the researcher (Braun and Clarke, 2006; Miles et al., 2014). Thematic analysis uses both inductive and deductive reasoning to analyse data. In inductive ‘bottom up’ reasoning categories of meaning and relationships between categories are derived from the data. In deductive ‘top down’ reasoning analysis is driven by the research question and broader theoretical assumptions. In the earlier stages of data analysis cross checking was conducted with the supervisor of the project and the wider project team of four experienced researchers.

In accordance with the guidelines of Spencer, Richie, O’Connor et al. (2014) and Braun and Clarke (2006), thematic analysis consisted of six sequential and linked phases in the present study. These are described below:

1. Familiarisation – The researcher was immersed in the data from the outset, gaining an overview of it. The researcher conducted all the interviews and was very closely involved in the identification of patterns emerging from the data collection process (Braun and Clarke, 2006). This guaranteed that labels developed were based in and supported by the data (Spencer et al., 2014).
2. Generating initial codes- A set of initial codes was created from the data. Codes are the smallest element of data that can be assessed (Braun and Clarke, 2006). Codes were comprised of emergent themes from the interviews, observations, research questions and key questions from the interviews (Spencer et al., 2014). These codes were then used to label the data. The data were coded for as many themes as possible (Braun and Clarke, 2006). A sample of this stage of coding can be found in appendix I.
3. Searching for themes – When the data had been initially coded, a list of different codes was formed and the codes were sorted into potential themes, e.g. information, relationships etc. These were examined twice to ensure the data was relevant to the


identified themes (Braun and Clarke, 2006). A sample of this phase of coding can be found in appendix J.

4. Reviewing themes – The themes were then reviewed and refined. Firstly, the themes were reviewed at the level of coded data in the extracts. Secondly, the validity of the themes was considered and whether the themes accurately revealed the meanings evident in the dataset. A sample of this phase of coding can be found in appendix K.
5. Defining and naming themes – The researcher further defined and polished the themes. A detailed analysis of each theme was then conducted and written up. At this phase the themes were clearly defined and the process of naming them began. The names needed to be precise in order to give the reader an immediate sense of the definition of the theme (Braun and Clarke, 2006). For example, the information theme name was changed to information transfer to more clearly reflect the definition of the theme. A sample of this phase of coding can be found in appendix L.
6. Producing the report - This involved a final analysis: the final list of themes was taken back to the original transcripts to verify the applicability of the themes to the actual data (Rosenthal, 2016). On completion of this, the write-up of the report then began. The report provides a concise, interesting explanation of the dataset and provides evidence of the themes within the data (Braun and Clarke, 2006).

Analysis was supported by using a data analysis software package called NVivo 12 (QSR International, 2018). This allowed the data to be gathered and processed in a coherent manner. Table 3.9 below shows the links between the stages and processes of Braun and Clarke's (2006) Thematic Analysis when conducted using NVivo software (QSR International, 2018). The six steps of data analysis and their corresponding application in NVivo are described. The elements of coding moved from descriptive coding to more interpretive coding, and then to the final abstraction to themes. The iterative nature of the tasks of coding, analysis and reporting are described.

Table 3.9: Stages and Process Involved in Qualitative Analysis - Adapted from Braun and Clarke (2006) and training materials of QDATRAINING (2013a and 2013b).

Analytical Process (Braun and Clarke, 2006).	Braun and Clarke Application in NVivo	Objective	Iterative process throughout
1- Familiarising yourself with the data	Transcribing data, reading the data, noting down initial ideas. Import data into the NVivo	Data Management (Open and hierarchal coding)	Assigning data to refined concepts to show meaning
2- Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collecting data relevant to each code		Refining and distilling more abstract concepts
3- Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme	Descriptive Accounts (Reordering, 'coding on' and annotating)	Assigning data to themes/concepts to show meaning
4- Reviewing themes	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis		Assigning meaning
5- Defining and Naming themes	On-going analysis to refine the specifics of each theme, and the overall story [storylines]		

	the analysis tells, generating clear definitions and names for each theme	Explanatory Accounts	 Generating themes and concepts
6- Producing the report	The final opportunity for analysis and selection of vivid, compelling extract examples to support the write-up of the report which links the data itself, the research question and broader research together.	(Extrapolating deeper meaning, drafting summary statements and analytical memos)	

3.7 Validity and Reliability

Validity and reliability are both crucial characteristics of high quality research. Validity typically refers to the truthfulness of research and accuracy of presenting information about the phenomenon under study (Silverman, 2005). Reliability represents stability and consistency “with which instances are assigned to the same category by different observers or by the same observer on different occasions” (Hammersley, 1992, pg. 67 in Silverman, 2005, pg. 210).

Those working within a positivist paradigm often criticise qualitative research as their validity and reliability cannot be attended to in the same way as in the quantitative tradition (Shenton, 2004). Qualitative research does not have established tools for measuring validity and reliability (Robson, 2011). In quantitative research, the replication of the study by an independent researcher and achievement of the same results is the evidence of validity, in qualitative research the same approach may not achieve the same results, as findings are closely related to the contexts and times (Guba, 1990). Unbiased representation of data is not plausible in qualitative research as phenomena are studied from the perspective of meanings that people attach to them, and numerous realities that exist in the minds of people (Guba, 1990; Kvale and Brinkmann, 2009). Kvale and Brinkmann (2009 pg. 253) argue that the difficulties with validity may not be a limitation of qualitative research, but conversely may represent its “extraordinary power to picture and question the complexity of the social world investigated”.

In this subsection, the validity of this study is be discussed through a validity framework developed by Maxwell (1992). The framework comprises five validity categories through which a qualitative research is judged: descriptive validity, interpretive validity, theoretical validity, generalisability and evaluative validity.

3.7.1 Descriptive validity

Descriptive validity is the factually accurate presentation of the data (Maxwell, 1992). To ensure descriptive validity audio recordings of interviews were carefully transcribed. Transcripts were reviewed against audio recordings to ensure they were accurately transcribed. A transcription can be descriptively invalid if it fails to include important features of speech, such as, for example pitch or intonation. The researcher’s educational background in linguistics helped her to be attentive to the non-verbal elements of communication. During transcribing, notes were made of pauses and their possible meaning (e.g., recollecting, hesitating), emotional aspects of interviews (e.g., when informants sighed, laughed) and also of information which

was particularly stressed by informants. After each interview immediate reflections and reactions were noted by the researcher and these formed an important part of the analytical process.

3.7.2 Interpretive validity

Interpretive validity involves being able to capture informants' perspectives, what informants actually mean, their 'intention, cognition, affect, belief, evaluation' (Maxwell, 1992, p.288). To ensure correct interpretation of the participants' perspectives', member checking was used. Member checking is a technique for exploring the credibility of results. The data is returned to participants to check for accuracy and resonance with their experiences (Birt, Scott, Cavers et al., 2016). This involved questions with simple rephrasing or questions beginning "Do you mean that", "Is it correct that" to ensure accurate interpreting.

The researcher played an integral role in this project. The researcher's knowledge as a speech and language therapist (SLT), working clinically with children with ASD and their caregivers in a different geographical location, is important to note. The researcher's experience in this area may have influenced and shaped the interpretation of the results of this project (Austin and Sutton 2014). The researcher was acutely aware of this potential bias throughout and constantly reflected on the research as it developed in a research diary (Laverty, 2003; Watt, 2007). The researcher engaged in frequent supervision meeting with the research supervisor who was not in clinical practice, and a wider research team of academics. The collection and analysis of data were also carefully structured to support trustworthiness and rigour as it was impossible to eliminate bias in research which involved people (Robson 2011; Lewis and McNaughton-Nicholls, 2014).

3.7.3 Theoretical validity

Theoretical validity concerns the theory used in the study and its relevance to the phenomenon under study (Maxwell, 1992). Maxwell emphasises the importance of using theory which is recognised by the academic community. Similarly, Creswell (2013) maintains new research is granted solidity if it based on previous studies. The theoretical validity of this study is represented by the comprehensive literature review in Chapter 2. The Chronic Illness and Care Trajectory Framework, chosen as theoretical framework for this research, was previously used by other researchers concerned with capturing continuity of care experiences (e.g. Gallagher et al., 2012 in the case of primary health care services for those with chronic conditions). Robson (2011) states that staying in the realms of one theory and not considering alternative

understandings poses a threat to validity. In this study, the researcher was open to multiple theoretical influences and to data that did not conform to findings in the literature review. This can be seen in chapter two, where several/many/numerous theories that had potential for use in this research process were explored. Theory was not forced to fit the context of this thesis but ideas of the CICTF were developed and extended by applying it to a new context of the health and social care transition from EIT to PCCCT services.

3.7.4 Generalisability

Generalisability refers to the extent to which the theory resulting from the study can be applied to other persons and settings (Maxwell, 1992). There are two types of generalisability that can be drawn from research, internal and external generalisability. Internal generalisability entails drawing inferences within the setting of the study, while external generalisability entails drawing inferences beyond this setting. For qualitative studies external generalisability is often difficult to achieve (Maxwell, 1992; Robson, 2011). The present research did not aim to achieve external generalisability. The small number of informants and the purposive sampling used in the research had the aim of maximising the range of information uncovered in a certain area, which did not allow for external generalisability (Guba, 1990). However, the findings uncovered in this study may allow for some transferability. The study provided a detailed account of the participants and context under study, and this may allow findings to be transferable to similar contexts with a similar cohort of participants. For example, the findings of this study may be transferable or relevant to other EITs and PCCCTs in Ireland since the organisational structure and culture is similar.

Authors such as Flyvbjerg (2001, 2006) and Ruddin (2006) defend the concept of qualitative generalisability. They argue cases can be generalised to other circumstances and situations, with the help of in-depth analytic investigation (Yin, 2012). Cases build theoretical premises which function as tools to make assertions about situations similar to the one studied. Likewise, if further case studies show resembling outcomes, they can be said to support the hypotheses and therefore be a part of constructing the theory (Yin, 2012). In generalising case study results, researchers must practise a high level of accuracy and cautiousness to succeed. This is due to the limited applicability of evaluation rules (Kennedy, 1979), the risk of the case not being representative (Gerring, 2004), and the probability of biased and subjective influences interfering with the researcher in the analysis (Firestone, 1993). In summary in order to generalise from case study research, the research must be conducted carefully and with much consideration.

3.7.5 Evaluative validity

Evaluative validity, according to Maxwell (1992), judges the validity of evaluations made by researchers. To ascertain evaluative validity regular debriefing sessions were held with the research supervisor and academic colleagues, which aided the researcher in cross-checking evaluations. Moreover, the strategies mentioned above—reflectivity and minding the bias—were used (Laverty, 2003; Watt, 2007).

3.7.6 Reliability

Providing an audit trail, which is “a methodologically self-critical account of how the research was done” (Seale, 1999, p. 468), in some ways assured the “reliability” of the present study. Chapter 3 presents a detailed account of philosophical and methodological standpoints of this study, the reasoning behind the choice of sample and data collection tools and detailed descriptions of procedures of collecting and analysing the data. To further ensure reliability external to the data collection procedure, the researcher used a diary to document and reflect on the research process. The researcher engaged in frequent meetings with the supervisor for the project and in discussions with an external research team: this enhanced the trustworthiness of the data and analytical product.

3.8 Ethical Considerations

Before conducting this research, ethical approval was obtained through the Research Ethics Committee in Sligo University Hospital. The ethical procedures also followed the code of practice for the quality assurance of postgraduate research in Sligo IT (Institute of Technology: Sligo, 2014). Ethical approval involved providing the Ethics Committee with a detailed account of the study, how ethical issues would be handled, sample information letters and sample topic guides for review. The Sociological Association of Ireland – Ethical guidelines (SAI, 2013) and guidelines set out by IT Sligo (Institute of Technology: Sligo, 2014) were used to guide and inform the researcher during both the ethical application process and throughout the research itself.

There are many ethical challenges that may have implications in qualitative research. These primarily arise from the evolving and variable nature of qualitative methodology (Houghton, Casey, Shaw and Murphy, 2010). The unpredictability of qualitative research means that a universal direction for ethical conduct is not always possible. Therefore, the

researcher must be constantly mindful of the ongoing impact that the research might have on those involved, whilst simultaneously being ethically sensitive and morally competent. The ethical challenges pertinent to this research included the issues of informed consent, the researcher-participant relationship, confidentiality, anonymity and data storage. In the context of research ethics, the challenges that arose during this study will be discussed and the means by which they were overcome when conducting the interviews will be described.

3.8.1 Informed participant consent

The first issue which arose during the research planning stage was that of obtaining informed consent and assent to partake in the research. When using qualitative methods, one cannot guarantee the direction of data collection in interviews. As a consequence, one-off consent may not be suitable for this type of research (Denscombe, 2014). Furthermore, from an interpretivist perspective, it can be acknowledged that ethics is subjective (Schwandt, 2000). Participants may have different perceptions about what they consider to be ethical and, therefore, constant negotiation with informants is crucial (Denscombe, 2014). This can be referred to as the informed consent process (Flick 2014; Bryman, 2016). Informed consent makes it possible to negotiate and revise arrangements throughout the course of the research study. It also allows participants to play a collaborative role in the decisions regarding their ongoing participation (Bryman, 2016). The researcher reiterated the right that the participant might withdraw from the study at any time.

In the current study and in line with ethical approval, information leaflets were sent to potential participants by the gatekeeper. These leaflets detailed the aims of the study, why it was being conducted and by whom so that the recipients could make an informed decision about whether they wished to take part. As this study included gathering the perspectives of many individuals, written consent was sought from all potential participants prior to data collection. Individuals who wished to partake were able to return consent forms to the gatekeeper or contact the researcher directly. Sample information letters for the different stakeholders can be found in appendices M and N. It was important that all participants understood why they were being asked to participate and were able to indicate their willingness to do so. Prior to interviews, all participants were verbally asked if they still wished to partake and their right to withdraw at any time was also repeated.

3.8.2 Researcher-participant relationship and the “dual role” of therapist-researcher

Another challenge pertinent to this research study was the potentially unequal relationship that

could arise between the researcher and the participant. Because of the use of interviewing in data collection, this relationship raises significant ethical issues (Orb et al., 2001; Hofman, 2004). These issues include the manner in which relationships are formed and managed, the nature of the power imbalance between the two parties and the way the relationship affects the participants psychologically, emotionally and personally (Orb et al., 2001; Cutliffe and Ramcharan, 2002; Hofman, 2004). The literature indicates that the boundaries of the relationship can become blurred as the research progresses and role confusion may lead to ethical concerns during the study (Casey, 2006; Streubert, Speziale and Carpenter, 2007). The researcher must be mindful of the ethical implications when managing the relationships that develop through the research.

In the present study, since the researcher was a working therapist, this issue could have been contentious (Ferguson et al., 2006). For this reason, the researcher's own area of practice was not included during the process of site selection. This ensured that a potentially unequal relationship would not occur between the researcher/clinician and service users. Participants expressed a willingness to be involved in the study. Furthermore, the use of informed process consent ensured that this willingness was continued throughout the data collection.

Conflict can arise for the researcher if she or he also has a professional interest in the study topic. The separation of researcher and clinical roles in health and social care services research can be challenging (Orb et al., 2001; Casey, 2004). Role confusion can occur for the researcher, particularly during in-depth immersion into a culture (Ensign, 2003). Participants may begin to perceive the researcher as "one of their own" and lose sight of the real reason for their presence. The purpose of the research and the role of the researcher need to be clearly explained to, and understood by, the study participants. This should reduce false expectations by the participants (Orb et al., 2001).

The literature reveals that the use of a reflective diary promotes an internal dialogue for analysing and understanding important issues in the research project and may go some way to help resolve the conflicting roles of the researcher (Houghton et al., 2010). Therefore, in the current study, a reflective diary was maintained which allowed for acknowledgment of this conflict and its resolution. Reflective writing enabled the researcher to consider her role and how to stay focused on the investigation.

3.8.3 Risk-Benefit Ratio

In qualitative research, it is often difficult to predict in advance the balance of risks to benefits (Ramcharan and Cutliffe, 2001; Cutliffe and Ramcharan, 2002). However, researchers have an

obligation to anticipate the possible outcomes of an interview and to weigh both the benefits and the potential harm (Orb et al., 2001). For example, if a participant becomes distressed during an interview, the researcher should be able to acknowledge that the benefit of the interview does not outweigh the harm of distress upon the participant. Therefore, it is recognised that the researcher must be prepared to cease the interview at this point (Streubert et al., 2007). In this study, the researcher had a process in place so that participants were able to contact appropriate professional services for intervention (e.g. counselling) or ensure that they had regained control of the situation before recommencing (Houghton et al., 2010). It was important that the researcher was mindful of the impact of the research on the participant and when to take the appropriate steps to minimise associated risks.

In the current study, in addition to gaining approval from the Research Ethics Committee, meetings were held with the key gatekeeper, research supervisor and a wider research team. These meetings provided an opportunity to highlight and discuss any potential ethical issues that might arise and provided mentoring and support to the researcher. No such incident arose during data collection. However, having that process in place ensured that any risks to the participants could be minimised and handled appropriately.

3.8.4 Confidentiality and Data Storage

The conduct of research and treatment of its data were two of the key ethical considerations in this study. Confidentiality can be challenging to maintain in qualitative research due to the illustrations and descriptions given by participants that are reported in the findings. Confidentiality must be addressed for each participant, for individuals mentioned within interviews and in relation to sites where the research is conducted. By its nature, case study research is interested in personal views, opinions and circumstances. Those who partake risk exposure and embarrassment if too much personal detail is disclosed (Stake, 2000). It is essential that robust methods are incorporated into the design of the study to ensure confidentiality. The researcher was cognisant of these issues when describing defining characteristics of participants during the write up which could potentially have revealed their identity (Polit and Beck, 2006). To ensure continued confidentiality, participant codes were used. The researcher and supervisor were the only individuals with access to the key to identify participants. In this study, absolute confidentiality of service providers could not be guaranteed, owing to the small nature of the research site. Individuals were made aware that while all their data would be anonymised, they might be able to be identified by readers as they were the only member of their discipline within the site, making their identity deducible from the findings.

Audio recordings of interviews were transcribed, removing all identifying information. The audio was transferred to a password-protected memory key. These recordings were then stored in a locked filing cabinet in IT Sligo. Interview transcripts were stored on a password-protected computer with only the researcher having access to this. The reflective logs and fields notes from interviews were also stored in a locked filing facility.

3.9 Chapter summary

This chapter outlined the methods used to explore perspectives on continuity of care associated with the transition from EIT to PCCCT. The chapter began with a description of the epistemological basis of the study (interpretivism) as well as its theoretical framework, the Chronic Illness and Care Trajectory Framework or CICTF. The study's methodology (case study) and methods were then described. The chapter concluded with an overview of the reliability, validity and ethical considerations of this study.

Chapter 4 describes key findings of the study.

Chapter 4: Findings

4.1. Introduction

This chapter presents the key results from the study. The findings are drawn from the thematic analysis of data. The chapter presents four interrelated core themes developed during the iterative process of data collection and analysis. The themes pertain to perspectives of continuity of care in the context of transitioning from EIT to PCCCT in the North West of Ireland in line with the analytical method outlined in *Section 3.6*. Each theme and the final conclusions will be presented, reporting on the interplay across and between the four major themes. The results are framed in key concepts and ideas from the CICTF (Strauss and Corbin, 1985) which have previously been described in *Chapter 2*. Caregivers' perspectives are central to the study and service provider accounts aimed to contextualise caregivers' perspectives and highlight factors (in theoretical terms “**organisational contingencies**”) which may have shaped an individual's experience of continuity of care in this context. The key themes and their related subthemes are presented in Figure 4.1. These include:

- Varying constructions of services (section 4.2)
- Relationship transitions (section 4.3)
- Information transfer (section 4.4)
- Management practices (section 4.5)

Figure 4.1: Thematic framework of continuity of care experiences when transitioning from EI to PCCC services in the North West of Ireland.

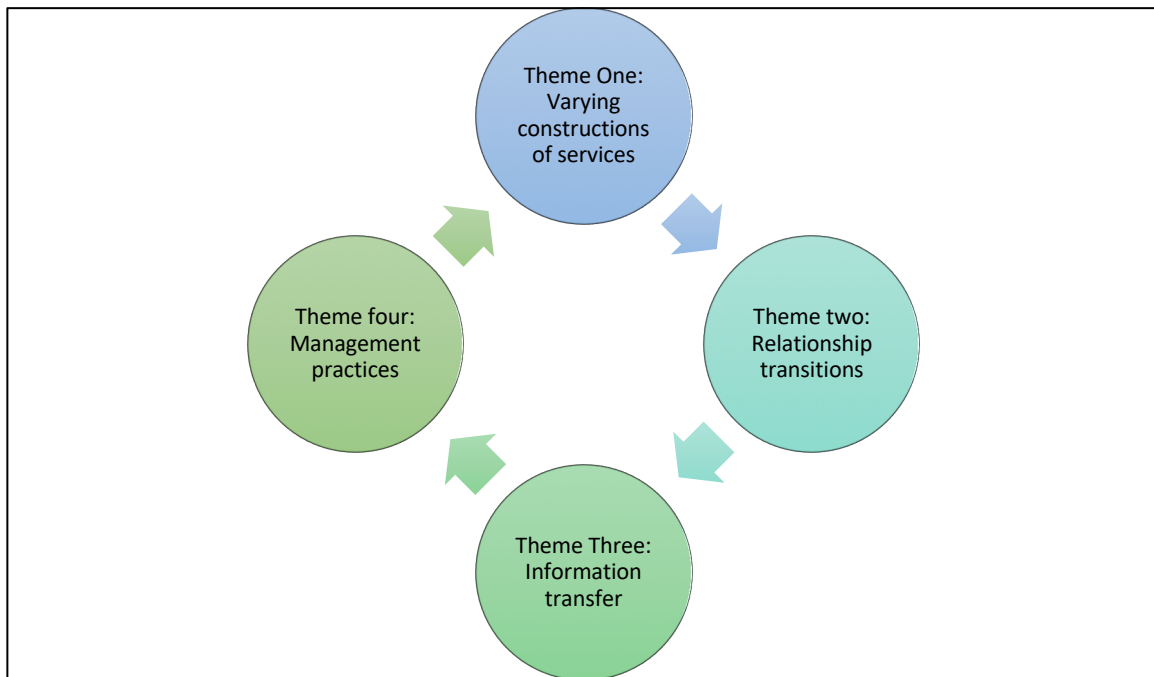


Table 4.1 provides a short description of each theme and its related subthemes.

Table 4.1: Definitions of each theme and subtheme emerging from the present study exploring caregivers’ and service providers’ perspectives on continuity of care associated with the transition from EIT to PCCCT in the North West of Ireland.

Theme and Subthemes	Description of themes and subthemes
Theme one: Varying construction of services	This theme relates to participants’ social constructions of the services in question namely EIT, PCCCT, Transition and PDS.
1.1 Constructions of Early Intervention	This subtheme relates to participants’ social constructions of the Early Intervention service.
1.2 Constructions of the transition to PCCCT	This subtheme relates to participants’ views and experiences on the transition from EIT to PCCCT.
1.3 Constructions of various aspects of transition	This subtheme relates to participants’ perspectives on the construction of various aspects related to the transition from EIT to PCCCT.
1.4 Constructions of Progressing Disability Services	This subtheme relates to participants views on the HSE’s policy “Progressing Disability Services for Children and Young Adults”.
Theme two: Relationship transition	This theme relates to participants’ accounts of their continuing relationships with their service providers and the termination of these during the transition between services
2.1 The experience of relationships	This subtheme relates to participants' expectations and experiences of terminating and building relationships associated with the transition from EIT to PCCCT.
2.2 Consequences of poor relationship transfers	This subtheme relates to the consequences experienced by caregivers and service providers when the transfer of relationships is not managed appropriately.

2.3 Proposed solutions to facilitate relationship transfer	This subtheme relates to proposed solutions by participants to improve relationship transfer from EIT to PCCCT.
Theme three: Information transfer	This theme relates to participants' accounts of information transfer following the course of the client's trajectory associated with the transition from EIT to PCCCT.
3.1 Experience of information transfer	This subtheme relates to the expectations and experience of information transfer during this transition
3.2. Results of poor information transfer	This subtheme relates to consequences to caregivers and service providers when poor information transfer occurs
3.3 Solutions to improve information transfer	This subtheme relates to proposed ideas by caregivers and service providers to improve information transfer associated with the transition.
Theme four: Management practices	This theme relates to participants' accounts of management practices associated with the transition from EIT to PCCCT. Namely, the consistency of clinical management, including care planning, physical environments and intervention type.
4.1 Management practices experience	This subtheme relates what participants expect of and how they experience clinical management practices (as described above) associated with this transition.
4.2 Consequences of poor management practices	This subtheme relates to the consequences experienced by caregivers and service providers when poor clinical management occurs.
4.3 Proposed Solutions to improve management practices	This subtheme relates to proposed solutions by participants to improve management practices associated with this transition.

4.2. The constructions of services

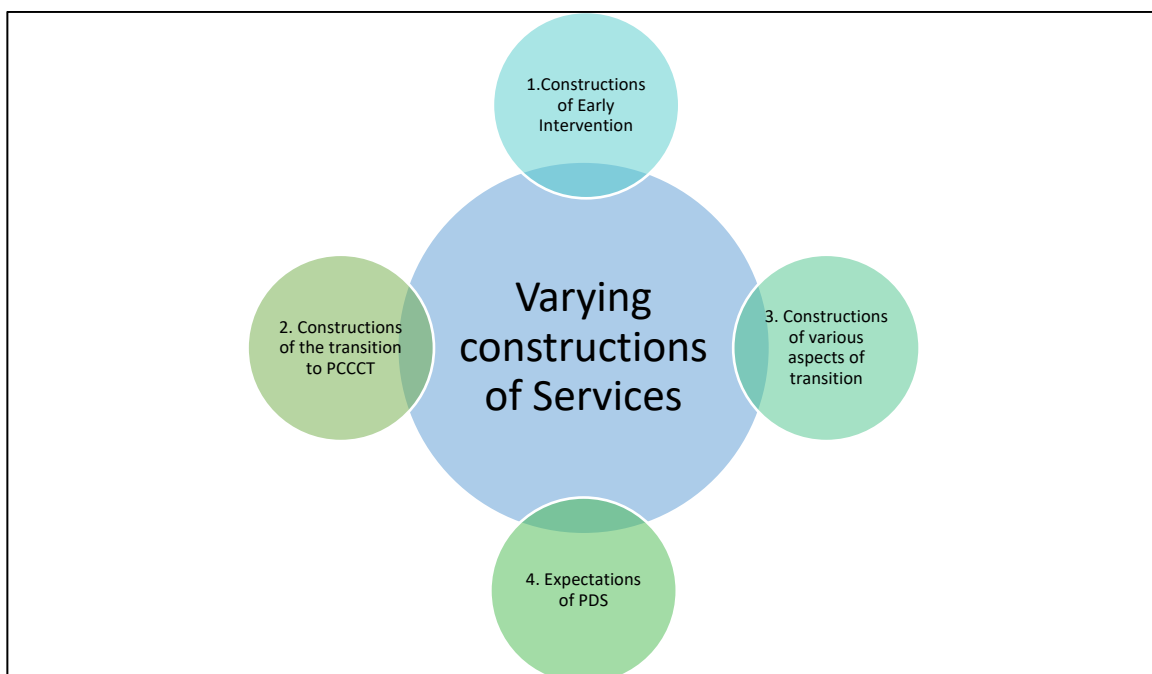
In order to understand the experience of the transition from EIT to PCCCT and the continuity of care experiences associated with it, both service users and providers were asked to describe what each service means to them. By understanding what each individual expects from a service and how he or she interpret the service, one can begin to understand the meanings behind interpretations of their experiences. This section aims to describe how these social constructions of the EIT and PCCCT services impacted interpretations of the experiences of continuity of care before, during and after the transition. These accounts are the framework against which experiences of continuity of care presented in subsequent sections of this chapter can be fully understood and analysed.

This central theme contains four subthemes which explore caregivers' and service providers' accounts on:

- Constructions of Early Intervention
- Constructions of the transition to PCCCT
- Constructions of various aspects of transition
- Expectations of 'Progressing Disability Services for Children and Young Adults' (PDS)

An overview of the theme constructions of services and its subthemes can be seen below in figure 4.2.

Figure 4.2: An overview of the theme of varying constructions of services and its related subthemes.



4.2.1. Constructions of Early Intervention

To contextualise understanding of their experience and perceptions of continuity of care, participants were asked what their understanding of the EIT was. Individuals' expectations can shape how they feel about their experience (de Lang, Helibron and Kok, 2018). For example, expectations throughout their time in a given service can affect their overall perception about their experience of care.

Parent Two described how throughout her time in Early Intervention, she felt that there was a significant emphasis on assessment of her child's needs and indeed on diagnostic therapy.

“You know it's an Early Intervention Team, but intervention seems to be lost. It's diagnostics, and that was it; then discharge” (P2).

Parent four also expressed similar thoughts on what early intervention is. She described it as

“The best to go to if you have a problem with your child and they can look for it [a diagnosis)]. However, they can push you aside after they find out what the problem is and not help [with intervention]” (P4).

As their expectations around “intervention” were not met, this resulted in emotional impacts and feelings of disappointment.

“You know, you're full of hope when you hear the first meeting and people realise there is something wrong with the child and you can get all the help and intervention. And actually it wasn't the case—in our case anyway” (P2).

These emotional impacts are consistent with the concept of '**sentimental work**' described by Corbin and Strauss (1991) in the CICTF. Service providers spoke of the high expectations that caregivers have when coming to early intervention. The community facilitator described:

“Sometimes their expectations are so high because they're so glad to get the support. They merely expect we do a lot more than we do do— than we're actually able to provide”. (CFD).

Service providers described how caregivers have '*preconceived ideas*' (AONO) about the service. This may in turn shape their experience of continuity of care in the EI service and

indeed across the EIT to PCCCT boundary. The Assessment of Need Officer described how parents believe that EIT is a more specialised ASD service than the community-based service that they were involved with prior to the referral into EI services

“So parents can take that as being that the early intervention team are a more specialist service than maybe the clinician they were seeing. That's quite a common misconception”

(AONO).

4.2.2. Constructions of the transition to PCCCT

Caregivers and service providers were also asked about their interpretations of the experience of the transition to PCCC services and how children and families were prepared for their transition. The preparation the service users received will be reported on further in subsequent themes. Service user participants described not being aware that the transition was going to happen, and therefore they felt insufficiently prepared. Service providers repeated this point, emphasising that they felt that service users were unaware of the transition from EIT to PCCCT. This is evidenced in the quotes below:

- *“I don't think they know it's coming”. -OT1*
- *“I still do have parents coming back saying ‘I wasn't aware I was going to be discharged’”- EITM*
- *“Some of them didn't know what was happening [the transition from EIT to PCCCT]” – SLT1*
- *“We just received the discharge letter in the post and that was the end of early intervention”- P3*

When service providers were asked how service users were prepared for the impending transition to PCCCT, the majority spoke about the preparation for transition to primary school. Results indicated that these children transition to primary school approximately three months before they transition to PCCC services and the focus of the child's preparation is mostly on his/her transition to school, not on the impending health and social care transition. This is evident within the quotes below:

- *“The main focus is looking for schools and places in schools” – AT1*
- *“preparing for going to school and things like that with the children” -AT2*
- *“they're [service providers] working on school readiness”- EITM*

The data reveals that there appears to be extensive preparation for school and lack of preparation for the health and social care transition. A factor within the EIT setting (in theoretical terms an **organisational contingency factor**) which may affect this transition is that the care pathway was not written until during the time of data collection for this project: *“We’re working on formalising our school starters pathway at the moment”* (EITM). Without a written procedural document, there is no formal pathway to guide service providers as to how they could prepare and support children and their families in relation to the transition to PCCC services.

4.2.3 Constructions of various aspects of transition

Participants constructed various accounts of the transition process across the EIT to PCCCT boundary throughout the interviews. There were various aspects which impacted the overall experience of care across the transition. These included the timing of this transition, individualisation of transition and language used regarding transition from EIT to PCCCT. There were mixed views by all involved about when the transition should take place. Caregiver two described the timing as

“a very difficult time because the child is starting school and the same time you don't feel like the autism services know your child yet. They're going to an autism unit and the Early Intervention are kind of dealing with the younger kids... So you're kind of discharge from there as well, but it's such a pivotal time in the child's life and the parents' because the parent have to decide on the school [and] what resources they need” (P2).

Service providers were empathetic and understanding of caregivers' accounts; *“it is such a difficult time”* (AT2), but they also spoke about how the children *“have to transition sometime”* (AT1), *“so there has to be a timeline on everything to be fair and equitable”* (AT2). Many of the service providers were of the opinion that the January after transition to primary school was the optimal time for this transition to happen. They agreed that getting the children settled in primary school (from September to December) before the health and social care transition was best. However, they spoke about how a service- led arrangement in which the transition happens should be worked, developed and improved: *“it's probably the way in which we do it needs to be worked on”* (SLT4).

A point raised by some was that the transition from EIT to PCCCT may need to be an individualised process, pertaining to the specific needs of the child and their family, rather than a service-led arrangement.

“It [the transition to PCCCT] should be more client-led than service-led, for some children. It makes sense—let them get settled with someone familiar to them and then have another change after the first term” (SLT3).

“I don’t think one size fits all. I think there some children are fine to transfer over in the January window, and then there’s others you need longer to get to know [in order to best support the child and family in the transition]” (AT2).

This individualised timing of transitioning is something that is considered by the Autism Therapists but only in some particular cases. For example, two of the Autism Therapists described a case where they transitioned two children a few months early in order to best support the family and children. The Autism Therapists report *“Our manager here is very flexible and she says whenever suits yourselves”*(AT3). The timing of the transition is an issue on which there were varying opinions. There was a consensus that the needs of the client and the preparation for transition are key factors which support the most successful transition time.

Another issue of relevance to the continuity of care experience in transition concerned the type of language used to refer to the transition from EIT to PCCCT. In this context in the North West of Ireland, the health and social care practitioners from EIT were using two different terms to describe this transition, ‘discharge’ and ‘graduation’. Health and social care practitioners described how the word discharge *“brings such fear and anxiety”* (AONO) to parents. Many of the practitioners discussed how the word ‘graduation’ is also being used—but not consistently by all professionals. There was an opinion amongst participants that the images conjured by the word ‘graduation’ versus ‘discharge’ are significantly different. The word ‘graduation’ suggests completion and promotion to a higher level, a distinctly positive image. The health and social care professionals described how the transition/graduation to PCCCT should be a positive move for families. Results revealed that the use of this positive wording made the conversation about the transition much easier. An SLT from EIT described when discussing the progress of the child she was able to use this wording, preparing the family for their transition: *“All roads are leading to kind of graduating from the early intervention team”* (SLT1).

4.2.4 Constructions of Progressing Disability Services (PDS)

In an effort to provide context with regard to service provider's interpretations of the continuity of care experience of service users, the meaning, place and value of the key policy of PDS were explored. The PDS policy emphasises continuous and seamless care for children with disabilities aged between 0 and 18 years. Service providers were asked to describe what the introduction of PDS meant to them and to the services they provide and work in. As the PDS policy will be implemented in the near future, service providers spoke of their expectations and hopes for this initiative. Results indicated that service providers are very hopeful that PDS will inform and shape a more effective service and transition across services. They look forward to a more integrated and coordinated approach to managing transitions between EIT and PCCCT in order to ensure a more seamless experience of care. Some service provider quotes below highlight their perspectives on this:

"I imagine things like that [the transition] could be much more coordinated and a much more coordinated approach to the transition across if there were these school age teams". – AT2.

"They won't be discharged from early intervention and referred to school aged services. There should be a seamless transfer—transition as they say" – EITM.

"When you look at the principles behind PDS, the aims and objectives of the programme, down the line when we have reconfigured, we're going to address a lot of these issues [around seamless transition]" – EITM.

There is a strong hope that this service development will address many of the issues currently experienced by caregivers and service providers. Yet, there were some reservations about the success of effective implementation of this policy, as is emphasised by Autism Therapist Two. She describes how service providers will still need to work together to achieve these positive changes; *"We could all spend time working towards better goals, better standards and just making sure it's a little more streamlined"* (AT2). Section 4.4.4 of this chapter discusses the present difficulties around joint working.

Service providers also discussed how under PDS both EIT and PCCC providers will all be located in one building. The impact of the location of service providers and their teams on services resonates with the concept of '**organisational contingency factors**' from Corbin and Strauss'(1991) CICTF. Service providers viewed co-location as a positive change, describing how it would bring about better '*continuity of care*' (AT2) for the children and their families.

4.2.5 Section Summary

Participants' interpretations of services, which can be seen throughout this subsection provide the backdrop against which the continuity of care experience following transition can be analysed and understood. The way in which an individual views EIT and the transition to PCCCT can affect how he or she views the experience. Many service providers spoke about their hopes for the introduction of Progressing Disability Services for Children and Young Adults. They hope and envision that this service development initiative will bring about significant changes to the experience of caregivers and children as they move through the health and social care system. At present, there is no timeline in place for when this service development will come into effect in the North West of Ireland. The findings also suggest that the word 'graduation' should be used as an alternative to the word 'discharge', to promote a more positive image of transitioning for these families and their children.

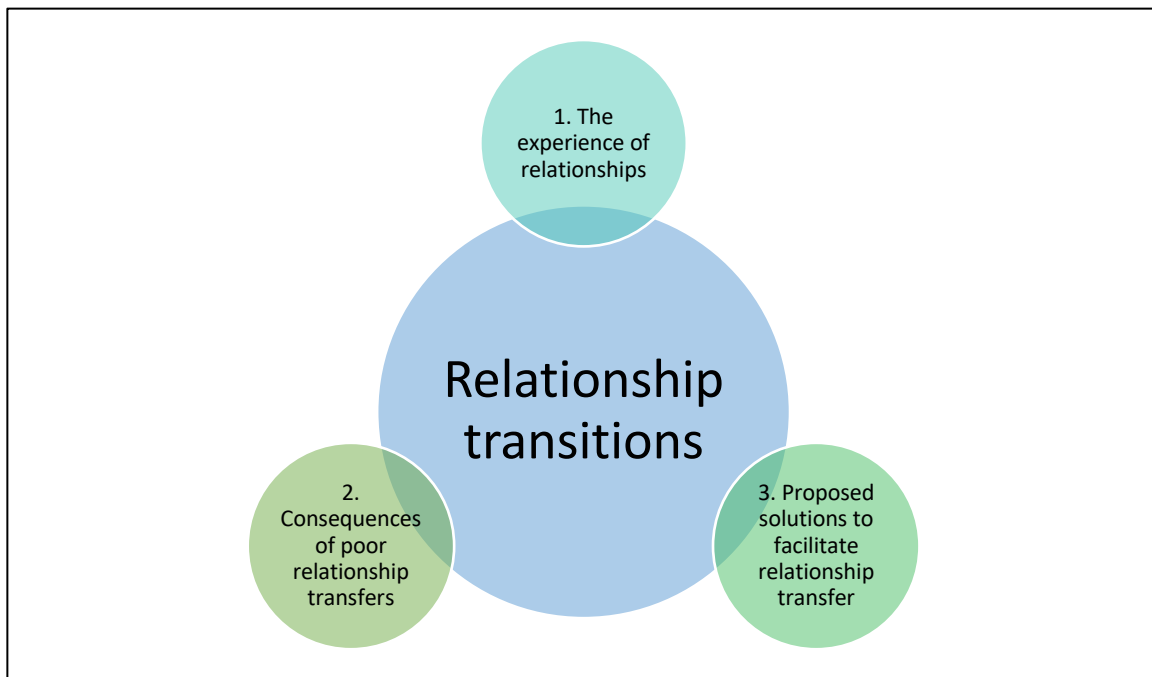
4.3. Relationship Transitions

This subsection refers to the act of ending and developing relationships with the child and his/her family in the context of the transition from EI services to PCCC services. It will present participants' accounts of their perceived bonds with their service providers and will describe how these relationships are ended in EIT and how new relationships are developed in PCCCT. Participants' perceptions of the reasons why relationships are important in this transition process, and the consequences of the current practices in relationship transfers, will also be described. The theme of relationship transfer will present:

- accounts of participants' experiences of therapeutic relationships,
- the perceived consequences of poor relationship transfers in this context and
- proposed solutions to any problematic experiences reported, to facilitate a more positive relational continuity of care experience.

An overview of the theme of relationship transitions and its subthemes can be seen below in figure 4.3.

Figure 4.3: Overview of the theme of relationship transitions and related subthemes.



4.3.1 The experience of relationships

The relationship experience of caregivers with their service providers was revealed during analysis. It showed that in the EIT setting, therapeutic relationships are not perceived to be strong between caregivers and service providers with the exception of one discipline—Autism Therapy, which will be discussed in the final paragraph of this subsection. Caregivers described how they and their child did not form strong relationships with the professionals as there was insufficient continued contact with them throughout their time in EIT. As their relationships were not strong, the data revealed that the handover experience in terms of losing relationships was something that did not cause difficulties for caregivers or their children. As Parent One explains:

“It wasn't too bad [ending relationships], I wouldn't have met them that much”(P1).

“He [child one] probably didn't notice [the change of therapists], not that I know anyway. He probably wouldn't have known because he was quite young”(P1).

Parent Two also reported similarly:

“I guess a lot of it didn't feel like you ended [relationships]” (P2).

“I don't think it really impacted on her [the child] because she didn't have that relationship”
(P2).

These interpretations were further validated by Parent Four..

“We didn’t really have any difficulties saying goodbye because we didn’t know them [EI service providers] well anyway” (P4).

The data revealed that caregivers did not have any expectations about how their relationships would be handed over. During this discussion about the handover of relationships, Parent One pondered on the significance of these relationships and how the transition between therapists might impact his child,

“I used to think that stuff [relationships] would just pass over his head—that he was too young to realise, you know, but not. Now you know he can, he's taking in stuff a lot more now anyway” (P1).

When the issue of relationships and bonds with service users was discussed with service providers, many different words were used to describe how relationships should be built, maintained and ended. These included ‘*trust*’ (OT2) and ‘*mutual respect*’ (AONO). From the data, there was an overall impression that service providers longed to have good relationships with caregivers and children yet a variety of structural or organisational factors impacted upon this within the EIT context.

When discussed with service providers about the lack of relationships formed, several factors (in theoretical terms ‘**organisational contingency factors**’) emerged which affected maintaining relationships in the EIT setting. These ‘**contingency factors**’ include long waiting lists, large caseloads and staff shortages. Service providers described how due to these factors a named therapist who is taking over the child’s case is not often given to parents upon discharge from EIT. They also describe being reluctant to give their names as “*I [service provider] can’t guarantee I’m going to be seeing you [child and family] in the next 6 -12 months*” (OT1). Parents described how facing into an unknown service with uncertainties is very emotional. These emotional consequences will be described in the following subsection.

Many service providers and all caregivers described the stronger relationship bonds that are formed with the Autism Therapist on both teams. The role of the Autism Therapist is to provide home and family support alongside organising and running relevant training and intervention courses. Results indicated that these Autism Therapists act as the support system for the child and family during their transition, the individuals that caregivers can approach if they have any queries about their trajectory management going forward. Their role is consistent with Strauss and Corbin’s (1991) role of **trajectory manager**. Participants talked about the

fact that the Autism Therapist was involved with them for considerable lengths of time and at a much more personal level than was the case with other providers. This ‘*ongoing*’ involvement meant that caregivers and the autism therapists developed an interpersonal relationship over time: “*You feel maybe they get you*” (OT2). The continuity of these bonds allows caregivers to ‘feel known’ on a personal level by their health and social care providers. Participants felt that this relationship was important in providing effective care for the child and their family, particularly at the time of transitioning from EIT services.

4.3.2 Consequences of poor relationship transfers

As described above, strong relationships are not developed between service users and providers. Without relationships, caregivers are faced with the ‘*unknown*’ (OT2) and because of this ‘*they get so anxious*’ (AONO). These emotions highlight how there is a need for continuous relationship with service providers. The lack of relationships can have emotional impacts on these caregivers, resonating with Corbin and Strauss’ (1991) concepts of **sentimental work** and **reciprocal impact** (i.e. when contingencies have consequences for trajectory management). Parent Two described being able to contact the manager or the community facilitator for disabilities if she had any issues during the time in EIT but since being discharged “*we had nobody*” (P2) to contact. The time between EIT and PCCCT was described as “a very difficult time” (P2) for parents as ...

“it’s such a pivotal time in the child’s life and the parents’ because the parents have to decide on the school, what resources they need and you kind of don’t know who to contact or who to get the reports from” (P2).

Parent Three described a case where she and her child became very “*confused*” and “*upset*” when the relationship between her son and their autism therapist ended.

“You know [child’s name] found it very hard when she left. He was obsessed with death at the time and he thought she was dead. I found it very hard to explain that she was still alive but just couldn’t see him anymore. It made it worse case – ‘cause she didn’t call to say goodbye.

One day she was here and the next she was gone” (P3).

This abrupt end to a relationship has sentimental consequences for the child and family but it also created added ‘work’ for the mother as she felt the need to explain the situation to her

child as this had not been done. This ties in with the concepts of **sentimental work** and **substitute work** from the CICTF (Corbin and Strauss, 1991).

4.3.3 Proposed solutions to facilitate relationship transfer

In this section, proposed solutions by service users and providers to improving relationship handover will be presented. As there are multiple **organisational contingency factors** which impact upon the way relationships are formed and transferred, caregiver and service providers were asked to suggest solutions which could be implemented in the current climate.

An idea which many participants agreed with was having a ‘joint handover meeting’. A joint handover meeting includes service users and all the service providers involved in the child’s care from EIT and PCCCT coming together to discuss the child’s trajectory to date, follow up care and transition needs.

“The therapist would just get in with the family much much quicker if we could do a proper handover”(SLT4)

As part of the meeting, caregivers would get the chance to meet their new service providers and the ending of relationships with their EIT providers could be talked through and explained in person. Caregivers would have the opportunity to discuss with both the EIT and new PCCCT therapists any questions they have regarding the changeover of care and coherence of same.

Another idea which stemmed from the discussion about joint handover meetings was the possibility of therapists from individual professions (e.g. EIT OT and PCCCT OT) having a meeting with the caregiver and child. Similar to the above idea, the EIT therapist could introduce the family to the new therapist, signalling the change of care.

“It’s nice for them to see us working together and they get to say goodbye to X and thank her etc.” (CFD).

Several ways of organising and conducting joint handover meetings were discussed, as many service providers described how external influences, e.g. staff shortages, long waiting lists and large caseloads (i.e. **organisational contingency factors**) may impact on the ability to have these meetings. This is discussed further in section 4.4.3 below.

4.3.4 Section Summary

The findings show that relationships between caregivers and service providers are in general not strong. Caregivers have not been able to build these strong relationships with their service providers from day one (with the exception of the autism therapists) and therefore do not have many expectations around the relationships they build with their future service providers. There are many organisational contingency factors which influence the formation and development

of relationships. These weak bonds have many consequences for families: they can feel uninformed about their care trajectory; difficulties with information transfer can occur; and caregivers can feel isolated and alone (this relates to subthemes 4.4 and 4.5 below).

On the contrary, caregivers speak about the stronger relationship that they form with their autism therapists. This resonates with the concept of ‘**trajectory manager**’ from the CICTF (Corbin and Strauss, 1991). The way in which these therapists form continuous relationships supports a positive handover of care, which then encourages the formation of a new relationship with another autism therapist. The ‘**trajectory manager**’ has a role in more than just relationship handovers: he/she has a role in the coordination of transition and acts as the key point of contact for the family. Proposed solutions to encourage positive relationship transitions include joint working practices and a joint team handover meeting similar to practices carried out by the Autism Therapists.

4.4. Information transfer

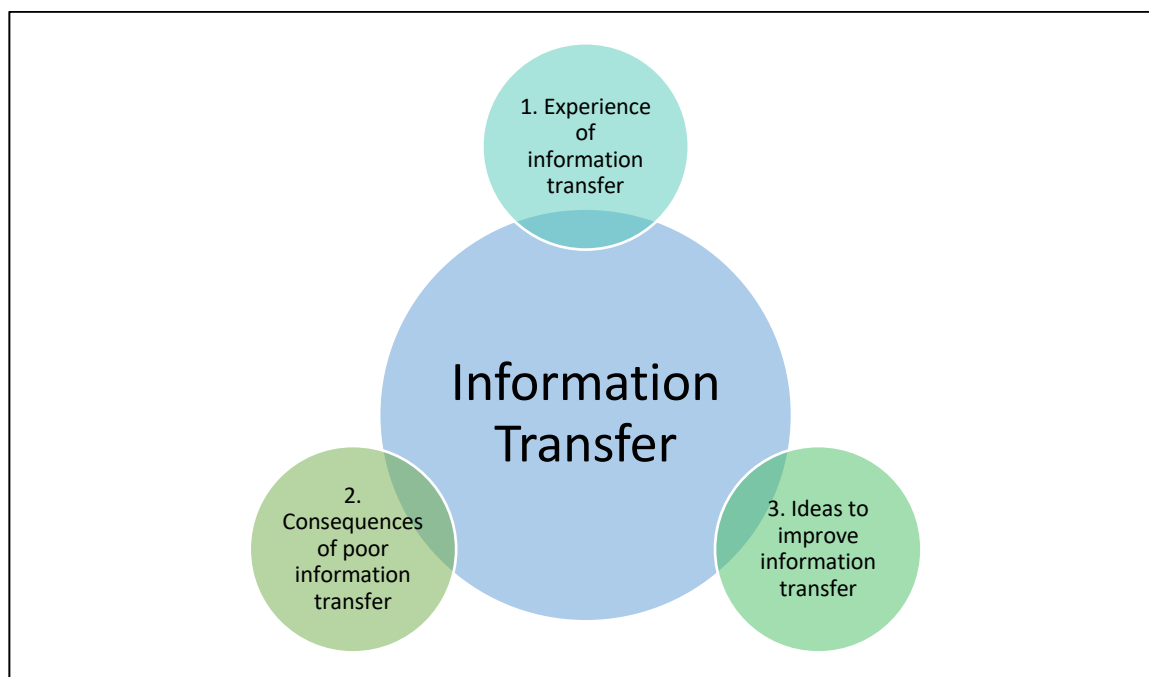
This subsection refers to the act of information sharing pertaining to the child and his or her family/caregiver in the context of the transition from EI services to PCCC services. It will present participants’ accounts of who they perceive to be the primary actors involved in the information sharing process (**information work**) in this context. It will also detail the roles and responsibilities of these actors in the information sharing process and their perceived attitudes to these role and responsibilities. Throughout the theme, participants’ accounts of the reasons why information sharing takes place (and what its consequences are for the experience of continuous care in this transition) will be presented.

The theme of information transfer was found to be the most prominent theme of this study and formed a significant part of the interview discussions with both service users and providers. The theme of information transfer will follow a similar structure to that of the previous theme in presenting:

- accounts of participants’ experiences of the information sharing process;
- the perceived consequences of a lack of appropriate information sharing in this context; and
- proposed solutions to any problematic experiences reported to facilitate a more positive continuity of care experience.

An overview of the key content of the theme of information transfer along with its sub-themes is presented below in figure 4.4.

Figure 4.4: The theme of information transfer and its related subthemes.



4.4.1 Experience of information transfer

In order to fully understand how an individual experiences information handover, expectations around how one's information should be handled across the team and organisational boundaries were explored. Analysis revealed that caregivers and service providers both have a strong desire and need for a smooth and seamless transfer of information pertaining to the child's symptoms and management from the Early Intervention context to the PCCCT context. This is evident in the following quotations:

"They should pass it [information regarding the child's care trajectory] through quite well" -P1.

"I thought that they'd have all our information in the new team" -P5

Service providers spoke about how the information transfer should be a formalised and standardised process. They expressed a desire for this information to be "*very clearly laid out, [with] everyone using the same structure*" (SLT3). It was felt that this would ensure that all the relevant and desired information would be included in the handover and that everyone would be very aware of their role and responsibilities in relation to the transfer of information from EIT to PCCCT. All participants expected that the following information would be handed over:

biographical details about the child (“*our child’s name, address, date of birth*” (P4)); the child’s medical history including, in particular, the behaviours associated with ASD that the child presents with; the child’s and family’s care trajectory to date (i.e. intervention and assessment to date and which key professionals were involved); and an outline of proposed future management of this trajectory. Additionally, parents and service providers, when prompted by the researcher, agreed strongly that more personal information about the child’s likes (e.g. games they enjoy playing) and dislikes (e.g. loud noises) would be ‘*incredibly beneficial*’ (PT) for new providers on the PCCC team who are unfamiliar with the child.

Both caregiver and service providers described how an individual’s information was not always transferred seamlessly by EIT to PCCCT; ‘*well we didn’t feel that it [information handed over seamlessly] did*’ (P2). This means that when children and their caregivers begin working with new professionals in PCCC, these professionals do not have access to the desired details about the children’s care trajectories (i.e. the key information as described in the section above). The findings suggest that the method by which a child’s trajectory information is transferred and the number and nature of details shared vary greatly from discipline to discipline within each team setting. In general, “*the last report generally that parents received is reports that are coming for them [the child with ASD] going into school*” (AT1). Numerous providers gave accounts of how this report is completed around the February time prior to starting school, approximately nine months before discharge. Understandably, there were concerns about the relevance and recency of this information when the time actually comes for the child to transition to his/her new team. Service providers also discussed how the minutes of a multidisciplinary review meeting attended by caregiver and child before their discharge from EI are completed. These reports and minutes are included in children’s central files and these in turn are then physically handed over to their new therapist in the PCCCT. The Community Facilitator for Disabilities described how when these files are handed over “*There’s no joined up integrated working [between professionals]. That [in-person] handover piece just doesn’t happen*” (CFD). This was repeated by many service provider participants throughout the course of the interviews.

The Autism Therapists in this study gave accounts of how the information handover process occurs differently for them from other professionals—how, for example it involves a private meeting between both EIT and PCCCT therapist. At this meeting, the child and his or her **care trajectory** to date are discussed including assessments, intervention and more personal details, for instance, family and child preferences. This meeting is described as ‘*very beneficial*’ (AT1) and ‘*invaluable*’ (AT3) for information handover and was recommended by

the Autism Therapists for use by other professions. The new PCCCT Autism Therapist after this meeting knows *‘the children ... the issues ... the advice given and ...the plan that’s in place’*(AT2) This impacts on experiences of continuity of care.

4.4.2 Consequences of poor information handover

As described in the above section, participants feel that key information regarding an individual’s trajectory is not consistently shared between EIT and PCCCT. As a result of the current information practices, service providers experience gaps in information that they expect to be handed over. Because of this, the consequences—or in theoretical terms the **‘reciprocal impact’**—are significant for both service providers and caregivers, and for the experience of continuity of care in this context. In particular, current, problematic information handover practices result in several **‘sentimental’**, **‘information and substitute work’** consequences for caregivers. Specifically, parents discuss how they often have to take on the role of key information agents in this transition process. They themselves have to share key details about their child and his or her trajectory to providers in the PCCCT context. Parents are burdened by this **‘work’** to ensure that key information regarding their child’s trajectory (in particular their journey to receiving an ASD diagnosis) is available to all of the child’s new health and social care professionals in PCCC. The quotations below capture the perceived burden of this work for caregivers

“You feel like you’re kind of explaining yourself again and again and again” – P2.

“It’s an ongoing thing, them [caregivers] having to rehash their story” -AT1

“I have parents that tell me they are sick of telling the same story over and over again. I understand why the girls [service providers] are asking the questions but it must be incredibly frustrating having to fill in the gaps about their child to so many people” -PT

These descriptions illustrate Strauss and colleagues’ (1985) concepts of **kin work** (that is, the work that caregivers do in order to manage one or more aspects of the condition) and **information work** (the talk and record work involved in the passing on of information from one worker to another associated with the trajectory of the child with ASD).

This burden has emotional consequences for caregivers. Many providers’ accounts describe this process as *‘enormously frustrating’* (AON), *‘exhausting’* (OT2) and *‘really tough [on caregivers]’* (PT). In Strauss’s terms it involved great **‘sentimental work’**. PCCC service providers are also sometimes obliged to do extra work in order to access key information that

was not shared concerning their ‘new’ service users. For example, providers from a variety of disciplines in PCCC describe scenarios where they have to contact the previous therapists or are unnecessarily burdened by ‘*having to go through a really thick file and notes*’ (SLT3) to find this key information.

4.4.3 Solutions to improve information handover

This subsection presents accounts of how information sharing practices could be better coordinated in order to facilitate improved information transfer experiences for children with ASD and their families in this transitional context. Some of the proposed solutions to improve information handover were proposed by service providers and caregivers. Other ideas from the health and social care transitions literature were introduced by the researcher to prompt reflection and debate and explore possibilities. Ideas taken from the literature (for instance, the ‘All About Me’ information transfer booklet outlined below) were first discussed with caregivers to examine their potential for improving information handover. All the ideas developed or discussed with service users were then brought to service provider interviews to further explore the potential utility and practicality of implementing them in clinical practice.

All caregivers and many service providers described a need for ‘discharge’ or ‘graduation’ reports to be completed as standard practice, to improve information sharing and handover, that is, informational continuity. The quotes below represent the views of many participants:

“Getting discharge reports consistently—that should come before this [in reference to another proposed solution]”- SLT1.

“I’d like to have seen the discharge reports”. – SLT1

“Having discharge reports ... they would definitely be useful”- SLT3

There was much debate among parents about the content of, and details to be included, in such reports. For example, parents described how they would like to include positive achievements of their child concerning their management in EIT services alongside the projected needs of their child in these reports.

When brought to the service providers, there was much agreement that the wording of reports (for example, jargon terms) and the structure of the reports might be difficult for caregivers to understand. Many agreed that changing these reports would be beneficial in order to get a more holistic picture of the child. They described how the “personal” representation of the child is often lost or absent in these reports. The Assessment of Need Officer described

how parents find the current reports *'very cold'* (AON) and this was echoed by a Speech and Language Therapist: *"...maybe parent-friendly. without a lot of jargon, would be useful"* (SLT1).

A further, unprompted, idea from service providers was the introduction of standardised referral forms, which should be completed by EIT providers when referring children on to PCCCT teams. While there was the general opinion amongst providers that the implementation of PDS policy is likely to introduce the use of such forms, providers discussed how the introduction of temporary referral forms in the interim would be very useful. Some of the PCCC speech and language therapy participants discussed how their team had recently implemented their discipline-specific onward referral forms to ensure better and more positive experiences of information sharing practices for all stakeholders. They were introduced by service providers because, if completed accurately, they contain much of the key information about the child and family.

"Once they've filled out our form that's usually enough"- SLT3

"If they fill out the referral form, then that provides us with a general background into the child and family situation"- SLT4

Other service providers also advocated how having a referral form would benefit information handover: *"A referral form - that might be the first thing [to address]"* –CFD.

The idea of a booklet with the aim of sharing key details about the child's trajectory management to date and projected future management, as well as important contextual information about the child's preferences and family information, was explored by both caregivers and service providers to improve the information handover. The idea of this booklet—titled 'All About Me' book—was sourced by the researcher within the literature. The details concerning the child/family context that it would be useful to include within such a book were discussed. An 'All About Me' book, according to the participants, should contain the caregivers' and their child's more personal information, for instance, *"Their interests, what they like and what they don't like"* (SLT 2). Caregivers and service providers described how this more personal information was often not shared as part of the formal information handover procedures. In particular, service providers from the PCCCT welcomed the use of an 'All About Me' book in order to gain missing information that *"The EIT therapists already have"* (SLT3).

“I think the All About Me book, from EIT to School Age Team [PCCCT] is a great idea” –

SLT 2.

“In terms of transitioning it’s something I can see the usefulness of”- SLT 3

Service providers described how they would like to see information regarding the medical symptoms and behaviours that are often associated with an ASD diagnosis e.g.

“triggers” (AT1)

“how I communicate” (AT2),

“sensory [preferences]” (EITM)

“what is going to help to bring that child out [of distress]” (AT1)

Service providers agreed that using the ‘All About Me’ book could easily be implemented into their practice with immediate effect describing how *“it doesn't need to be reams and reams of paper, you could have two sheets front to back”* (SLT1). The manager of Early Intervention also described how she thinks it’s *“a nice idea”* (EITM) and that it could become a standard practice for these and indeed other children with other disabilities who are transitioning services.

Another idea which received many positive affirmations from both parents and service providers was that of introducing joint team handover meetings in the case of each child prior to the transition. A joint team handover meeting would involve service providers from EIT, PCCCT and caregivers gathering to discuss the child’s care **trajectory** to date. Such meetings were briefly mentioned in section 4.3.3 as a potential way to improve provider-user relationships and therapeutic bonds; they will again be discussed in 4.5.3 as a way of improving management practices. The findings of this study suggest that these joint team meeting would be beneficial for improving the child’s and caregivers’ overall experience of various components of care. Participants described how this team meeting would include caregivers, EIT staff and PCCCT staff in one room. As part of this meeting, the child and his or her trajectory course to date could be discussed. A Speech and Language therapist describes how *“the new therapist doesn't start from scratch, asking parents [the]same questions”* (SLT4) if they have all attended a *‘proper handover meeting’* (SLT4). Parents could tell their story once. This would reduce the burden of information work and frustration (described in section 4.4.2) associated with re-telling the story. Some participants showed opposition to this idea, asserting that it could only work in *“an ideal world”* (OT1,) whereas others were more positive about its

introduction, explaining that if therapists *'block booked a week in our diaries'* (CFD) [all the handover meetings could occur].

4.4.4 Section Summary

In this section the theme of information handover is outlined. The findings indicate that information handover is an area of significant importance to all participants in this study. Done well, it ensures a positive experience of continuous information sharing when transitioning from EIT to PCCCT. One can see, from a lack of good relationships and therapeutic bonds, that having strong policies and standardised procedures around information management is perceived as vital. Service providers and caregivers expect key information to be handed over between EIT and PCCCT but this is not always the case. Information handover varies greatly between teams and disciplines. As a result, caregivers are burdened by having to explain the key facts about their child's care trajectory and can become frustrated as they retell their story over and over again, a **reciprocal impact** leading to **information work, kin work and substitute work**, in theoretical terms. The final subtheme looked at possible solutions to improve information handover. The findings show that, in particular, a joint team handover meeting, the 'All About Me' booklet, consistent use of discharge/graduation reports and the introduction of a standardised referral form would be highly beneficial to both caregiver and service providers and would benefit more than just information handover.

4.5 Management practices

This subsection refers to the changes in the clinical management (that is, care planning, physical environments and intervention styles) pertaining to the child and his or her family/caregivers in the context of the transition from EIT services to PCCC services. It will present participants' accounts of management practices in EIT and PCCCT. It will also detail participant accounts of the perceived changes, preparation for these changes and participants' perceived attitudes to these. Throughout the theme, the impact of management practices on the experience of continuous care in this transition will be presented.

The theme of management practices will follow a structure similar to that of the previous theme in presenting:

- accounts of participants' experiences of the changes in management practices
- the perceived consequences of the lack of appropriate management practices in this context and

- proposed solutions to any problematic experiences reported, to facilitate a more positive care experience.

An overview of the theme of management practices and its subthemes can be seen below in figure 4.5.

Figure 4.5: The theme of management practices and its related subthemes.



4.5.1 Experiences of management practices

During the transition from EIT to PCCCT, the way in which the child’s trajectory is managed changes. The parents involved in this study appeared happy about the changes to the management which they believed would happen in the PCCC setting. These management changes include the way in which services are provided, the styles of intervention and the location in which these interventions take place.

Caregivers described how the change in the base location of their therapists was a positive thing, as Parent One remarks:

“Well actually it was great for me because for meetings and stuff before I had to go to X” (P1).

“It was quite a journey and now the last few were ... only 40 minutes away ”(P1).

Caregivers and Service providers describe how the styles and modes of intervention begin to change from a more parent training basis in EIT to more direct intervention with the child in

PCCCT. This is a significant finding as it implies a change in overall clinical management practices in EIT and PCCCT. Caregivers also welcomed this change, as Parent One also says:

“I feel I got plenty of parent training and I thought it was quite good and very beneficial and I feel that now that [child’s name] is that little bit older he’s at school—and, to be honest, what really more parent training could I get?”(P1).

An area of the child’s management which changes for many families as they transition from services is that place in which intervention occurs and the main agent of intervention changes. For many children *“their intervention is in school”* (OT1). There was a perception that the intervention the children receive now comes primarily from their teachers. Their therapists provide *“more a consultative role than direct intervention”* (OT1). However, analysis revealed that parents perceived this as positive. Many caregivers described how their lives were very busy and taking days off work or organising care for other children in order to attend therapy appointments was difficult. They described how service provision in school would alleviate this burden. This model of service provision was an influential factor in deciding where a caregiver might send their child to school. Parent Two explains:

“One of the factors why we decided to put [child’s name] into a unit was to get those services because otherwise, you know, they were in the school, you know. You know you’re kind of guaranteed them” (P2).

Parents had expectations that some of the factors which affected their experiences in EIT may also be present in the PCCC setting (in theoretical terms, **organisational contingency factors**). The quote by Parent Two above suggests that this affected her decision around where she would send her child to school. She believed that if service providers were within the educational setting then it was more likely that in that setting her child would receive services if organisational contingency factors occurred, for example, long waiting lists or staff shortages.

4.5.2 Consequences of poor management practices

There are many changes in the clinical management of these children as they transition to PCCCT, including shorter journey times to appointments and fewer appointments as services are within the school setting.

“It’s much easier for parents [receiving services in school]”- AT1.

The fact that services are mainly provided in schools/clinics means there is less of a focus on service provision within the home setting. As SLT 4 explains, this model can also be difficult for parents. *“The parents say, ‘I don’t like this, I don’t know what’s going on in school, I’m not sure what’s being done’* (SLT4). Parent Three also said this type of service delivery has pros and cons:

“It’s great that I don’t have to take him in on the bus anymore. That was really hard for him because of crowds and noises. The therapists come to his school now but I don’t know when they’re coming, so I can’t go and see what’s being done. I can’t do the stuff at home then, ‘cause [child’s name] won’t tell me what the homework is”. (P3).

SLT 1 describes how intervention in the school setting doesn’t allow for easy ‘carry over’ (SLT1) to the home setting just as Parent Three described above. Another consequence of this type of service delivery model is that it more difficult to build relationships with parents. This was an area which service providers mentioned repeatedly.

“You wouldn’t get that parent interaction” (SLT1).

As described in section 4.3, continuous relationships and the management of the termination of these are important factors in a positive care experience. The data revealed that current service delivery does not promote strong relationship building.

4.5.3 Proposed solutions to improve management practices

As there are many management changes across the two settings which caregivers and children are not always ready for, solutions to improve awareness of these changes were discussed with caregivers and service providers. An idea which resonated with many participants was a PCCCT welcome day. The day would include a visit to the location where PCCCT appointments would be held and a ‘meet and greet’ with the PCCCT service providers. SLT 3 explained how having an information talk would allow parents *“to know about what we do”* (SLT3). SLT 4, who works in the EIT setting, described how these meetings would provide caregivers with more information and *“the more information they [the parents] would have, the better”* (SLT4). This signifies the links between information and management practices. Service providers discussed how, practically, this may take some time to implement. Autism Therapist Two suggested that a PCCCT Welcome Booklet could be made in the interim. When this was put to other service providers, they added suggestions that the Welcome Booklet should contain *“the therapists’ names, a picture and a phone number”* (SLT 4) and *“pictures of the room, and pictures of the front of the building so that the child ... has a bit more of an expectation of what’s going on”* (SLT 2). Service providers described how the

booklet could be given at the joint team meeting which was described as one of the proposed ways to improve relationship and information continuity. As part of this meeting caregivers could get verbal information about the changes in their and their child's management as well as the written information to support discussions at meetings.

4.5.4 Section Summary

This section discusses findings related to clinical management practices. Participants describe the many positive management factors which occur when a child transitions from EIT to PCCCT. These include a more localised service, access to services in school and direct intervention with the child. As a consequence of the changes in location, the intervention in the child's home and training with caregivers to carry over interventions across setting can be missed or less frequent than when in EIT. This also results in less time spent with parents building bonds and relationships the consequences of which were described in section 4.4.3. Proposed solutions to help in preparation for the changes in management include the hosting of a Welcome to PCCC Day and the creation of a Welcome to PCCC Booklet.

4.6 Chapter Summary

In this chapter, key findings associated with caregivers' and service providers' experiences of continuous care in the transition between EIT and PCCCT in the North West of Ireland were presented. The findings were drawn from thematic analysis of the data, which was developed using concepts of the Chronic Illness and Care Trajectory Framework (Strauss et al., 1985) Caregivers and service providers discussed how they perceive these services and their expectations around how their and the child's trajectory should be managed. These perceptions significantly shaped caregivers' experiences related to continuous and coordinated care as they transition across services and service providers, that is, their relationships, as presented in section 4.3, and their information transfer and their management practices as discussed in sections 4.4 and 4.5 respectively.

One of the key consequences of a lack of relational knowledge and poor information management practices is that caregivers and service providers have to engage in extensive **information work** to ensure that key information regarding the child's trajectory is available. In effect, caregivers become key agents of the continuous care process across the EIT to PCCCT setting. This **information work**, in combination with lack of relationships, has significant sentimental consequences for caregivers including frustration, upset and anxiety.

Throughout the chapter proposed solutions to problematic experiences are discussed. Many participants felt that improved information sharing across the organisational boundaries (in theoretical terms, **cross-boundary information work**) would alleviate some of the problems experienced. Many were of the opinion that a joint team meeting between caregivers, EIT personnel and PCCCT personnel would alleviate many of the problematic experiences related to continuous care encountered during this transition.

So, what do these results tell us about caregivers' and service providers' perspectives on continuity of care? In particular, and in line with the present study's objectives, what do these findings tell us about the meaning and experiences of continuity of care across these setting? This will be the focus of discussion and reflection in the next chapter.

Chapter 5: Discussion

5.1 Introduction and overview of chapter

Chapter 2 highlighted the need for further research in the area of health and social care transitions and experiences associated with them for young children with ASD (aged 0-7). It was concluded that this further research should focus on:

- The caregivers' qualitative perspective of HSCTs and associated continuity experiences
- The perspectives of their associated health and social care providers
- The experienced continuity of care throughout the transition process
- The system and organisational factors that influence the continuity of care experiences.

Drawing on the above, this case study, using key concepts of the *Chronic Illness and Care Trajectory Framework (CICTF)* (Strauss et al., 1985), explores caregivers' and service providers' perspectives on continuity of care as a child with ASD transitions across the organisational boundary of EIT to PCCCT.

In line with the study's aims and objectives, results reveal *theoretical advancements* in relation to knowledge about experienced continuity of care in the context of health and social care transitions for children with ASD from the perspectives of their caregivers and service providers. The study also reveals novel insights and proposed solutions to improve the experience of continuity of care associated with this transition.

The purposes of this chapter are to summarise key findings of the study, to explore how the results contribute to the literature on continuity of care and health and social care transitions and, finally, to discuss the methodological strengths and weaknesses of the study.

5.2 Summary of key findings

Caregivers' constructions, interpretations and expectations of the EIT and PCCCT services proved to be important in shaping their perceptions and expectations of their experience of care throughout the transition. Caregivers and their children follow along their individual care '*trajectories*' throughout their time in EIT. Upon their transition to PCCCT, *a trajectory sequence point*, this care trajectory can be disrupted in a number of ways. The aspects which

disrupt a smooth trajectory include on a lack of effective communication and information sharing between EIT and PCCCT. The participants describe ‘not being known’ or not knowing who to contact if they have questions about their management. Participants expressed positive emotions about the changes in the management of their trajectories in PCCCT. Yet, they had a strong desire to be better informed of changes prior to transitioning to the PCCCT service.

Many of these experiences of lacking information are upsetting for caregivers and as a result they are burdened with *work* when they meet the PCCCT service providers—to have to make important aspects of their trajectories known. These caregivers are asked to share details about their child’s medical and care needs as well as personal biographies, filling in information gaps in relation to their clinical histories and therapeutic interventions. Service providers also called for the improved experience of continuity of care for their service users. However, providers feel that a number of *organisational conditions* will shape the extent to which this is possible. In particular, a lack of formalised procedures and protocols on transitioning between services exists, and large caseload numbers influence the extent to which service providers can ensure appropriate coordination of care. To address the most predominant problem, service users and providers call for improved information sharing across the boundaries of EIT and PCCCT.

5.3 Contribution of findings to the literature

In this section, the key findings are linked to existing literature about continuity of care and health and social care transitions for children with ASD. The findings will be compared to current knowledge on:

- Definitions and experiences of continuity of care
- Caregivers’ and service providers’ understanding and interpretation of health and social care transitions for individuals with ASD

In *Chapter 2* literature defining and explaining continuity of care was presented and reference was made to how continuity of care could be an important quality of care outcome associated with a health and social care transition and in particular in the case of a child with ASD. The findings of this study suggest that many aspects of continuity of care are in fact important in this context. Findings of this study give the service users and service providers a *voice* to discuss important insights into the daily challenges they face and to discuss how the concepts of continuity of care are associated with many of these issues.

The findings also show that the *CICTF* can be used a tool of abstraction and generalisation (Lincoln and Guba, 2007) to link and extend to theory in relation to how continuity of care is constructed and conceptualised in the context of transitioning from EIT to PCCCT by service users and providers.

Key findings in relation to participants' experiences will be discussed as follows:

- Expectations of and satisfaction with health and social care services
- Experience of health and social care transition and possible solutions to challenges
- Relationships and continuity of care as a component of health and social care transitions
- Service users as 'agents' of informational continuity during transition

5.3.1 Expectations of and satisfaction with health and social care services

In Chapter 4, the expectations and social constructions of EIT, the transition and aspects associated with the transition were presented. Results indicated that service users' and providers' expectations and constructions were dissimilar. Caregivers indicated that they believed that they would receive 'intervention' in the EIT setting but instead underwent a lengthy diagnostic process. Caregivers expected to receive more information on the discharge/graduation procedure from EIT. As their expectations were not met, service users were dissatisfied with their experience. Service providers confirmed that service users' expectations were not always met by the service but indicated that they believed that these expectations were unrealistic. The findings in this study did not indicate that service user and providers had open discussions about expectations of the service and the reality of what it can provide.

Research has shown that all humans have beliefs and expectations about health and health conditions which they may or may not be overtly aware of (Krupic, Sadic and Fatahi, 2016). These expectations are based on one's understanding of the condition, cultural background, health beliefs, attitudes, and level of understanding (Lateef, 2011). Expectations, with reference to healthcare, refer to the anticipation or the belief about what is to be encountered in a healthcare service (Lateef, 2011). It is the mental picture that service users have of the process they will undergo in a given service. For example, in the case of EI, service users expected to receive a higher proportion of intervention to diagnostics. Expectations and beliefs can influence one's perception of an experience—expectations around health and social

care services can influence an individual's overall experience of that service (de Lang, Helibron and Kok, 2018). If an individual has an unsatisfactory experience of a health and social care service, this can generate negative outcomes for the service (Crisafulli, Wasil, Singh and Benoit, 2019). As service users are ultimately the receivers of health and social care services, understanding their experiences of care is pivotal to ensure satisfaction (Care Quality Commission, 2018). Understanding the psychological processes of their perceptions and evaluations of services is crucial in understanding their overall satisfaction (Crisafulli et al., 2019). Taking an individual's beliefs and expectations into account and managing these avoids negative reactions to providers, enhances service users' experiences, and reduces a service's exposure to liability (Lateef, 2011). The literature suggests that as much as 70% of litigation relates to real or perceived problems involving service provider communication: interactions influence service users' expectations (Ranjan, Kumari and Chakrawarty, 2015). Service users with unmet expectations may never complain directly to the service providers but instead may not comply in full with therapeutic interventions (Lateef, 2011). This is important to note in the case of a child with ASD as early intervention has been found to be optimal for this population.

Service users' and providers' communication about expectations around health and social care services is considered one of the fundamental solutions to solve the mismatch between expectations and reality (Ranjan et al. 2015). Internationally, there have been calls to improve communication training for health and social care providers (Wilner and Feinstein-Whittaker, 2013). This is an area which could also be considered by the EIT and PCCCT in this study as service users' expectations do not meet their reality. Developing caring and supportive relationships between health and social care professionals and service users is necessary to improve communication. This relationship continuity will be discussed further in Section 5.3.3, as relationships have been found to have a considerable bearing on the outcome of health and social care service experiences (Crisafulli et al., 2019). Coordination and experienced continuity of care are described as important factors in meeting expectations of services users and in providing an overall positive experience of health and social care services (Lateef, 2011). The experience of health and social care transitions for children with ASD in this study will be discussed in relation to international literature in the proceeding section.

5.3.2 The experience of health and social care transition: challenges and possible solutions

In Chapter 2, an overview of literature on health and social care transitions (HSCTs) for people with ASD was presented. There is a scarcity of literature which looks at early years (0-8)

transitions for these children. While many papers present findings on the transition from paediatric to adult services, only one has looked at a HSCT in the early years. In summary of these, transitioning is described as being a difficult and emotional process for caregivers and the results of this study are in keeping with those findings (Taylor and Seltzer, 2011; Cheak-Zamora et al., 2014). Caregivers in this study describe the difficulties and burden they are faced with as their child transitions from EIT to the next health and social care service, PCCCT. The findings contribute to the literature that transitioning for the caregiver of an individual at any age with ASD is difficult and in some cases impacts on the individual himself or herself. The difficulties and the emotional burden faced (*sentimental work* in Corbin and Strauss' (1991) theoretical terms) indicate that transitions need special attention and planning to ensure a more positive experience for those involved. Another study by Lovett and Haring (2003), investigated the transition between EIT and kindergarten health and social care services in the USA for parents of children with a variety of developmental disabilities. The study by Lovett and Haring (2003), did not include any parents of children with ASD however it found that the transition from EIT is perceived as very difficult for parents (Lovett and Haring, 2003). The current study adds to the limited literature on transitioning from EIT and to Lovett and Haring's (2003) study, to extend the interpretations of this transition to include children with ASD. The use of the CICTF allowed this HSCT to be seen as part of a journey, "*a trajectory*", as this transition is more than a single moment in time. The use of the CICTF allowed for analysis to reveal many factors (*contingencies*) which impact on the management of a child's trajectory throughout this transition.

The findings of this study suggest many proposed solutions to improve the experience of transitioning services and these proposed solutions aim to improve relational, informational and management continuity in order to improve the overall experience of continuity of care for caregivers and children with ASD. The proposed solutions correspond with many of the solutions that are presented in the literature. Both this study and others (Hodgetts et al., 2013; Kuhlthau et al., 2015; Havlicek et al., 2016), call for improved transition planning for this cohort of individuals in order to reduce the impact of this transition on the child and his/her caregiver. The Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK) study (Singh et al., 2010) set out to identify factors which facilitate or challenge the transition process. It found those with neurodevelopmental disorders (including those with ASD) are more likely to experience more difficulties in their transition between child and adult services. Much can be learned from the recommendations of the TRACK study, which suggested that in order to improve transition experiences joint planning

meeting should take place (Singh et al., 2010). The idea of transition planning meetings was strongly called for by caregivers and service providers in the present study in the transition from EIT to PCCCT in the North West of Ireland. Singh et al. (2011) also suggest that formal transition plans should be drawn up. A finding of the present study was that there was not a care pathway document that outlined procedures that should be carried out in the transition from EIT to PCCCT. This is an area that could be addressed as a matter of priority and will be called for in the recommendations for policy and service provision in Section 6.3.2. Singh et al. (2011) recommend multi-agency involvement in transition planning. The participants in the present study emphasised the need for joint team meetings between EIT and PCCCT personnel to improve information transfer, relationship building and information on new management practices. These three factors resonate with informational continuity, relational continuity and management continuity and with improvements in these areas it is hoped that the overall experiences of continuity of care associated with this transition will improve. Finally, Singh et al (2011), emphasised that information needs to be transferred during transition in a timely manner. The findings of this study indicate that information is not successfully transferred across this organisational boundary and agrees with the research of Singh and colleagues that poor information transfer is an inhibitor to a successful transition experience. Ideas to improve information sharing between the two services are suggested in Section 4.4.3 and further recommendations are outlined in the section above, 5.3.3. Another facilitator to smoother transition that has been described within the literature is designated transition workers who collaboratively work between both services (Forbes et al., 2002; Anderson, 2006; Social Exclusion Unit, 2015). In theoretical terms, this is consistent with the role of the Autism Therapist as a '*trajectory manager*' in the current study. Autism Therapists explain that facilitating this transition is part of their role, yet it is not explicitly stated within their job description. In order for Autism Therapists to successfully fulfil this role, it should be written into the job description and they should receive formal training on the responsibilities of this role. As called for before, having a formalised 'transition' care pathway which designates the role and responsibilities of all would be beneficial in promoting a positive experience of transition.

The findings of this study are largely in keeping with the limited literature on health and social care transitions for individuals with ASD. Health and social care transitions are described as a difficult experience for individuals with ASD. The findings of this study related to barriers of transitioning and the solutions to improve the transition experience are also in line with the international literature.

5.3.3 Relationships and continuity of care as a component of health and social care transitions

Relational Continuity is described as a therapeutic relationship between a service user and one or more providers that spans across time spent within the health care service (Burge et al., 2011). Disability services involve a multitude of complex, personal and professional relationships because an individual can receive a variety of therapeutic interventions from various health and social care providers (Carroll and Smithsix, 2016). It can be seen that relational continuity could be a major aspect in the case of the child with ASD involved with EIT services for many years before their transition to PCCCT services. Relational continuity has the potential to be jeopardised as a child transitions through different health and social care services. Within early intervention practice, there is an expectation that parents and professionals collaborate and form a partnership in order to support the child to reach his or her full potential (Paige-Smith and Rix, 2011; Yung, 2010). Yet, in the case of the early intervention service associated with the present thesis, participants report that they do not have strong bonds with their health and social care providers—with the exception of the Autism Therapists. This means that service users in the EIT do not experience relational continuity. Service providers mentioned many organisational factors which explained this, as described in Section 4.3.1. But what does a lack of relational continuity mean in the context of health and social care transitions and in particular for these service users as they transition to PCCCT? Thompson (2017), describes how relational continuity with health and social care providers brings comfort and trust, motivation and adherence to interventions, clarity of information and also the platform from which to ask questions and ensure personal coordination of care (*flexible continuity*) for service users. The transition from EIT has been described as overwhelming for caregivers (Janus, Lefort, Cameron, and Kopechanski, 2007; Rous, Hallam, Harbin, McCormick, and Jung, 2007; Janus, Kopechanski, Cameron, and Hughes, 2008; Villeneuve et al., 2013).

The participants in the present study also described how they were unaware of the complexity of the transition and how they did not know who to contact to find answers about the transition and the resultant impact their child's care. During this overwhelming and stressful time, a strong relationship or case manager (*trajectory manager*) may prove helpful in alleviating some of the concerns expressed by service users in this study. It can be seen that having this trust with one's health and social care provider may allow for information to be shared more freely and caregivers may benefit from having a point of contact to answer their

questions. It has been argued that strong service user/provider therapeutic relationships (*relationship continuity*) provide a sense of attachment for service users (Guerrero, Anderson and Afifi, 2011). In particular, in the case of a child with ASD there may be heightened need for relational continuity. As is characteristic for people with ASD, change is difficult and because of this having a consistent relationship with a service provider can be seen as more important. Since these children and their families have to transition services, it is important to ensure that the cessation of relationships is handled appropriately. This was emphasised by Parent 4 in this study: she spoke about the time when her son's autism therapist finished working with him, and she said that her son was very 'confused', asking her repeatedly about where the therapist had gone. Fialka, (2006) suggests that in preparation for the 'goodbye,' service providers should follow a checklist which targets the personal dimensions of leaving as well as following professional checklists.

Another core concept of continuity of care, '*longitudinal continuity*' also links to the concept of relational continuity in health and social care transitions. Longitudinal continuity refers to the ongoing pattern of health care interaction with the same professional, in the same place, sharing the same informational record. Because of this, there is a growing knowledge of the service user available to those providing the care. A lengthy relationship with health and social care providers allows for stronger bonds, increased trust and dependency. This longitudinal relationship allows for the service providers to have a store of information on the service user which they can in turn pass forward to the child's new team of service providers. Unfortunately, many service users in the service in question did not describe a lengthy relationship with service providers, except in one case with the autism therapist. This longitudinal sense of knowing service users and providers is in harmony with another core concept of continuity of care; '*flexible continuity*'—and with one of the findings of this study.

Flexible continuity refers to adjustment of care plans to the changing needs of the individual over time (WHO, 2018). The case of two children whose care plans were individualised by the Autism Therapist was discussed. Due to relational and longitudinal continuity, the service providers felt that it was best for these service users to have an individualised care plan, that is, '*flexible continuity*', in order to improve their experience as they transitioned from EI to PCCC. Without this relationship over time and the knowledge of the service providers about the child and family, this personalised transition plan might not have been created. This flexible continuity was not experienced by any of the parent participants in this study, and this may be an area to investigate further as the needs of every child and family

are very different (Keegan, 2016). The timing and nature of transition supports could be more child-centred and could be taken into account in the future of HSCTs for children with ASD.

Discussions from Carroll and Sixsmith (2016) may prove informative in this regard. These authors conducted research into developing a six step trajectory for relationship development and cessation within the early intervention setting. This model was developed in an Irish early intervention setting, combining the views of children, parents and professionals. This was also not mapped under the PDS policy. Their model shows strong potential for use within this EIT setting. Using their developmental trajectory allows for caregivers 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*” (Carroll and Sixsmith, 2016 p. 138). This trajectory framework could inform practices that may result in improved experiences of relational continuity of care. It allows service providers to be equipped with the knowledge of the relationship stages. This, combined with an awareness of what stage each participant is at in the relationship, will let the early intervention relationship journey begin, progress and end smoothly.

In the EI setting under study, the lack of relational and longitudinal continuity means that caregivers rely heavily on successful transfers of information from one service to the next as they don’t have a relationships built with service providers to transfer this information personally. The findings show that information transfer in this setting is not always carried out effectively, which leads to an increased workload (*information work*) on caregivers to ensure a successful transition. Caregivers role as ‘agents’ of informational continuity will be discussed in the following subsection.

5.3.4 Service users as ‘agents’ of informational continuity during transition

In Chapter 4, the importance of information transfer between EIT and PCCCT settings was described as the key and most prominent topic discussed by all participants. A desire for improved information transfer was emphasised by both service users and service providers. The idea of information and its availability to service providers is closely linked with the concept of continuity of care referred to as *informational continuity* in the literature (Reid et al., 2002). Informational continuity is described as the link of information between one care episode and the next and from one health and social care provider to the next (Reid et al., 2002). Participants in this study called for improved informational continuity as they transition. They expressed a desire for the new PCCCT therapists to have access to the information related to their care in the EIT setting. Results also confirm the idea that ensuring good informational

continuity of care for service users is a complex task and becomes more challenging as they go from seeing the same health care providers to seeing a range of providers in different sites and health care organisations (Haggerty et al., 2001).

The use of CICTF and particularly the concepts of “*information work*” and “*kin work*” during the in-depth analysis in this study shed light on some of the smaller processes that are involved in the informational continuity of care process. One of the most significant contribution of this work relates to the finding which highlights the central role of the service users in the informational continuity of care process in this transition. Caregivers perceive themselves to be what, in theoretical terms, are *primary agents of informational continuity of care*. Results indicated that there is informational discontinuity across these boundaries and caregivers are forced to retell the key details of their child’s trajectory to each new health and social care provider they encounter. In theoretical terms, caregivers are subject to *kin work* and *substitute work* to ensure informational continuity for them and their children.

In this study, caregivers and service providers described how service users must engage in information work when interacting with new service providers to ensure that there is sufficient information on their child’s trajectory to provide care that is appropriate to the child’s family’s needs and that is in line with care previously provided. These findings indicate that informational continuity (and the work to ensure it) is an integral component of providing effective care for the next stage of the service user’s journey. The retelling of their stories is emotionally draining for service users and is a process that has been described in the literature as something that runs the risk of devaluing the importance of the case in service users’ terms (Von Bültzingslöwen et al., 2006). Studies by Hjortdahl (1992) and Von Bültzingslöwen et al. (2006), describe how when new health and social care providers become involved with the care of an individual, their need to ask confirming questions may account for feelings of devaluing the story or a story not being believed. Such findings have important implications for practice. In particular, they imply a need for practices and procedures that will lead to reducing information work for service users.

The literature sets forth several frameworks that have been suggested to improve informational continuity, yet none of these are widely accepted (McDonald, Schultz, Albin et al., 2010; National Quality Forum, 2010). The literature pertaining to the use of electronic health records in health services to improve continuity of care may also be beneficial here (Rudin and Bates, 2014). In Estonia, a national electronic health care system is currently being used across all health and social care services including EI services. It has been found to improve information sharing between health care providers and to make that information

sharing timely (WHO, 2016). It supports communication and decision making between providers as each provider can access shared reports and notes on the client quickly (WHO, 2016). Further research is needed in relation to care coordination using informatics, in particular to ensure that multiple providers have access, that their roles and interactions are detailed, and that they are able to share information with each other without creating information overload. Service providers and information technology specialists will need to work closely together for this research to succeed (Rudin and Bates, 2014). The use of electronic health records shows merit for use in the case of transitioning from EIT to PCCCT as it could potentially facilitate the sharing of information more seamlessly. The use of electronic health records would mean that all service providers would have access to all reports and notes on the client and the data could be managed in a more streamlined and co-ordinated manner.

Another idea to improve communication and information sharing involves encouraging interprofessional education (IPE) in continuing professional developmental (CPD) course for existing practitioners and third level education courses. In IPE, health professionals from more than one discipline intentionally learn with, from and about each other (Darlow, Brown and Gallagher, 2018). It has been found to increase knowledge and skills required for collaborative practice, to improve attitudes towards collaboration, and also to improve clinical behaviour and service user care (Darlow et al., 2018). IPE shows merit and scope for CPD initiatives in this particular context because a variety of professionals from different disciplines work together to provide care for these children with ASD.

The transition from EI to the next health and social care service is a significantly under-researched topic nationally and internationally. Service users in the present study felt that efficient sharing of information relating to important aspects of their care trajectories would significantly improve the overall experience of transitioning health and social care services. Such insights for the first time provide valuable and practical ideas for service delivery and development in relation to informational continuity of care in the context of the transition from EI to a new health and social care service.

5.4 Strengths and limitations

This research explored perspectives on experiences of continuity of care. It also explored potential solutions to problems and the *organisational contingencies* or *conditions* shaping implementation of these. As already outlined in *Chapter 2*, to date there has been a dearth of

research in relation to continuity of care experiences in health and social care transitions for youth with ASD. The use of theory (the CICTF) throughout is seen as a strength of the present research. The CICTF was thought to be a good theoretical ‘fit’ for the study because it was developed through years of studying service users’ and providers’ difficulties in managing a multitude of conditions and disabilities (Corbin, 1998). Also, it has been noted that this framework has potential for application to any health care discipline if key concepts resonate with the study and its aims and objectives (Corbin and Strauss, 1991). The comprehensiveness of CICTF makes it sensitive to many dimensions of continuity of care (Diederiks and Bal, 1997). Other frameworks did not offer the same potential for the present study, given that they were not grounded in the study of health conditions and/or health and social care services. The CICTF was consistent with the overall epistemological, theoretical approaches, the methods used in data generation (*semi-structured interviews*) and analysis (*techniques from grounded theory*). This provides an overall robustness to this research, which was carefully considered a incorporating a *reflexive* process throughout.

The case study methodology is seen as a strength of this research. It was a good methodological fit with the epistemological stance of the research. Case study methodology allowed the researcher to work with theory i.e. as a conceptual ‘lens’. This methodological framework facilitated the intended objective to develop theoretical insights and innovation into the exploration of the concept of continuity of care. Limitations of case study research exist which include the following (Creswell and Poth, 2018): 1) Challenges in the identification of the case, for instance, broad vs. narrow, instrumental vs. intrinsic, single vs multiple; 2) Case study research can be resource-heavy, in particular in multiple case studies; and 3) Rigour relating to case study methodology has been historically critiqued. Yet, the explicit presentation of this study’s methodological approach and structured data collection and analysis enhances its rigour.

Semi-structured interviews were thought to be the most suitable approach for data generation in this study; alternatively, *sequential interviewing* could have been used (Creswell and Poth, 2018). Sequential interviewing could have been conducted at two different points along the child’s trajectory. This would have helped capture perspectives longitudinally in line with changes in his or her individual trajectory and health care needs. This was, however, beyond the aims and scope of the present research but may prove useful in further continuity research.

As previously noted in *Section 3.7*, the data were subjected to a number of techniques throughout the analysis process to enhance their reliability and validity. Yet, it should be noted

that there are strengths and limitations of using data analysis software (Creswell and Poth, 2018). NVivo (QSRInternational, 2018), used in this research, records the movement of data and the development of patterns of coding. It allows all stages of analysis to be traceable and transparent, which helps the researcher to produce a detailed and comprehensive audit trail. Limitations include the potential for data loss and over-coding. Regular backups of data files were used to address potential data loss, while over-coding was addressed by following the aforementioned analytical strategy.

It should be noted that limitations of qualitative research include the influence of the researcher on the research process and findings. This area has previously been discussed in section 3.8.2 in chapter 3.

There are strengths and limitations to the sample of participants included. A strength included the variety and number of service provider participants across the two services, whilst a limitation is the lack of participants from a managerial or administrative background of the services. The sample also lacked the voice of the child with ASD. Interviewing a child with ASD about his or her experience would have contributed to a more holistic view of the transition.

It has been noted that a significant limitation of case studies, especially single case studies, is the inability to generalise beyond the single case. As discussed in section 3.7.4 of chapter 3, however, it is argued that it may indeed be possible to generalise from the findings presented in this study. It is debated that cases can be generalised to other circumstances and situations through in-depth analytical investigation (Yin, 2012). Cases build theoretical premises which function as tools to make assertions about situations similar to the one studied. Case studies, if replicated can be said to support hypotheses and therefore become a part of constructing and expanding the theory used in them (Yin, 2012).

Chapter 6: Conclusions and Recommendations

6.1 Introduction and overview of chapter

This chapter outlines key conclusions of the study. It proposes recommendations for policy initiatives as well as service development and delivery.

6.2 Key conclusions of the study

The key conclusion to this study is:

1. Service users and Service providers do have concerns about continuity of care in this context:
 - Service users and service providers have differing perceptions about the meaning of EI and PCCC services. These differing perceptions cause dissatisfaction among service users as their expectations are not met.
 - Informational continuity from EIT to PCCCT is poor, causing many problems for service users and providers. This creates a need for service users to fill the information gap and act as ‘agents of continuity’.
 - Relational continuity between service users and providers is generally poor in both EIT and PCCCT contexts (with the exception of relationships formed with Autism Therapists). Service users accept this as the norm and therefore relationship discontinuity does not occur across the transition from EIT to PCCCT. With the lack of relational and longitudinal continuity, flexible continuity cannot occur. This can impact an individual’s overall experience. The need for strong information-sharing practices is increased due to the absence of relational continuity.
 - Service user management changes across the EIT to PCCCT organisational boundary. Many caregivers report this to be a positive change that meets the changing developmental needs of their children. Yet, they express a desire to be better informed about the how the nature, context of ‘care’ and trajectory

management will change following the transition to PCCC services. Furthermore they express a desire to be more involved in the transition planning process.

6.3 Recommendations for policy, service development and delivery

The following recommendations and strategies are intended to improve the experience of continuity of care in order to increase positive care experiences for service users, enhance the experience of providers, improve health outcomes and advance health system performance (WHO, 2018).

6.3.1 Recommendations for Policy

International policy emphasises integrated care, collaborative working, interdisciplinary practice and service user-centredness and their importance for continuity of care (WHO, 2018). There are also several national policies that emphasise this approach for children with ASD (HSE 2001, HSE 2006, HSE, 2010, HSE, 2012, HSE 2016, HSE, 2017)—the most pertinent of which, Progressing Disability Services for Children and Young People, is currently being phased into implementation. The implementation of this should continue to be developed monitored. The results of this study emphasise that improving the experience of transitions and of continuity of care will improve overall satisfaction with these services. A delay in the full implementation of PDS runs the risk of impeding integrated and collaborative working and care.

6.3.2 Recommendations for service development and delivery

Informational continuity between EI service providers and PCCC service providers needs to be improved. Standardised procedures for the transfer of information between services needs to be developed. Formalised procedures which allow for the sharing of information on the child and the nature of his or her presentation. This could include key aspects of his or her trajectory history, and current and previous therapeutics in order to facilitate improved continuity of care for service users. Service users need to be involved in the process of developing formal protocols for information sharing as they are currently the ones burdened by work in sharing these key facts. Information-sharing procedures should be continually monitored and evaluated using evidence-based practices and procedures. Autism Therapists in their role as ‘trajectory

managers' could facilitate information sharing sessions for all service users and service providers. There may be scope for the development of their responsibilities as an Autism Therapist to formalise their role as 'trajectory manager'.

Management need to think about ways of informing their service users about the purpose of these services and the process of transitioning through them. The autism therapists may play an important role here, providing reminder explanations of the services and the transition process. Pamphlets or information meetings before the time of transition may also inform service users in advance. Service providers should be encouraged to develop a responsibility to improve the care experience for their client and for the management of their trajectories. Training at service level and third level education needs to address team working and transitioning in general, in order to promote an integrated and seamless journey through health and social care services. As a matter of priority, a formalised care pathway document should be created which address the roles and responsibilities of all in the preparation for the transition from EIT to PCCCTs.

6.4 Recommendations for further research

- Further qualitative work should explore the experience of continuity of care associated with this transition for children with ASD in other areas, nationally and internationally, and should consider having the voice of the child included.
- Qualitative research of this nature should also explore the continuity of care experiences of children with other developmental disabilities in the transition from EI to PCCC.
- Further qualitative work should examine other important stakeholders' or key informants' views on the structural or organisational contingencies influencing continuity of care in this context, for instance, management personnel and members of the professional bodies.
- Further qualitative work should explore the constructions and perceptions of disability services in Ireland.
- Given that case study research follows a 'replication logic' (Yin, 2003), this study could be repeated in a separate but contrasting EIT to PCCCT context within the Irish system. A case study where PDS has already been implemented should be considered in this regard. Such a case would provide a 'heterogenous case' (Yin, 2003) from which to compare and contrast perceptions and experiences.

- Continued research into the implementation of PDS should be undertaken to monitor and review its execution and satisfaction of service delivery.
- Longitudinal research tracking the service user's trajectory over time and throughout multiple health and social care transitions should be undertaken. This would allow varying aspects of continuity of care associated with health and social care transitions to be compared and contrasted over time.

References

- Abrams, K., Theberge, S. and Karan, O. (2005). Children and Adolescents Who Are Depressed: An Ecological Approach. *Professional School Counselling*, 8(3), pp. 284.
- Adams, C. (2003). Relationship of early intervention service coordination model to quality of transition and family empowerment. *Dissertation Abstract International*, 64(8), 112A. (UMI No. 3103705).
- Al-Azri, M. (2008). Continuity of Care and Quality of Care - Inseparable Twin. *Oman medical journal*, 23(3), pp.147-149.
- Alegria, M., Pecosolido, B.A., Santos, D. and Vera, M. (1997). Can we conceptualise and measure continuity of care in individual episodes? The case of mental health services in Puerto Rico. *Sociological Focus*, 30(2): pp.113-129.
- American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110(6), pp. 304–306.
- American Academy of Pediatrics, American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128, pp. 182-200.
- American Psychiatric Association (APA). (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-V-TR)*. 5th ed. Text revision. Arlington: American Psychiatric Publishing.
- Anderson, B. (2006). Families and chronic illness research: Targeting transitions and tools-- Commentary on Trief et al. (2006). *Families, Systems, and Health*, 24(3), pp. 332-335.
- Anderson, K., Sosnowy, C., Kuo, A. and Shattuck, P. (2018). Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*, 141(4), pp. 318-327.
- Austin, Z. and Sutton, J. (2014). Qualitative Research: Getting Started. *Canadian Journal of Hospital Pharmacy*, 67(6), pp. 436-440.
- Australian Government. (2016). *National Strategic Framework for Rural and Remote Health*. Canberra (ACT): Australian Government.
- Avgerou, C. (2005). Doing critical research in information systems: some further thoughts. *Information Systems Journal*, 15(2), pp.103-109.
- Aylott, J. (2010). Improving access to health and social care for people with autism. *Nursing Standard*, 24(27), pp. 47–56.
- Bagnell, A. and Santor, D. (2012). Building Mental Health Literacy: Opportunities and Resources for Clinicians. *Child and Adolescent Psychiatric Clinics of North America*, 21(1), pp.1-9.

- Baker-Ericzen, M. J., Stahmer, A. C., and Burns, A. (2007). Child demographics associated with outcomes in a community-based Pivotal Response Training program. *Journal of Positive Behavior Interventions*, 9, pp. 52–60.
- Bazeley, P. (2009). Analysing Qualitative Data: More Than ‘Identifying Themes’. *The Malaysian Journal Of Qualitative Research*, 2(2).
- Binks, J., Barden, W., Burke, T. and Young, N. (2007). What Do We Really Know About the Transition to Adult-Centered Health Care? A Focus on Cerebral Palsy and Spina Bifida. *Archives of Physical Medicine and Rehabilitation*, 88(8), pp.1064-1073.
- Birt, L., Scott, S., Cavers, D., Campbell, C. and Walter, F. (2016). Member Checking. *Qualitative Health Research*, 26(13), pp.1802-1811.
- Bloom, S., Kuhlthau, K., Van Cleave, J., Knapp, A., Newacheck, P. and Perrin, J. (2012). Health care transition for youth with special health care needs. *Journal of Adolescent Health*, 51, pp. 213–219.
- Blum, R., Garell, D., Hodgman, C., Jorissen, T., Okinow, N., Orr, D. and Slap, G. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper for the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14(7), pp. 570–576.
- Blumberg, S., Bramlett, M., Kogan, M., Schieve, L., Jones, J. and Lu, M. (2014). *Changes in prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011-2012*. Centre for Disease Control.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Boje, D. (2001). *Narrative methods for organization and communication research*. London: SAGE.
- Borghans, I., Kleefstra, S., Kool, R. and Westert, G. (2012). Is the length of stay in hospital correlated with patient satisfaction?. *International Journal of Quality Health Care*, 24, pp. 443–451.
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp. 77-101.
- Brodhead, M. (2015). Maintaining Professional Relationships in an Interdisciplinary Setting: Strategies for Navigating Nonbehavioral Treatment Recommendations for Individuals with Autism. *Behavior Analysis in Practice*, 8(1), pp.70-78.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge: Harvard University Press.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), pp.723-742.

- Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development*. Thousand Oaks: SAGE.
- Brooker, L. (2008). *Supporting transitions in the early years*. Milton Keynes: Open University Press.
- Brown, G., and Yule, G. (1983). *Discourse analysis*. Cambridge University Press.
- Bruns, D. A., and Fowler, S. A. (1999). Designing culturally sensitive transition plans for young children and their families. *Teaching Exceptional Children*, 31(5), pp. 26-30.
- Bryman, A. (2016). *Social research methods*. 5th ed. Oxford: Oxford University Press.
- Burge, F., Haggerty, J., Pineault, R., Beaulieu, M., Lévesque, J., Beaulieu, C. and Santor, D. (2011). Relational Continuity from the Patient Perspective: Comparison of Primary Healthcare Evaluation Instruments. *Healthcare Policy | Politiques de Santé*, 7(SP), pp.124-138.
- Camarata, S. (2014). Early identification and early intervention in autism spectrum disorders: Accurate and effective? *International Journal of Speech-Language Pathology*, 16, pp. 1–10.
- Cambridgedictionary.org. (2019). *Transition*. In: Cambridge Dictionary. [online] Available at: <https://dictionary.cambridge.org/dictionary/english/transition> [Accessed 13 Aug. 2019].
- Cameron, A., Lart, R., Bostock, L. and Coomber, C. (2012). *Research briefing 41: Factors that promote and hinder joint and integrated working between health and social care services*. London: SCIE.
- Care Quality Commission. (2018). *The state of health care and adult social care in England, 2017/18*. London, House of Commons. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/751538/State_of_Care_17-18_web.pdf.
- Carroll, C. and Sixsmith, J. (2016). 'A Trajectory of Relationship Development for Early Intervention Practice for Children with Developmental Disabilities'. *International Journal of Therapy and Rehabilitation*, 23(3), pp.131-140.
- Carroll, C., Murphy, G. and Sixsmith, J. (2013). 'The Progression of Early Intervention Disability Services in Ireland'. *Infants And Young Children*, 26, pp.17-27.
- Casey, D. (2004). Challenges of collecting data in the clinical setting. *Nursing Times Research* 9(2), pp. 131-141.
- Casey, D. (2006). Choosing an appropriate method of data collection. *Nurse Researcher* 13(3), pp. 75-93.
- Centers for Disease Control and Prevention (CDC). (2012). Prevalence of autism spectrum disorders—autism and developmental disabilities monitoring network. *Surveillance Summaries*, 61(3), pp. 1–19.

- Cheak-Zamora, N., Farmer, J., Mayfield, W., Clark, M., Marvin, A., Law, J. and Law, P. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation Psychology*, 59(3), pp.340–348.
- Cheak-Zamora, N. and Teti M. (2015a). “You think it’s hard now ... It gets much harder for our children”: youth with autism and their caregiver’s perspectives of health care transition services. *Autism*, 19(8), pp. 992–1001.
- Cheak-Zamora, N., Teti, M. and First, J. (2015b). ‘Transitions are Scary for our Kids, and They’re Scary for us’: Family Member and Youth Perspectives on the Challenges of Transitioning to Adulthood with Autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), pp.548-560.
- Clandinin, D. and Connelly, F. (2000). *Narrative Inquiry: Experience and Story in Qualitative Research*. Jossey-Bass, San Francisco.
- Clarke, V. and Braun, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: SAGE.
- Collins, C. and Stockton, C. (2018). The Central Role of Theory in Qualitative Research. *International Journal of Qualitative Methods*, 17(1).
- Collins, H. (2010). *Creative research*. 1st ed. New York: AVA Publishing.
- Corbin, J. and Strauss, A. (1988). *The Jossey-Bass health series and The Jossey-Bass social and behavioral science series. Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Corbin, J. and Strauss, A. (1991). A Nursing Model for Chronic Illness Management Based upon the Trajectory framework. *Scholarly Inquiry for Nursing Practice*, 5, pp. 155-174.
- Corbin, J. and Strauss, A. (2007). *Basics of Qualitative Research (3rd ed.)*. Techniques and Procedures for Developing Grounded Theory. Thousand Oaks: SAGE.
- Creswell, J. (2013). *Qualitative inquiry and research design*. 3rd ed. Los Angeles: SAGE Publications.
- Creswell, J. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches (4th ed.)*. Thousand Oaks: SAGE.
- Creswell, J. and Poth, C. (2018). *Qualitative inquiry and research design*. 4th ed. Thousand Oaks: SAGE.
- Cridland, E., Jones, S., Caputi, P. and Magee, C. (2014). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semi-structured interviews. *Journal of Intellectual and Developmental Disability*, 40(1), pp.78-91.
- Crisafulli, B., Wasil, M., Singh, J. and Benoit, S. (2019). Managing patient expectations through understanding health service experiences. *BJMP*, 12(2).

- Critical Appraisal Skills Programme. (2017). *CASP Checklist*. [online] Available at: <http://www.casp-uk.net/>. Accessed: 14th February 2018.
- Crotty, M. (1998). *The foundations of social research*. London: SAGE.
- Crowther, D. and Lancaster, G. (2008). *Research methods*. 2nd ed. London: Routledge.
- Cuddy, N., Keane, A. and Murphy, A. (2001). Rural general practitioners' experiences of the provision of out of hours care: A qualitative study. *British Journal of General Practice*, 51, pp. 286-290.
- Cutcliffe, J. and Ramcharan, P. (2002). Levelling the playing field? Exploring the merits of the ethics-as-process approach for judging qualitative research proposals. *Qualitative Health Research*, 12(7), pp. 1000-1010.
- Dansereau, E., Masiye, F., Gakidou, E., Masters, S., Burstein, R. and Kumar, S. (2019). Patient satisfaction and perceived quality of care: evidence from a cross-sectional national exit survey of HIV and non-HIV service users in Zambia. *BMJ*, 5(12).
- Darlow, B., Brown, M., Gallagher, P. on behalf of LIP Study Group. (2018). Longitudinal impact of interprofessional education on attitudes, skills and career trajectories: a protocol for a quasi-experimental study in New Zealand. *BMJ*, 8.
- Dawson, G., Rogers, S., Munson, J., Smith M, Winter, J., Greenson, J., Donaldson, A. and Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics* 125(17-23). <https://doi.org/10.1542/peds.2009-095819>.
- de Lange, F., Heilbron, M. and Kok, P. (2018). How Do Expectations Shape Perception?. *Trends in Cognitive Sciences*, 22(9), pp.764-779.
- Denscombe, M. (2014). *The good research guide*. 5th ed. Maidenhead: Open University Press.
- Dew, A., Balandin, S., and Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities*, 20(5), pp. 485-507.
- Diederiks, J. and Bal, R. (1997). Perspectives on Patient Career in Chronic Illness: Theoretical Status and Practical Implications. *Sociological Focus*, 30(2), pp.167-175.
- Eapen, V., Crnčec, R. and Walter, A. (2013). Clinical outcomes of an early intervention program for preschool children with Autism Spectrum Disorder in a community group setting. *BMC Pediatrics*,13(3). <https://doi.org/10.1186/1471-2431-13-320>.
- Eapen, V., Grove, R., Aylward, E., Joosten, A., Miller, S., Watt, G., Fordyce, K., Dissanayake, C., Maya, J., Tucker, M. and DeBlasio, A. (2017). Transition from early intervention program to primary school in children with autism spectrum disorder. *World Journal of Clinical Pediatrics*, 6(4), pp.169-175.

- Ekas, N., Lickenbrock, D. and Whitman, T. (2010). Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 40(10), pp.1274-1284.
- Ensign, J. (2003). Ethical issues in qualitative health research with homeless youths. *Journal of Advanced Nursing* 43(1), pp. 43-50.
- European Agency for Development in Special Needs Education. (2002). *Transition from School to Employment*. The European Agency. Retrieved from http://www.european-agency.org/sites/default/files/transition-from-school-to-employment_Transition-en.pdf.
- Evans, N., Forney, D., Guido, F, Patton, L., and Renn, K. (2010). *Student development in college: Theory, research, and practice* (2nd Ed.). San Francisco: Jossey-Bass.
- Feilzer, M. (2010). Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research*, 4(1), pp. 6-16.
- Ferguson, L., Myrick, F. and Yonge, O. (2006). Ethically involving students in faculty research. *Nurse Education Today*, 26, pp. 705-711.
- Fialka, J. (2006). Pieces of the bye: The importance of preparing to say good bye to children and their families. *Infant Crier*. <http://www.danceofpartnership.com/January06InfantCrier.pdf> (accessed 14 August, 2019).
- Firestone, W. (1993). Alternative Arguments for Generalizing From Data as Applied to Qualitative Research. *Educational Researcher*, 22(4), pp.16-23.
- Fitzpatrick, J. and Kazer, M. (2011). *Encyclopaedia of nursing research*, 3rd Ed. New York: Springer Publications.
- Flick, U. (2014). *An introduction to qualitative research*. 5th ed. London: SAGE.
- Flyvbjerg, B. (2001). *Making Social Science Matter: Why Social Inquiry Fails and How It Can Succeed Again*. Cambridge: Cambridge University Press.
- Flyvbjerg, B. (2006). Five Misunderstandings about Case-Study Research. *Qualitative Inquiry*, 12, pp. 219-245.
- Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L. and Griffiths, P. (2002). A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. www.sdo.lshtm.ac.uk.
- Freeman, G., Shepperd, S., Robinson, I., Enrich, K. and Richards, S. (2001). *Continuity of Care: Report of a Scoping Exercise*. NHS Service Delivery and Organisation Research and Development Programme.

- Friedman, N., Warfield, M. and Parish S. (2013). Transition to adulthood for individuals with autism spectrum disorder: current issues and future perspectives. *Neuropsychiatry* 3(2), pp.181–192.
- Gallagher, N., MacFarlane, A., Murphy, A., Freeman, G., Glynn, L. and Bradley, C. (2012). Service Users' and Caregivers' Perspectives on Continuity of Care in Out-of-Hours Primary Care. *Qualitative Health Research*, 23(3), pp.407-421.
- Geertz, M. (1973). *The Interpretation of Cultures*. New York: Basic Books, Inc., Publishers.
- Gerhardt, U. (2000). Ambivalent Interactionist: Anselm Strauss and the “schools” of Chicago sociology. *The American Sociologist*, 31(4), pp. 34-64.
- Gerring, J. (2004). What Is a Case Study and What Is It Good for?. *American Political Science Review*, 98(2), pp. 341-354.
- Ghaziuddin, M., Ghaziuddin, N. and Greden, J. (2002). Depression in persons with autism: implications for research and clinical care. *Journal of Autism and Developmental Disorders* 32(4) pp. 299–306.
- Gill, P., Stewart, K., Treasure, E. and Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *BDJ*, 204(6), pp. 291-295.
- Glaser, B. and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Mill Valley: Sociology Press.
- Glaser, B., and Strauss, A. (1968). *The discovery of grounded theory*. Chicago: Aldine.
- Golnik, A., Ireland, M. and Borowsky, I. (2009). Medical Homes for Children With Autism: A Physician Survey. *Pediatrics*, 123(3), pp.966-971.
- Gorter, J., Stewart, D. and Woodbury-Smith, M. (2011). Youth in transition: care, health, and development. *Child: Care, Health and Development*, 37(6), pp. 757–763.
- Guba, E. (1990). *The paradigm dialog*. Newbury Park: SAGE.
- Guerrero, L., Andersen, P. and Afifi, W. (2011). *Close encounters: Communication in relationships*. Thousand Oaks: SAGE.
- Guest, G., MacQueen, K.M. and Namey, E.E. (2011). *Applied thematic analysis*. Thousand Oaks: SAGE.
- Gulliford, M., Naithani, S. and Morgan, M. (2006). What is 'continuity of care'?. *Journal of Health Services Research and Policy*, 11(4), pp.248-250.
- Guthrie, B., Saultz, J., Freeman, G. and Haggerty, J. (2008). Continuity of care matters. *BMJ*, 337(7), pp. 867.
- Guthrie, W., Swineford, L., Nottke, C. and Wetherby, A. (2013). Early diagnosis of autism spectrum disorder: stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry*, 54(5), pp.582-590.

- Haggerty, J., Freeman, G. and Adair, C. (2003). Continuity of care: a multidisciplinary review. *BMJ*, 327(7425), pp.1219-1221.
- Haggerty, J., Roberge, D., Freeman, G. and Beaulieu, C. (2013). Experienced Continuity of Care When Patients See Multiple Clinicians: A Qualitative Meta-summary. *The Annals of Family Medicine*, 11(3), pp.262-271.
- Hains, A. H., Rosenkoetter, S. and Fowler, S. (1992). Transition planning with families in early intervention programs. *Infants and Young Children*, 3(4), pp. 38-47.
- Hamel, J., Dufour, S. and Fortin, D. (1993). Case study methods. Newbury Park: SAGE.
- Hammersley, M. (1992). On Feminist Methodology. *Sociology*, 26(2), pp.187-206.
- Harper, C., Symon, J., and Frea, W. (2008). Recess is time-in: Using peers to improve social skills of children with autism. *Journal of Autism and Developmental Disorders*, 38, pp. 815–826.
- Harris, Z. S. (1952). 'Discourse Analysis'. *Language*, 28, pp.1-30.
- Havlicek, J., Bilaver, L. and Beldon, M. (2016). Barriers and facilitators of the transition to adulthood for foster youth with autism spectrum disorder: Perspectives of service providers in Illinois. *Children and Youth Services Review*, 60, pp.119-128.
- Hay, C. (2002). *Political analysis*. Basingstoke: Palgrave.
- Health Service Executive (2001). *Primary Care - A New Direction*. Dublin: Department of Health and Children.
- Health Service Executive. (2006). *A Vision for Change*. Dublin: Department of Health and Children.
- Health Service Executive. (2011). *Progressing Disability Services for Children and Young People*. Dublin: Department of Health and Children.
- Health Service Executive. (2012). *A National Review of Autism Services, Past, Present and Way Forward*. Dublin: Department of Health and Children.
- Health Service Executive. (2016). *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay*. Dublin: Department of Health and Children.
- Health Service Executive. (2018). *Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders*. Dublin: Department of Health and Children.
- Healy, M. (1947). "Le Play's Contribution to Sociology: His method". *The American Catholic Sociological Review*, 8 (2), pp. 97–110.
- Henning, E., van Resburg, B. and Smit, B. (2004). *Finding Your Way in Qualitative Research*, Pretoria: Van Schaik Publishers.

- Hicks, C. (2009). *Research methods for clinical therapists*, 5th Ed. Edinburgh: Churchill Livingstone.
- Hirschman, K., Shaid, E., McCauley, K., Pauly, M., Naylor, M. (2015). "Continuity of Care: The Transitional Care Model". *The Online Journal of Issues in Nursing*, 20(3), Manuscript 1.
- Hjortdahl, P. (1992). Continuity of care: general practitioners' knowledge about, and sense of responsibility toward their patients. *Family Practice*, 9, pp.3–8.
- Hodgetts, S., Nicholas, D., Zwaigenbaum, L. and McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. *Social Science and Medicine*, 96, pp.138-146.
- Hofman, N. (2004). Towards critical research ethics: transforming ethical conduct in qualitative health care research. *Health Care for Women International*, 25, pp. 647-662.
- Hollander, J. and Haber, L. (2009). Ecological transition: Using Bronfenbrenner's model to study sexual identity change. *Health Care for Women International*, 13(2), pp.121-129.
- Holloway, I. and Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research*, 3(3), pp. 345-357.
- Houghton, C., Casey, D., Shaw, D. and Murphy, K. (2010). Ethical challenges in qualitative research: examples from practice. *Nurse Researcher*, 18(1), pp.15-25.
- Humphrey, N. and Lewis, S. (2008). What does 'inclusion' mean for pupils on the autistic spectrum in mainstream secondary schools?. *Journal of Research in Special Educational Needs*, 8(3), pp.132-140.
- Interagency Autism Coordinating Committee (IACC). (2014). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research —2013 Update*. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/strategic-plan/2013/index.shtml>.
- Jackson, J., MacKean, G., Cooke, T. and Lahtinen, M. (2017). Patient and provider experiences with relationship, information, and management continuity. *Patient Experience Journal*, 4(3), pp.38-47.
- Janus, M., Kopechanski, L., Cameron, R., and Hughes, D. (2008). In transition: Experiences of parents of children with special needs at school entry. *Early Childhood Education Journal*, 35(5), pp. 479–485.
- Janus, M., Lefort, J., Cameron, R., and Kopechanski, L. (2007). Starting kindergarten: Transition issues for children with special needs. *Canadian Journal of Education*, 30(3), pp. 628-648.
- Javalkar, K., Johnson, M., Kshirsagar, A., Ocegueda, S., Detwiler, R. and Ferris, M. (2016). Ecological factors predict transition readiness/ self-management in youth with chronic conditions. *Journal of Adolescent Health*. 58, pp. 40-46.

- Johnson, C. and Myers, S. (2007). Identification and Evaluation of Children With Autism Spectrum Disorders. *Pediatrics*, 120(5), pp.1183-1215.
- Kaae, S. and Traulsen, J. (2015). Qualitative methods in pharmacy practice research. In Z. Babar (eds), *Pharmacy Practice Research Methods*. Switzerland: Springer International.
- Kaehne, A. and O'Connell, C. (2010). Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*, 14(2), pp.133-145.
- Keegan, K. (2016). *Accessing Supportive Services: Parents Caring for Children with Autism Spectrum Disorder*. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/msw_papers/612.
- Keen, J. and Packwood, T. (1995). Qualitative Research: Case study evaluation. *BMJ*, 311(7002), pp. 444-446.
- Kelly, A. and Tincani, M. (2013). Collaborative Training and Practice among Applied Behavior Analysts Who Support Individuals with Autism Spectrum Disorder. *Education and Training in Autism and Developmental Disabilities*, 48(1), pp.120-131.
- Kennedy, M. (1979). Generalizing From Single Case Studies. *Evaluation Quarterly*, 3(4), pp.661-678.
- Khanlou, N., Haque, N., Mustafa, N., Vazquez, L., Mantini, A. and Weiss, J. (2017). Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada. *International Journal of Mental Health and Addiction*, 15(2), pp.239-259.
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P. and Petrenchik, T. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modelling analysis. *Children's Health Care*, 35, pp. 209–234. doi:10.1207/s15326888chc3503_2.
- Kivunja, C. and Kuyini, A. (2017). Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, 6(5), pp. 26.
- Klein, H. and Myers, M. (1999). 'A set of principles for conducting and evaluating interpretive field studies in information systems'. *MIS quarterly*, 23(1), pp. 67–93.
- Klimmek, R. and Wenzel, J. (2012). Adaptation of the Illness Trajectory Framework to Describe the Work of Transitional Cancer Survivorship. *Oncology Nursing Forum*, 39(6), pp. 499-510.
- Koegel, R., Werner, G. A., Vismara, L. A., and Koegel, L. K. (2005). The effectiveness of contextually supported play date interactions between children with autism and typically developing peers. *Research and Practice for Persons with Severe Disabilities*, 30, pp. 93–102.
- Koegel, L., Singh, A. K., and Koegel, R. L. (2010). Improving motivation for academics in children with autism. *Journal of Autism and Developmental Disorders*, 40, pp. 1057–1066.

- Koegel, R., Koegel, L., Ashbaugh, K. and Bradshaw, J. (2014). Improving Question-Asking Initiations in Young Children with Autism Using Pivotal Response Treatment. *Journal of Autism and Developmental Disorders*, 44(4), pp. 816-827.
- Kogan, M.D., Bloomberg, S.J., Schieve, C.A. (2009). Prevalence of Parent Reported Diagnosis of Autism Spectrum Disorder in the US- 2007. *Pediatrics*, 124 (5), pp. 1395-1402.
- Kothari, C.R. (2004) *Research Methodology: Methods and Techniques*. 2nd Edition. New Delhi: New Age International Publishers.
- Krogh, K. and Lindsay, P. (1999). Including people with disabilities in research: implications for the field of augmentative and alternative communication. *Augmentative and Alternative Communication*, 15(4), pp. 222-233.
- Krupic, F., Sadic, S. and Fatahi, N. (2016). Contact with Health-care Service Expectation and Reality of Situation Experienced by Immigrants Seeking Swedish Health-care. *Materia Socio Medica*, 28(2), pp. 141.
- Kuhlthau, K., Warfield, M., Hurson, J., Delahaye, J. and Crossman, M. (2015). Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: current strategies and promising new directions. *Autism*, 19(3), pp. 262–271.
- Kuhlthau, K., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M. and van der Weerd, E. (2016). Health Care Transition Services for Youth With Autism Spectrum Disorders: Perspectives of Caregivers. *Pediatrics*, 137, pp.158-166.
- Kuhn, T. (1962). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Kumar, R. (2011). *Research Methodology: a step-by-step guide for beginners*. 3rd ed. London: SAGE.
- Kuper, A., Reeves, S. and Levinson, W. (2008). An introduction to reading and appraising qualitative research. *BMJ*, 337(3).
- Kvale, S., and Brinkmann, S. (2009). *Interviews: Learning the Craft of Qualitative Research Interviewing* (2nd ed.). Thousand Oaks: SAGE.
- LaForest, J. (2009). *Guide to Organising Semi-Structured Interviews With Key Informant. Charting a course to save living*. Quebec: Government Quebec.
- Lamb, C., Hall, D., Kelvin, R. and Van Beinum, M. (2008). *Working at the CAMHS/Adult Interface: Good practice guidance for the provision of psychiatric services to adolescents/young adults*. London: The Child and Adolescent Faculty and the General and Community Faculty of the Royal College of Psychiatrists.
- Laswell, R. and Casey, H. (1946). Content Analysis: A New Evidentiary Technique. *The University of Chicago Law Review*, 15(4), pp. 910.
- Lateef, F. (2011). Patient expectations and the paradigm shift of care in emergency medicine. *Journal of Emergencies, Trauma, and Shock*, 4(2), pp.163.

- Lauche, R., Hauser, W., Jung, E., Erbsloh-Moller, B., Gesmann, M., Kuhn-Becker, H., Petermann, F., Weiss, T., Thoma, R., Winkelmann, A. and Langhorst, J. (2013). Patient-related predictors of treatment satisfaction of patients with fibromyalgia syndrome: results of a cross-sectional survey. *Clinical Experiments in Rheumatology*, 31, pp. 34-40.
- Laverty, S.M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*, 2(3), pp. 1-29.
- Leleu, H. and Minvielle, E. (2013). Relationship between longitudinal continuity of primary care and likelihood of death: analysis of national insurance data. *PLoS One*, 8(8).
- Lewis, J. and McNaughton Nicholls, C. (2014). Design Issues. In J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston (eds), *Qualitative Research Practice: A guide for social science students and researchers*, 2nd ed. London: SAGE, pp. 47-76.
- Lewis, J., Richie, J., Ormston, R. and Morrell, G. (2014). Generalising from qualitative research. In: J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston, (eds), *Qualitative Research Practice: A guide for social science students and researchers*, 2nd ed. London: SAGE, pp. 347-366.
- Liao, Y., Zeng, Q., Xu, Y. and Yang, Q. (2018). A Concept Analysis of Continuity of Care in Nursing. *Journal of Pharmacy and Pharmacology*, 6(6).
- Lincoln, Y. and Guba, E. (2007). Judging interpretations: But is it rigorous? trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*, 2007(114), pp.11-25.
- Lindgren, S. and Doobay, A. (2011). Evidence Based Interventions for Autism Spectrum Disorders.
<http://www.interventionsunlimited.com/editoruploads/files/Iowa%20DHS%20Autism%20Interventions%206-10-11.pdf> Last accessed 19th Feb, 2017.
- Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C. and Fryer, G. (2008). Disparities in Diagnosis and Access to Health Services for Children with Autism: Data from the National Survey of Children. *Health Journal of Developmental and Behavioural Pediatrics*, 29(3), pp.152-160.
- Lord, C. and Bishop, S. (2014). Recent Advances in Autism Research as Reflected in DSM-5 Criteria for Autism Spectrum Disorder. *Annual Review of Clinical Psychology*, 11(1), pp.53-70.
- Lovell, B., Moss, M. and Wetherell, M. A. (2012). With a little help from my friends: psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. *Research on Developmental Disability*, 33, pp. 682–687.
- Lovett, D. and Haring, K. (2003). Family perceptions of transitions in early intervention. *Education and Training in Developmental Disabilities*, 38(4), pp. 370-377.

- Maarsingh, O., Henry, Y., van de Ven, P. and Deeg, D. (2016). Continuity of care in primary care and association with survival in older people: a 17-year prospective cohort study. *British Journal of General Practice*, 66(649), pp. 531-539.
- Mackintosh, V.H., Goin-Kochel, R.P., and Myers, B.J. (2012). “What Do You Like/Dislike About the Treatments You’re Currently Using?” -A Qualitative Study of Parents of Children With Autism Spectrum Disorders. *Focus on Autism and other developmental disabilities*, 27(1), pp. 51-60
- Marshall, C. and Rossman, G. (2015). *Designing qualitative research*. Los Angeles: SAGE.
- Martin, P. and Turner, B. (1986). Grounded Theory and Organizational Research. *The Journal of Applied Behavioural Science*, 22(2), pp.141-157.
- Maternal and Child Health Bureau. (2008). *The National Survey of Children With Special Health Care Needs Chartbook 2005–2006*. Rockville: US Department of Health and Human Services.
- Maxwell, J. A. (1992). Understanding and Validity in Qualitative Research. *Harvard Educational Review*, 62(3), pp. 279-300.
- McDonald, K., Schultz, E., Albin, L., Pineda, B., Lonhart, J., Sundaram, V., Smith-Spangler, C., Brustrom, J. and Malcolm, E. (2010). *Care Coordination Measures Atlas*. Agency for Healthcare Research and Quality.
- McKeone, D. (1995). *Measuring your media profile*. Hampshire: Gower.
- McLoughlin, M., Armstrong, P., Byrne, M., Heaney, D., O’ Brien, N. and Murphy, A.W. (2005). A comparative study on attitudes, mental health and job stress amongst GPs participating, or not, in a rural out-of-hours co-operative. *Family Practice*, 22(3), pp. 275-279.
- McManus, MA., Pollack, LR., Cooley, WC., McAllister, JW., Lotstein, D., Strickland, B. and Mann, MY. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics*, 131(6), pp. 1090–1097.
- Meadan, H., Stoner, J. and Angell, M. (2009). Review of Literature Related to the Social, Emotional, and Behavioral Adjustment of Siblings of Individuals with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 22(1), pp.83-100.
- Mesibov, G. B., Shea, V., and Schopler, E. (with Adams, L., Burgess, S., Chapman, S. M., Merkler, E., Mosconi, M., Tanner, C., and Van Bourgondien, M. E.). (2005). *The TEACCH approach to autism spectrum disorders*. New York: Springer.
- Miles, M., Huberman, A. and Saldana, J. (2014). *Qualitative Data Analysis: A Methods Sourcebook*, 3rd ed. London: SAGE.
- Miller, A., Condin, C., McKellin, W., Shaw, N., Klassen, A. and Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Services Research*, 9(1).

- Missouri Autism Guidelines Initiative. (2010). *Autism spectrum disorders: Guide to evidence-based interventions*. St. Louis and Springfield: Thompson Foundation for Autism, the Division of Developmental Disabilities, the Office of Special Education, and Mercy Children's Hospital.
- Murray, M. (2003). *Narrative psychology*. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods*, pp. 111-131. London: SAGE.
- National Disability Authority Ireland. (2015). *Reasonable Accommodation for people with Autism Spectrum Disorder 2014 (updated 2015)*. <http://nda.ie/nda-files/Reasonable-Accommodation-for-People-with-Autism-Spectrum-Disorder-updated-20151.pdf> Last accessed 13th August, 2019.
- National Disability Authority Ireland. (2017). *Models of good practice in effectively supporting adults with autism*. <http://nda.ie/Publications/Disability-Supports/Autism/Good-practice-in-supporting-adults-with-autism.pdf> Last accessed 13th August, 2019.
- National Disability Strategy Implementation Group. (2012). *National Disability Strategy Implementation 2013-2015*. http://www.justice.ie/en/JELR/NDS_ImplementationPlan_FINAL.pdf/Files/NDS_ImplementationPlan_FINAL.pdf Last accessed 1st April, 2018.
- National Health Care Transition Center. (2013). *Six core elements of health care transition*. Available at: <http://www.gottransition.org/6-core-elements-table>. Last accessed 19 July, 2019.
- National Institute for Health and Clinical Excellence. (2011). *Autism spectrum disorder in under 19s: support and management*. NICE Clinical Guidelines.
- National Institute for Health and Clinical Excellence. (2013). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*. NICE Clinical Guidelines.
- National Quality Forum. *Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination: A consensus report*. (2010). New York: U.S. Department of Health.
- National Research Council (US), Committee on Educational Interventions for Children with Autism. (2001). *Educating children with autism*. Washington, DC: National Academies Press.
- Neuman, L. (2014). *Social Research Methods: Qualitative and Quantitative Approaches*. 7th ed. Essex: Pearson Education Limited.
- New Zealand autism spectrum disorder guidelines (2016). *Autism spectrum disorder guidelines for the Ministries of Health and Education*. Ministry of Health: Wellington.
- NHS England. (2016). *NHS Operational Planning and Contracting Guidance 2017–19*. NHS England. www.england.nhs.uk/wp-content/uploads/2016/09/NHS-operational-planningguidance-201617-201819.pdf.

- O'Kane, M. (2007). *Building Bridges: the Transition from Preschool to Primary School for Children in Ireland*. (PhD Thesis). Dublin Institute of Technology, Dublin: Dublin Institute of Technology.
- O'Toole, L. (2016). *A bio-ecological perspective on educational transition: experiences of children, parents and teachers*. Doctoral Thesis, Dublin Institute of Technology. doi:10.21427/D7GP4Z.
- Orb, A., Eisenhauer, L. and Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), pp. 93-96.
- Paige-Smith, A. and Rix, J. (2006). Parents' Perceptions and Children's Experiences of Early Intervention- inclusive practice?. *Journal of Research in Special Educational Needs*, 6(2), pp. 92-98.
- Pang, Y. (2008). Factors associated with the experiences of parents in the transitioning of their young children from early intervention to programs for three-year-olds. *Dissertation Abstract International*, 69(3), pp. 870.
- Pang, Y. (2010). Facilitating family involvement in early intervention to preschool transition. *The School Community Journal*, 20 (2), pp. 183-198.
- Parker, G., Corden, A. and Heaton, J. (2011), 'Experiences of and influences on continuity of care for service users and carers: Synthesis of evidence from a research programme', *Health and Social Care in the Community*, 19(6), pp. 576-601. <https://doi.org/10.1111/j.1365-2524.2011.01001.x>
- Patton, M., (2015). *Qualitative Research and Evaluation Methods*, 4th ed. London: SAGE.
- Perrin, J., Bloom, S. and Gortmaker, S. (2007). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association*, 297, pp. 2755–2759.
- Phelps, K., Hodgson, J., McCammon, S. and Lamson, A. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual and Developmental Disability*, 34(1), pp.27-35.
- Philipsen, H. and Stevens, F.C.J. (1997). Modernization, rationality and continuity of care: Theoretical concepts and empirical findings. *Sociological Focus*, 30(2), pp. 189-204.
- Pike, K. L. (1967). *Language in relation to a unified theory of the structure of human behaviour*. The Hague: Mouton.
- Plimley, L. and Bowen, M. (2007). *Social skills and autistic spectrum disorders*. London: Paul Chapman Publishers.
- Polit, D. and Beck, C., (2006). *Essentials of nursing research: methods, appraisal, and utilization* (6th ed). Lippincott: Williams and Wilkins.
- Potter, J. and Wetherell, M. (1987). *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: SAGE.

- Price, M. and Lau, F. (2013). Provider connectedness and communication patterns: extending continuity of care in the context of the circle of care. *BMC Health Services Research*, 13(1).
- QDA Training. (2013A). *Day 1 - Introduction to Nvivo: Setting up your Qualitative Database*. Dublin: QDA Training.
- QDA Training. (2013B). *Day 2 - Nvivo Underway: Analysing your Data*. Dublin: QDA Training.
- QSRInternational. (2018). *Analytical strategy for this study- Thematic Analysis*. Dublin: QDA Training.
- Ramcharan, P. and Cutcliffe, JR. (2001). Judging the ethics of qualitative research: considering the 'ethics as process' model. *Health and Social Care in the Community* 9(6), pp. 358-366.
- Ranjan, P., Kumari, A. and Chakrawarty, A. (2015). How can Doctors Improve their Communication Skills?. *Journal Of Clinical And Diagnostic Research*, 2(3), pp. 358-360.
- Reichow, B., Barton, E., Boyd, B. and Hume, K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database*, 10. <https://doi.org/10.1002/14651858.CD009260.pub221>.
- Reid, R., Haggerty, J. and McKendry, R. (2002). *Defusing the confusion*. Ottawa: Prepared for the Canadian Health Services Research Foundation, the Canadian Institute for Health Information, and the Advisory Committee on Health Services of the Federal/Provincial/Territorial Deputy Ministers of Health.
- Reiss, J. and Gibson, R. (2002). Health care transition: destinations unknown. *Pediatrics*, 110, pp. 1307-1314.
- Ridd, M., Shaw, A. and Sailsbury, C. (2006). 'Two sides of the coin'--the value of personal continuity to GPs: a qualitative interview study. *Family Practice*, 23(4), pp.461-468.
- Riessman, C. K. (1993). *Narrative Analysis*. Newbury Park: SAGE.
- Rimm-Kaufman, S. E., and Pianta, R. C. (2000). An ecological perspective on the transition to kindergarten: A theoretical framework to guide empirical research. *Journal of Applied Developmental Psychology*, 21(5), pp. 491-511.
- Robinson, S. E. (2011). Teaching paraprofessionals of students with autism to implement pivotal response treatment in inclusive school settings using a brief video feedback training package. *Focus on Autism and Other Developmental Disabilities*, 26, pp. 105–118.
- Robson, C. (2011). *Real World Research* (3rd ed.). Chichester: John Wiley and Sons Ltd.
- Rogers, SJ., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., Guo, M. and Dawson, G. (2012). Effects of a brief Early Start Denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: a randomized controlled trial. *Journal of American Academy of Child and Adolescent Psychiatry*, 24(3).

- Rosen, DS., Blum, RW., Britto, M., Sawyer, S. and Siegel, D. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33(4), pp. 309–311.
- Rosenthal, M. (2016). Qualitative research methods: Why, when, and how to conduct interviews and focus groups in pharmacy research. *Currents In Pharmacy Teaching And Learning*, 8(4), pp. 509-516.
- Rous, B., Hallam, R., Harbin, G., McCormick, K, and Jung, L. (2005). *The transition process for young children with disabilities: A conceptual framework*. University of Kentucky: Human Development Institute.
- Rous, B., Hallam, R., Harbin, G., McCormick, K., and Jung, L. A. (2007). The transition process for young children with disabilities: A conceptual framework. *Infants and Young Children*, 20(2), pp. 135-148.
- Ruddin, L. (2006). You Can Generalize Stupid! Social Scientists, Bent Flyvbjerg, and Case Study Methodology. *Qualitative Inquiry*, 12(4), pp.797-812.
- Rudin, R. and Bates, D. (2014). Let the left hand know what the right is doing: a vision for care coordination and electronic health records. *Journal of the American Medical Informatics Association*, 21(1), pp.13-16.
- Russell, D., Rosati, R., Rosenfeld, P. and Marren, J. (2011). Continuity in Home Health Care: Is Consistency in Nursing Personnel Associated with Better Patient Outcomes?. *Journal for Healthcare Quality*, 33(6), pp.33-39.
- Ryan, GW. and Bernard, HR. (2000). "Data management and analysis methods". In NK Denzin and YS Lincoln (Eds.) *Handbook of qualitative research* (2nd Edition). Thousand Oaks: SAGE, pp. 769-802.
- Sallis, J. F., and Owen, N. (1997). Ecological models. In: Glanz, K., M.Lewis, F. and Rimer, B.K., *Health Behaviour and Health Education: Theory, Research, and Practice*, (2nd ed.) San Francisco: Jossey-Bass, pp. 403-424.
- Sanclemente-Ansó, C., Salazar, A., Bosch, X., Capdevila, C., Giménez-Requena, A., Rosón-Hernández, B. and Corbella, X. (2015). Perception of quality of care of patients with potentially severe diseases evaluated at a distinct quick diagnostic delivery model: a cross-sectional study. *BMC Health Services Research*, 15(1).
- Sandberg, J. (2005). How Do We Justify Knowledge Produced Within Interpretive Approaches?. *Organizational Research Methods*, 8(1), pp.41-68.
- Saultz, J. (2004). Interpersonal Continuity of Care and Patient Satisfaction: A Critical Review. *The Annals of Family Medicine*, 2(5), pp.445-451.
- Schieve, L., Rice, C., Devine, O., Maenner, M., Lee, L., Fitzgerald, R., Wingate, M., Schendel, D., Pettygrove, S., van Naarden Braun, K. and Durkin, M. (2011). Have Secular Changes in Perinatal Risk Factors Contributed to the Recent Autism Prevalence Increase?

- Development and Application of a Mathematical Assessment Model. *Annals of Epidemiology*, 21(12), pp.930-945.
- Schor, E. (2015). Transition: changing old habits. *Pediatrics*, 135, pp.958-960.
- Schwandt, TA. (2000). Constructivist, interpretivist approaches to human inquiry. In: Denzin, N.K. and Lincoln, Y.S. (eds) *Handbook of Qualitative Research*, Thousand Oaks: SAGE.
- Schwartz, L., Tuchman, L., Hobbie, W. and Ginsberg, J. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health and Development*, 37(6), pp.883-895.
- Scottish Intercollegiate Guideline Network. (2016) *Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorder*. Scottish Intercollegiate Guidelines.
- Seale, C. (1999). Quality in Qualitative Research. *Qualitative Inquiry*, 5(4), pp. 465-478.
- Serpe, R. and Stryker, S. (2011). The Symbolic Interactionist Perspective and Identity Theory. *Handbook of Identity Theory and Research*, pp. 225-248.
- Shafritz, J., Ott, J. and Jang, Y. (2006). *Classics of organization theory*. 6th ed. Belmont: Thomson.
- Shea, V. and Mesibov, G. (2005). Adolescents and adults with autism. In: Volkmar FR, Paul R, Klin A, and Cohen, A. (eds) *Handbook of Autism and Pervasive Developmental Disorders: Diagnosis, Development, Neurobiology, and Behavior*. Hoboken: Wiley, pp. 288–311.
- Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, pp. 63-75.
- Silverman, D. (2005). *Doing Qualitative Research* (2nd ed.). London: SAGE.
- Singh, S. (2009). Transition of care from child to adult mental health services: the great divide. *Current Opinion in Psychiatry*, 22(4), pp.386-390.
- Singh, S., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., Hovish, K., Islam, Z., Belling, R. and White, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: multi-perspective study. *British Journal of Psychiatry*, 197(4), pp.305-312.
- Sligo Institute of Technology. (2014). *Code Of Practice For The Quality Assurance Of Postgraduate Research*. Sligo: IT Sligo.
- Sobotka, S., Francis, A. and Vander Ploeg Booth, K. (2015). Associations of family characteristics with perceptions of care among parents of children with autism. *Child: Care, Health and Development*, 42(1), pp.135-140.
- Social Exclusion Unit. (2015). *Transitions: A Social Exclusion Unit interim report on Young Adults*. London: Social Exclusion Unit.

- Sociological Association of Ireland. (2013). *Ethical Guidelines*. Maynooth: The Sociological Association of Ireland.
- Spencer, L., Richie, J., O'Connor, W., Ormston, R. and Barnard, M. (2014). Analysis: Principles and Processes. In J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston (eds), *Qualitative Research Practice: A guide for social science students and researchers* 2nd ed. London: SAGE, pp. 269-294.
- Stake, R. (2000). Case Studies. In: Denzin, N.K. and Lincoln, Y.S. (eds) *Handbook of Qualitative Research* (2nd ed.). Thousand Oaks: SAGE.
- Starr, E., Martini, T. and Kuo, B. (2014). Transition to Kindergarten for Children With Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities*, 31(2), pp.115-128.
- Sterling-Turner, H. and Jordan, S. (2007). Interventions addressing transition difficulties for individuals with autism. *Psychology in the Schools*, 44(7), pp.681-690.
- Stewart, D. (2009) Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine and Child Neurology*, 51, pp. 169–173.
- Strauss, A. (1978). A Social World Perspective. *Studies in Symbolic Interaction*, 1, pp.119-128.
- Strauss, A. (1982). Interorganizational Negotiation. *Urban Life*, 11(3), pp.350-367.
- Strauss, A. and Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Beverly Hills: SAGE.
- Strauss, A., Fagerhaugh, S., Suczek, B. and Wiener, C. (1982). 'The work of hospitalized patients'. *Social Science and Medicine*, 16, pp. 977–86.
- Strauss, A., Fagerhaugh, S., Suczek, B., Wiener, C. (1985). *Social Organization of Medical Work*. London: The University of Chicago Press.
- Streubert, B., Speziale, H. and Carpenter, D. (2007). *Qualitative Research in Nursing. Advancing the Humanistic Imperative*. (4th ed.). Philadelphia: Lippincott Williams and Wilkins.
- Tashakkori, A. and Teddlie, C. (2003). *Handbook of Mixed Methods in Social and Behavioral Research*. Thousand Oaks: SAGE.
- Taylor, J. and Seltzer, M. (2011). Employment and Post-Secondary Educational Activities for Young Adults with Autism Spectrum Disorders During the Transition to Adulthood. *Journal of Autism and Developmental Disorders*, 41(5), pp.566-574.
- Tehee, E., Honan, R. and Hevey, D. (2009). Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders. *Journal of Applied Research in Intellectual Disabilities*, 22(1), pp.34-42.
- The Australian Capital Territory (ACT). (2014) KPMG: *Early Childhood Intervention- An overview of best practice*. New South Wales.

- The Pact Consortium and Salomone, E., Leadbitter, K., Aldred, C., Barrett, B., Byford, S., Charman, T., Howlin, P., Green, J., Le Couteur, A., McConachie, H., Parr, J., Pickles, A. and Slonims, V. (2018). The Association Between Child and Family Characteristics and the Mental Health and Wellbeing of Caregivers of Children with Autism in Mid-Childhood. *Journal of Autism and Developmental Disorders*, 48(4), pp.1189-1198.
- Thomas, G. and James, D. (2006) —Re-inventing grounded theory: some questions about theory, ground and discovery. *British Educational Research Journal*, 32(6), pp. 767–795.
- Thomas, J. and Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1).
- Thomas, W. I. and Znaniecki, F. (1958). *The Polish Peasant in Europe and America Volumes I and II*. New York: Dover Publications.
- Thompson, C., Bölte, S., Falkmer, T. and Girdler, S. (2018). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PLOS ONE*, 13(3).
- Thompson, J. (2017). *Scoping review: perspectives from primary healthcare in Latin America and the Caribbean on the role of compassion in healthcare users' experience of care and continuity of care* [MPH dissertation]. Edinburgh: University of Edinburgh Global Health Academy.
- Thornberg, R. (2012). Informed Grounded Theory. *Scandinavian Journal of Educational Research*, 56(3), pp.243-259.
- Tobin, H., Staunton, S., Mandy, WPL., Skuse, D; Hellriegel, J., Baykaner, O. and Anderson, S. (2012). A qualitative examination of parental experience of the transition to mainstream secondary school for children with an autism spectrum disorder. *Educational and Child Psychology*, 29(1), pp. 75–85.
- Turnbull, A. (2000). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River: Merrill/Prentice Hall.
- Turnbull, A. P., Turnbull, R. L., Erwin, E. J., and Soodak, L. C. (2005). *Families, professionals, and exceptionality* (5th ed.). Upper Saddle River: Prentice Hall.
- URBIS. (2015) *Review of the Disability Standards for Education 2005*. London: URBIS.
- van Servellen, G., Cook, R., Render, M. and Woods, D. (2000). Gaps in the continuity of care and progress on patient safety. *BMJ*, 320(7237), pp.791-794.
- van Servellen, G., Fongwa, M. and D'Errico, E. (2006). Continuity of care and quality care outcomes for people experiencing chronic conditions: A literature review. *Nursing and Health Sciences*, 8(3), pp.185-195.
- Villeneuve, M., Hutchinson, N., Minnes, P., Perry, A., Dionne, C. and Chatenoud, C. (2013). The Experience of Parents as Their Children with Developmental Disabilities Transition from Early Intervention to Kindergarten. *Canadian Journal Of Education*, 36(1).

- Volger, P., Crivello, G. and Woodhead, M. (2008) *Early childhood transitions research: A review of concepts, theory, and practice. Working Paper No. 48*. The Hague: Bernard van Leer Foundation.
- von Bültzingslöwen, I., Eliasson, G., Sarvimäki, A., Mattsson, B. and Hjortdahl, P. (2006). Patients' views on interpersonal continuity in primary care: a sense of security based on four core foundations. *Family Practice*, 23(2), pp. 210-219.
- Vygotsky, L. (1962). *Thought and language*. Cambridge: MIT Press.
- Vygotsky, L. (1978). *Mind in Society: the Development of Higher Psychological Processes*. Cambridge: Harvard University Press.
- Wagner, M., Newman, L., Cameto, R. and Levine, C. (2005). *National Longitudinal Transition Study 2: Changes over Time in the Early Postschool Outcomes of Youth with Disabilities*. Menlo Park: SRI International.
- Waibel, S., Vargas, I., Aller, M., Coderch, J., Farré, J. and Vázquez, M. (2016). Continuity of clinical management and information across care levels: perceptions of users of different healthcare areas in the Catalan national health system. *BMC Health Services Research*, 16(1).
- Watson, R., Parr, JR., Joyce, C., May, C. and Le Couteur, AS. (2011) Models of transitional care for young people with complex health needs: a scoping review. *Child: Care, Health and Development*, 37(6), pp. 780–791.
- Watt, D. (2007). On Becoming a Qualitative Researcher: The Value of Reflexivity. *The Qualitative Report*, 12(1), pp. 82-101.
- Weiss, J., Robinson, S., Fung, S., Tint, A., Chalmers, P. and Lunskey, Y. (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with autism spectrum disorders. *Research in Autism Spectrum Disorder*, 7, pp. 1310–1317.
- Wierdsma, A., Mulder, C., De Vries, S. and Sytema, S. (2009). Reconstructing continuity of care in mental health services: A multilevel conceptual framework. *Journal of Health Services Research and Policy*, 14(1), pp.52-57.
- Wilkinson, S. (2000). Women with breast cancer talking causes: comparing content, biographical and discursive analyses. *Feminism and Psychology*, 10(4), pp. 431-460.
- Williams, D. (2003). *Exposure Anxiety—The Invisible Cage: An Exploration of Self-Protection Responses in the Autism Spectrum and Beyond*. London: Jessica.
- Willig, C. (2003), ‘Discourse Analysis’ in J.A. Smith (ed.) *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE, pp. 159-183.
- Wilner, L. and Feinstein-Whittaker, M. (2013). Improving Communication Skills in Health Care. *Perspectives on Communication Disorders and Sciences in Culturally and Linguistically Diverse Populations*, 20(3), pp.109.

- World Health Organisation (2016). *Developing an integrated e-health system in Estonia. In: Lessons from transforming health services delivery: compendium of initiatives in the WHO European Region*. Copenhagen: WHO Regional Office for Europe; 107–11 (http://www.euro.who.int/_data/assets/pdf_file/0014/303026/Compendium-of-initiativesin-the-WHO-European-Region-rev1.pdf?ua=1, accessed 5 April 2018).
- World Health Organization. (2018). *Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services*. Geneva: WHO. Licence: CC BY-NC-SA 3.0 IGO.
- Yeo, A., Legard, R., Keegan, J. and Ward, K., (2014). In-depth Interviews. In J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston (eds), *Qualitative Research Practice: A guide for social science students and researchers*, 2nd ed. London: SAGE, pp. 177-210.
- Yin, R. (2014). *Case study research: Design and Methods*. 5th ed. Thousand Oaks: SAGE.
- Yung, L. (2010). Identifying families' supports and other resources. In McWilliam RA (Ed) *Working with families of young children with special needs*. New York: The Guilford Press.

Appendices

Appendix A

List of terms used in the literature review of service users' perspectives on definitions, experiences, perceived value and outcomes of continuity of care in the case of ASD

In the search the following **key words** were combined with 'user' or 'patient' or 'client' or 'consumer' and 'ASD' or 'Autism' or 'Autism Spectrum Disorder' or 'Autistic' or 'disability' and 'primary care' or 'health service' or social care' and 'evaluation' studies or 'qualitative' studies, 'quantitative' studies or 'systematic review' or 'randomised controlled trial' or 'clinical trial' and 'theory' or 'model' or 'concept'.

continuity of care	discontinuity of care	care process
continuity of patient care	discontinuity	inter-professional working
continuity	seamless care	multi-professional working
interpersonal continuity	care experience	multi-agency working
personal continuity	coordination/co-ordination of care	inter-agency working
longitudinal continuity	integration of care/	team working/teamworking
provider continuity	integrated care	transitions
client-provider relationship	team care	trajectory
informational continuity	key worker	problem(s)
experienced continuity	care planning	solution(s)
cross boundary continuity	case management	
relational continuity		

Appendix B


List of terms used in the literature review of service user' perspectives on and/or experiences of health and social care transitions

In the search the following **key words** were combined with 'user' or 'patient' or 'client' and 'ASD' or 'Autism' or 'Autism Spectrum Disorder' or 'Autistic' or 'disability' and 'primary care' or 'health service' or social care' and 'evaluation' studies or 'qualitative' studies, 'quantitative' studies or 'systematic review' or 'randomised controlled trial' or 'clinical trial'.

transition	model
transfer	model of care
move	Early Intervention
graduate	School aged team
continuity of care	Intervention
quality of care	Assessment
satisfaction	Diagnosis
outcomes	
clinical outcome	
experience/s	

Appendix C

Sample of Critical Appraisal Skills Programme Tool (CASP, 2017)



Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes

Can't Tell

No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

2

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
 - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
 - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
 - If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix D

Table D: summary of transition theories and their potential for use as theoretical frames for the present thesis

Framework	Description	Applicability to study
The Ecological Systems Theory (Bronfenbrenner, 1986)	The Ecological Systems Theory aims to explain how the inherent qualities of a child and his environment interact to influence how he will grow and develop.	It may be difficult to apply in practice. This is due to the following factors: <ul style="list-style-type: none"> • There are no detailed mechanisms of how to implement • It is difficult to achieve balance and hierarchy with collected information.
The Transition Process for Young Children with Disabilities: A Conceptual Framework (Rous et al., 2005)	The model was developed in order to describe how the complex interactions of multiple systems interact to influence the educational transition process for children with disabilities.	This framework was developed within the field of education and has not previously been used in health and social care research. As it is based in The Ecological Systems Theory, the critique stated above is also relevant to this framework.
The Chronic Care Trajectory Framework (Corbin and Strauss, 1991)	The trajectory framework purports to describe the experience of chronic illness/ condition, including	This framework has not previously been used to explore paediatric disability health and social care transitions but shows merit for use, having been developed through ethnographic research with families and patients with disabilities.

	<p>the cumulative effects of a disabling illness including physical symptoms, and the impact of the illness on an individual's social world. The key to the utility of the framework lies in the assumption that each individual with a chronic illness experiences the disease process in a unique way.</p>	
<p>Family Systems Theory (Turnbull, 2000; Turnbull et al., 2005)</p>	<p>This theory has three main areas which allow a researcher to systematically explore a family unit. Firstly, the family as a whole, their cultural background, socioeconomic level, and geographic location. In addition it looks</p>	<p>This theory does not take into account environmental factors which may affect continuity of care for the child and family.</p>

	<p>at each individual's characteristics, related to exceptionality, coping styles, and health status. Finally, unique circumstances that may be faced by a family such as economic hardships, addiction, abuse and neglect, chronic illness, teenage parenting, and parenting with a disability.</p>	
<p>Sociocultural theory (Vygotsky, 1962, 1978)</p>	<p>This theory stresses the interaction between developing people and the culture in which they live.</p>	<p>The theory does not recognize that individuals can rise above social norms based on their ability to bring about personal understanding (Lui and Matthews, 2005, p. 392). Sociocultural theory does not seem to apply to all social and cultural groups—that is, social groups may not be whole and equal, with all learners being able to gain the same meaning from engagement.</p>

Appendix E

Topic Guide and Sample Questions – Caregivers (Before)

Rapport building

- Tell me a bit about your child
- What does the Early intervention service mean to you?

Before Transition

Let's go back to before you left the early intervention service. When answering these questions keep this time in mind.

- How was the preparation for your move?
- Tell me about how you were prepared?
- What changes were you prepared for? (management/ environment)
- Tell me about the information you received about your move?
- What kind of information did you receive?
- Tell me about how it was ending that relationship you have had with some of the team members that you have been working with for years?
- Can you tell me about any specific things the team did to help you with this move?
- Are there any areas that you think could be improved in regard to preparation for this transition?

In Transition

So now you are currently going through this transition. Base your answering on how you are feeling now.

- How are feeling about your move now at this stage?
- How do you feel about how you and your child are managed now in this team?
- Tell me about the changes you have experienced from early intervention services to this service (Environment/ staff/ interventions)
- How does this make you feel?
- Do you feel you were adequately prepared for / informed about this?
- In terms of making new relationships with the team members, how does this make you feel? Are these relationships different / the same? Talk me through this?
- How do you feel your child's information was transferred?

- Do you feel you were prepared and informed about all the changes?
- Do you feel your child was prepared and informed?
- Do you think you could have been prepared in a different way?
- Can you give any tips to the service providers about how to improve this transition?
- Were there any things you found that were unhelpful?

After Transition

Now you are through this time of transition. Think back to your experience as a whole when we talk through these questions.

Appendix F

Topic guide and sample questions – Service providers' (before)

Rapport Building

- Introduce yourself and your background.
- What does the early intervention service mean to you?

Sample Questions

- Tell me about how you prepare the families for their transition? (talks/ documentation/ visits/ support groups)
- What areas in specific do you prepare them for? (people/ environments/ patient management)
 - discharge reports
 - Meetings
- What happens when the families arrive in PCCC/ SADT?
- How do you think the families experience this transition? How do they/you feel?
- Do you think there is anything you could do better or differently?
- Is there something you would like to do differently in an ideal world?

Scenarios giving the SPs cue cards:

I've been to see a few families and have done lots of reading of the literature surrounding transitions. There are a few ideas and suggestions that have come up and I was wondering what you think of these? Some of these you might already do but I would love to hear how they are working for you? For new suggestions would they be practical in your practice? Is there a way we could modify these to work in your practice? How would this look in your practice?

- Transition planning meetings
- Discharge reports
- Meeting with EIT, PCCC and family members
- Key transition co-ordinator
- Visitation and introduction days in PCCC setting
- All about me booklet
- EIT book (similar to baby 0-5 book)
- Changing the time of transition (i.e. not at the same time as transition to school)
- Transition module during the summer for children and parents
- Incorporating transition into July provision
- Thoughts about SLT and OT in school (CHO9) – could this work for you?
- *Other points*
- Early intervention: intervention vs. assessment.
- Changing the wording of reports e.g. goals achieved, goals to be achieved
- Involving parents more in transition process

Appendix G

Caregivers topic guide – After iterative process

Rapport building

- Tell me a bit about your child?
- What does early intervention mean to you?
- Tell me about where you are in your journey now after leaving the Early intervention team and starting in PCCCT/ SADT?

Before transition (discharge)/ in transition

1. Information sharing

Definition: information on prior events and personal circumstances surrounding the service user is used to provide care that is appropriate for each individual

Tell me about how you were prepared for your discharge from EIT?

- information received
- information you'd have liked to receive
- Discharge reports
- positives/ negatives experiences
- any changes you'd recommend

2. Relationship continuity

Definition: the ongoing therapeutic relationship between a service user and one or more service providers.

How did you feel about leaving the therapists/ physios / counsellors etc to go to a new team of professionals?

- ending relations
- making new relationships
- different/ same relationships
- positives/ negatives
- anything you'd do differently

3. Management continuity

Definition: a consistent approach to the management of a health condition that is respondent to the service users changing needs.

In regard to the ways the different teams work, what are the key differences/ similarities you have noticed?

- Intervention styles
- New systems
- New administration set ups

- new environments
- positives/ negatives
- anything you would do differently

Summary of interview key points and correct me

4. Anything else?

Definition: related to the experience of coordinated and seamless services from the perspective of the service user.

Talking about this move as a whole now is there anything else you'd like to mention/ discuss?

- Prompts as appropriate
- Any areas felt that further questions are necessary to get move information.

After transition

Now you are a few months on from your move, think back on your experience as a whole now as we go through these questions.

1. Information sharing

Definition: information on prior events and personal circumstances surrounding the service user is used to provide care that is appropriate for each individual.

Tell me about how you were prepared for your move?

- information received
- information you'd have liked to receive
- Discharge reports
- positives/ negatives
- anything you'd do differently

2. Relationship continuity

Definition: the ongoing therapeutic relationship between a service user and one or more service providers.

How did you feel your relationship is with your new team of professionals?

- making new relationships
- different/ same relationships
- positives/ negatives

3. Management continuity

Definition: a consistent approach to the management of a health condition that is respondent to the service users changing needs.

Tell me about how you feel you are managed now in comparison to your old team?

- intervention styles
- new environments
- positives/ negatives
- anything you would do differently

4. Anything else?

Definition: related to the experience of coordinated and seamless services from the perspective of the service user.

Talking about this move as a whole now is there anything else you'd like to mention/ discuss?

- Prompts as appropriate
- Any areas felt that further questions are necessary to get move information.

Appendix H

Topic guide and sample questions – Service providers’ after iterative process

Introduction

Hi there, thank you so much for meeting me to talk about your experience of how children with asd transition in your service. Let me start by explaining the project I am doing and what we shall be doing today.

I’m a masters student in IT Sligo and I have a degree in speech and language therapy from NUI Galway. I work clinically as a speech and language therapist also. I’ve always had a strong interest in hearing the stories and experiences of parents and children and using these to help them or others like them.

So this project includes getting the experiences of parents of children with autism as they move from early intervention services to primary care or school age disability team. I then hope to take this information to service providers you, to understand the experiences from different perspectives. I will finally summarise the data and make it available to all participants and the HSE.

Do you have any questions about this?

Before we start, I’m going to ask you to sign a consent form to agree to partake. By signing this form you understand that you can withdraw from the project at any stage without reason, you and your child will remain anonymous at all stages and partaking in this study will not affect any of the services you receive in any way.

- request to sign consent form

Rapport Building

- Introduce yourself and your background.
- What does the early intervention service mean to you?

TOPIC 1: Preparation for the transition from EIT to PCCC team

Question: I’d like to start by asking about how you prepare the families and children for discharge from EIT?

Prompts: (Informational continuity)

- **How do you/ your team prepare the families and children for the move from EIT to this new team of professionals**
 - How is the (*child’s name*) was prepared for this move?
 - What information do you give/receive about this discharge/ move?
 - Does this work? Is there anything else you’d like to do?
 - Do you complete discharge reports?
 - What information does this contain and who is it intended for?
 - Does it reflect the child and provide new team with information about X?
 - How else are the new team notified about X and his involvement with EIT
 - Any other recommendations on how parents/ children can be prepared for the move?
- I’d be really interested to hear your perspective on this!

-E.g. What about members of the EIT meeting with members of the new team, along with parents?

- What about an all about me booklet
- Would transition workshops/talks for parents be a useful

Relationship continuity

Next, I am interested in exploring your perspectives on the importance of *relationships* with team/professionals and the child and family

- How do you think the families feel about leaving the health care professionals etc. to go to a new team of professionals?
- How do you think the child feels about leaving these professionals? We know change for children with ASD can be difficult.
- How well do you think he/she are prepared and understands what is going to happen?
- Did the old professionals prepare families for meeting the new professionals?
- is there a key person (coordinator) who coordinates the move?
- If so, what do they do?
- If not, would you like someone to do this?
- Anything else that you can think of that might help at this time?

Management Continuity

How does the set up compare across the two teams, how is it the same/different?

- i) Physical environment- spread of services/physical contexts
 - ii) Different therapists
 - iii) Different approaches to therapy/care? How is that for you?
 - iv) Type if intervention e.g. group vs individual, parent training and support
 - v) HSE based or school based?
- Do you prepare the families about the changes in approaches to care that may occur?
 - By changes in care I mean the interventions received.
 - Did you feel you prepare the child and family for the change of environments?

Scenarios check through cue cards.

- *Discharge vs. transition*

Before we finish up, is there anything else you would like to add about the preparation for discharge from the early intervention team? Is there anything that has really struck a chord with you today?

Thank you so much for taking this time to talk to me.

Appendix I

Nodes\\Stage 2 - generating initial codes

Name	Description	Files	References
all about me	Any reference to an all about me/us booklet, child portfolio which contains more personal information on the child and family	19	152
caseloads	Any reference to the caseloads by service providers	8	33
diagnosis	Any reference to getting a diagnosis	5	18
discharge reports	Any reference to a discharge report and/or equivalent in these settings	19	122
early intervention	Any reference to the meaning behind early intervention for participants	18	12
EIT Book	Any reference to an early intervention book	8	26
expectations	Any reference to expectations of individuals or services	10	40
formality	Any reference to the formalities related to the transition	1	7
gap in the service	Any reference to gaps in services	10	78
Staffing	Any reference to levels of staffing	14	182
Individualised care	Any reference to how service providers individualise care based on the needs of the child or family.	4	26
information handover	Any reference to how information is transferred between the teams	9	118
infrastructure and policy	Any reference to how infrastructure and policy affect services	8	42
Joint work	Any reference to joint work between EIT and SAT	15	111
Management	Any reference to management continuity	9	29
MDT involvement	Any reference to MDT involvement with the child and family	18	56
needs of families	Any reference to the needs of families from the service providers perspectives	12	65
pathway planning	Any reference to the care pathways for EIT leavers	10	40
PDS	Any reference to progressing disability services	8	61
preparation for transition to SAT	Any reference to the preparation for transition to SAT by EIT or SAT	10	96

Name	Description	Files	References
Relationship handover	Any reference to relationship continuity across the transition	10	64
Roles	Any reference to the roles played by different team members	11	42
SAT welcome	Any reference to an idea which welcomes children and families to the school aged service.	17	92
service provision	Any reference to how services are provided to families and children in EIT, SADT, School, Clinic etc.	8	34
Appointments	Any reference to appointments	8	32
services in school	Any reference to services in school	16	64
Technology	Any reference to how technology could improve continuity of care	2	7
thoughts, ideas and emotions of parents	Reference to any emotions experienced by parent from service providers perspectives	10	67
Thoughts, Ideas and emotions of service providers	Any reference to emotions, ideas and thoughts about transition experienced by service providers	8	28
timing of transition	Any reference to the timing of transition from EIT to SAT	10	79
transition coordinator	Any reference to an individual who acts as a key/lead individual in the transition from EIT to SAT	13	38
transition planning meeting	Any reference to a meeting to plan the transition between teams	18	98
Transition to school	Any reference to the transition to school	17	100
transition workshop	Any reference to a workshop/presentation/day about the transition for parents/children	10	47
visitation day	Any reference to visitation day to prepare children for changes in environment	14	42
Wording around transition	Any reference to the wording around transition e.g. discharge, transfer,	17	56
work by parents	Any reference to the work carried out by parents throughout the transition	5	16

Appendix J

Nodes\\Stage 3 - Searching for themes

Name	Description	Files	References
Education	Any reference to how education may impact the transition process	18	88
Services in school	Any reference to services in school	15	62
transition to school	Any reference to the transition to school	16	91
Expectation of services	Reference to service users expectations of services	15	100
early intervention	Any reference to the meaning behind early intervention for participants	12	67
Expectations	Any reference to the expectations of PCCC	14	87
needs of families	Any reference to the needs of families from the service providers perspectives	10	63
External Factors	External factors which affect Continuity Of Care	15	49
case loads	References to caseloads	8	33
infrastructure	Any references to physical infrastructure	8	42
policy	Any reference to policy	10	118
timing of transition	Any reference to the timing of transition from EIT to SAT	10	79
staffing	Any reference to staffing levels	8	54
The established transition process	Reference to the transition process and how it has been completed over previous years	17	113
The experience around transition	The associated experience with transition	15	87
Individualised cases	Any reference to individualised cases	8	44
routine	Any reference to routine and sameness of routine	10	67
Appointments	Any reference to appointments	8	61
services in school	reference to services in school	8	44
thoughts, ideas and emotions of parents	Reference to any emotions experienced by parent from service providers perspectives	10	67
Wording around transition	Any reference to the wording around transition e.g. discharge, transfer,	17	121

Name	Description	Files	References
work by parents	Any reference to the work carried out by parents throughout the transition	10	100
What might help Continuity of Care information handover	Any reference to proposed solutions to improve continuity of care	18	136
information handover	Any reference to how information is transferred between the teams	17	118
all about me book	Any reference to an 'all about me book'	16	164
discharge reports	Any reference to a discharge report and/or equivalent in these settings	15	153
Management	Any reference to management continuity	17	120
transition workshop	Any reference to a workshop/presentation/day about the transition for parents/children	10	47
SAT welcome	Any reference to an idea which welcomes children and families to the school aged service.	14	98
visitation day	Any reference to visitation day to prepare children for changes in environment	15	89
Relationship handover	Any reference to relationship continuity across the transition	10	64
Joint work	Any reference to joint work between EIT and SAT	7	29
transition planning meeting	Any reference to a meeting to plan the transition between teams	9	62

Appendix K

Nodes\\Stage 4- Reviewing themes\\Stage 5 - Defining and Naming themes

On-going analysis to refine the specifics of each theme, and the overall story [storylines] the analysis tells, generating clear definitions and names for each theme

Name	Description	Files	References
Consequences of discontinuity and proposed solutions	This theme describes all consequences related to discontinuity of care and proposed solutions by services users and providers	0	0
People work	This sub theme relates to Strass' definition of information work in the CICTF. This is defined as the work or actions undertaken to manage or shape one's trajectory	16	98
Proposed solutions	This sub theme related to proposed solutions to discontinuity from SPs or SUs	10	105
Sentimental consequence	This subtheme relates to the emotional consequences related to the child's care trajectory	10	67
Organisational contingency factors affecting continuity	This theme relates to external factors related to higher organisational, infrastructure and policies which effect on experienced continuity of care. This theme is based upon the concept of organisational contingency factors from Strauss' CICTF.	0	0
Caseloads	This sub theme relates to how caseloads of SPs affects continuity of care	11	45
Infrastructure	This sub theme relates to how structural influences effect continuity of care.	16	62
Policy	This subtheme relates to how policy and procedures effect continuity of care across this transition.	13	65
Staffing	This sub theme relates to staffing levels in either EIT or PCCC or both.	9	34
The transition experience	This theme relates to the experience of service users and providers as they go through the transition from EIT to PCCC services	0	0
Expectations of services	This theme relates to service user and providers expectations of services and how these services should interact together.	10	87
Informational continuity	This sub theme relates to how informational continuity is managed over the transition.	19	118
Management continuity	This sub theme relates to how management continuity is managed over the transition.	19	129
Relational continuity	This sub theme relates to how relational continuity is managed over the transition.	18	84
The transition to educational settings	This theme relates to how the transition to the educational setting effects dimensions of	0	0

Name	Description	Files	References
	continuity or care and the child's trajectory.		
Preparation for school	This subtheme relates to the preparation for children and families on the transition to educational settings	15	145
Services in educational settings	This sub theme relates to the health and social services being provided in/ through the educational setting and comparing this to HSE centre service provision.	17	121

Appendix L

Nodes\\Stage 5- Defining and Naming themes

Name	Description	Files	References
Theme one: Varying construction of services	This theme relates to participants' social constructions of the services in question namely EIT, PCCCT, Transition and PDS.	0	0
1.1 Constructions of Early Intervention	This subtheme relates to participants' social constructions of the Early Intervention service.	19	287
1.2 Constructions of the transition to PCCCT	This subtheme relates to participants' views and experiences on the transition from EIT to PCCCT.	18	214
1.3 Constructions of various aspects of transition	This subtheme relates to participants' perspectives on the construction of various aspects related to the transition from EIT to PCCCT.	19	347
1.4 Constructions of Progressing Disability Services	This subtheme relates to participants views on the HSE's policy "Progressing Disability Services for Children and Young Adults".	15	199
Theme two: Relationship transition	This theme relates to participants' accounts of their continuing relationships with their service providers and the termination of these during the transition between services	0	0
2.1 The experience of relationships	This subtheme relates to participants' expectations and experiences of terminating and building relationships associated with the transition from EIT to PCCCT.	18	256
2.2 Consequences of poor relationship transfers	This subtheme relates to the consequences experienced by caregivers and service providers when the transfer of relationships is not managed appropriately.	18	255
2.3 Proposed solutions to facilitate relationship transfer	This subtheme relates to proposed solutions by participants to improve relationship transfer from EIT to PCCCT.	18	204
Theme three: Information transfer	This theme relates to participants' accounts of information transfer following the course of the client's trajectory associated with the transition from EIT to PCCCT.	0	0
3.1 Experience of information transfer	This subtheme relates to the expectations and experience of information transfer during this transition	19	217
3.2. Results of poor information transfer	This subtheme relates to consequences to caregivers and service providers when poor information transfer occurs	19	245

Name	Description	Files	References
3.3 Solutions to improve information transfer	This subtheme relates to proposed ideas by caregivers and service providers to improve information transfer associated with the transition.	19	366
Theme four: Management practices	This theme relates to participants' accounts of management practices associated with the transition from EIT to PCCCT. Namely, the consistency of clinical management, including care planning, physical environments and intervention type.	0	0
4.1 Management practices experience	This subtheme relates what participants expect of and how they experience clinical management practices (as described above) associated with this transition.	19	228
4.2 Consequences of poor management practices	This subtheme relates to the consequences experienced by caregivers and service providers when poor clinical management occurs.	19	237
4.3 Proposed Solutions to improve management practices	This subtheme relates to proposed solutions by participants to improve management practices associated with this transition.	19	198

Appendix M



Are you are a parent of a child with autism spectrum disorder who has recently been discharged from Early Intervention Team?

Then.....We would love to talk to you about you and your child's experiences of being discharged from the Early Intervention Team and your thoughts about moving to a new team of health professionals in Primary Care.

Why?

It is important to hear your views, your experiences and challenges to inform service development and improvements in how services are delivered.

Who?

The research is being conducted by IT Sligo. The researcher is Gráinne Quinn and it is being supervised by Dr Niamh Gallagher.

What?

Information will be used to create a picture of the move from the Early intervention Team to the Primary Care Team **and to inform improvements in service delivery and organisation.**

What am I required to do?

We would like to talk to you about your experiences on a one to one basis at a location convenient to you. The **informal** interviews will last approx. one hour and if you are willing, we would like to talk to you on two occasions, once in the near future and again in approximately 4-6 months.

Where can I get further information?

Please see our information leaflet or contact the researcher, Gráinne Quinn by email on **grainne.quinn2@mail.itsligo.ie or (071) 9305805.**

Interested?

Please contact Gráinne Quinn, Researcher who will be happy to discuss with you further the nature of the project and arrange a suitable time for the informal interviews.

Thank you for taking the time to read this information – I would be delighted to hear from you!

Appendix N

“Caregivers’ and service providers’ perspectives of continuity of care for children with Autism Spectrum Disorder following discharge from Early Intervention Services”

INFORMATION SHEET SERVICE PROVIDER PARTICIPANTS

Dear Service provider,

My name is Gráinne Quinn and I am a Masters student at Sligo IT conducting a research project on the topic of continuity of care experiences of caregivers of children with ASD when they transition from Early Intervention Teams (EIT) to Primary Continuing and Community Care Teams (PCCCTs) and/or School Aged Disability Teams (SADTs) in the HSE West area. I am writing to invite you to participate in this study.

In phase 1 of data collection I will be interviewing caregivers about their experiences of continuity of care following discharge from the EIT. In phase 2, I would like to conduct a focus group with you and other service providers to ask you about your perspectives on this transition for service users who are impacted by this transition. This research is being supervised by Dr Niamh Gallagher, Speech and Language Therapist and Lecturer in Inclusive Practice and Transitions in the Early Years, at IT Sligo.

Before you decide whether to take part in the study it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information and discuss it with others if you wish. It is up to you to decide whether or not to take part and you are welcome to phone or email me if you would like any further information (please see contact details below). If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form prior to participating in the focus group Please be assured that participation is voluntary and you can change your mind at any time and withdraw from the study without giving a reason.

The **purpose of the research study** is to explore the experience of the transition for families of children with ASD in the twelve months from discharge from the EIT. I would like to interview service providers about this transition, explore your thoughts, your feelings and experiences of working with children who are impacted by this transition, as well as bring situations and events from caregivers to contextualise and explore potential solutions to problems.

You have been chosen as a potential participant for this study because you work with children with ASD in the context of EI services and/or PCCC/ SADT services. The focus group will involve approximately 8-12 participants from a variety of disciplines on your multidisciplinary team. The focus group will last approximately 60 minutes during which I will explore topics such as transition/discharge planning processes, issues experienced by

service users prior to, during and after the transition and your experiences of working with and supporting children and caregivers throughout the transition process. If you choose to take part, I will organise a location and time for the focus group that is convenient to you and your colleagues.

The information gained from this research will be used to make recommendations for best practice and will offer insights and contextualise the experience of this transition for young children with autism spectrum disorder and their caregivers.

With your consent the focus groups will be recorded on audio tape and then transcribed onto a computer. The audio tapes will be stored in a locked secure place at all times and the computer data will be protected from intrusion also. Audio tapes will be stored in a secure location at Sligo IT for a period of five years and will then be destroyed.

Please be assured, your responses will be treated confidentially and anyone who takes part in the research will be identified only by code numbers or pseudo- names. Your name and any other identifying information will be anonymised. Following the interview, you can request a copy of the focus group transcript if you wish. At the end of the research, I will write a report and the results may be published in peer reviewed journals and conference presentations. Again, no research participant will be identifiable from any publications.

This study has been reviewed and approved by the Research Ethics Committee at Sligo General Hospital.

Please do not hesitate to contact me or my research supervisor, Dr Niamh Gallagher if you need further information

Thanking you in anticipation,

Yours sincerely,

Gráinne Quinn

Postgraduate student, Dept. of Social Sciences, Sligo IT and Speech and Language Therapist

Email: grainne.quinn2@mail.itsligo.ie / Gallagher.niamh@itsligo.ie

Phone: *to be added*

Title of Study: Caregivers' and service providers' perspectives of continuity of care for children with Autism Spectrum Disorder following discharge from Early Intervention Services

1. I confirm that I have received a copy of the Information Sheet for the above study. I have read it and I understand it. I have received an explanation of the nature and purpose of the study and what my involvement will be.
2. I have had time to consider whether to take part in this study and I have had the opportunity to ask questions.
3. I understand that my participation is voluntary and that I can decide to opt out of the research at any time.
4. I understand that all information gathered about me during this study will be treated with full confidentiality.
5. I agree to take part in the above study.

Name

Date

Signature