

Mothers' Perceptions and Sense-
Making of their Roles in Speech and
Language Therapy for Children with
Autism in Ireland

Thesis presented in fulfilment for Doctor
of Philosophy, Clinical Speech and
Language Studies, Trinity College
Dublin.

Eibhlin Marie Gorman, 2022

Declaration

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Summary

Introduction: This thesis is focused on the role of mothers in speech and language therapy for children with autism. Parental involvement is recommended by professional bodies (e.g., RCSLT, 2009) and service providers (e.g., HSE, 2018) alike. Yet despite the apparent consensus regarding the importance of the parent role in therapy, few studies have attempted an in-depth exploration of how parents and other stakeholders perceive the parent role. This thesis sought to explore how mothers perceive and make sense of their role in SLT for children with autism in Ireland.

Method: This study involved an Interpretative Phenomenological Analysis (IPA) study, informed by two supplemental research strands – two survey studies and a deductive analysis. The IPA study used interview data from six mothers of children on the autism spectrum, to explore how mothers perceived and made sense of their role in therapy. A preliminary analysis of the data inspired the development of two survey studies which opened further iterative cycles of analysis of the IPA data. One survey targeted parents and sought to address what behaviours and attitudes parents believed were expected of parents and therapists in SLT. The second survey targeted SLTs and sought to determine what diagnostic and intervention pathways were reported to be available for children with autism in Ireland. It also investigated therapists' reported practices regarding how they involved parents in decision-making. Following completion of these survey studies, I re-interrogated the original IPA findings, resulting in the construction of four superordinate themes. I then completed a deductive analysis of interview data from six additional mothers to investigate if the IPA themes were evident across other cases.

Findings: The survey results signal the challenging context in which parents may attempt to navigate their role in SLT in Ireland. The parent survey indicates that while many parents enter therapy with an expectation of being involved in therapy, their

expectations are grounded in traditional, therapist-led intervention approaches. The SLT survey findings indicate that many parents likely experience gaps in service provision at times. These gaps may impact on their expectations of their roles. Four superordinate themes were constructed through the IPA study. Two related to the participants' understandings and expectations. These themes pointed to the importance of participants' understandings and expectations of 1) autism and 2) SLT to their sense-making of roles. The third theme, "*Therapy Mother*" encapsulated two types of roles relating to the implementation of therapy. The first, "Apprentice Builder," involved mothers working hard to "*build*" their children's communication at home by learning from and being directed by the SLT. The second, "Manager-Therapist-Mother" involved mothers' feeling compelled to work in a professional capacity alone, because of perceived limitations in resources. This "Manager-Therapist-Mother" role was experienced as being in conflict with maternal identities and understood as striving to do the impossible, while incurring significant sacrifice. The fourth theme, "A Game of Survival," captured participants' interpretations that services and sometimes professionals acted as barriers to intervention, leading participants to approach role construction from a position of mistrust and to adopt roles as advocates for their children. The deductive analysis found evidence to support the potential relevance of the IPA findings to other mothers of children on the autism spectrum based in Ireland. The findings have implications for theories of role construction and how researchers seek to capture therapy roles. They also point to the importance of clinicians routinely discussing roles, being cognisant of how and why they invite parents to be involved in therapy and acknowledging the work done by parents often in personally challenging circumstances, to support therapists and children.

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Abbreviations

AAC	Augmentative and Alternative Communication
ABA	Applied Behavioural Analysis
ADHD	Attention Deficit Hyperactivity Disorder
AMO	Area Medical Officer – Doctor within the HSE, with specialism in child development, who provide medical assessments to determine the need for onward referral to hospitals and other services.
AoN	Assessment of Need – Legislative process part of the Irish Disability Act which requires the state to provide children at risk of having a “disability” with an assessment report stating their needs related to this disability.
CAMHS	Child and Adolescent Mental Health Service
CORU	CORU – Regulatory body for health and social care professionals
EIT	Early Intervention Team- therapy service for children aged 5 years or under, with complex needs requiring interdisciplinary care.
ENT	Ear, Nose and Throat
GDD	Global Developmental Delay
GDPR	General Data Protection Regulation
GP	General Practitioner
HSE	Health Service Executive – National health service provider
IPA	Interpretative Phenomenological Analysis – main methodological approach employed in this thesis
ODD	Oppositional Defiance Disorder
OT	Occupational therapy or occupational therapist
PDS	Progressing Disability Services- Programme to reconfigure paediatric disability services in Ireland
PECS	Picture Exchange Communication System
PHN	Public Health Nurse – Community based nurse.
SADT	School Aged Disability Team – Therapy service for children aged 5/ 6 years to 18 years with complex needs requiring interdisciplinary care.
SLT	Speech and language therapy or speech and language therapist

Chapter 1: Orientating the Reader

1.1 Introduction

This chapter is designed to orient the reader to this thesis. It begins with an introduction to the motivations underpinning my interest in the parent role in therapy. This is followed by a statement of the aims of the research and an overview of how the thesis is organised.

1.2 My Personal Focus on the Parent Role in SLT

This thesis is focused on roles, specifically the parent role in Speech and Language Therapy ([SLT](#)). It was born out of my experiences as a clinician and the accompanying frustrations that bubbled within me from the time I began work, fourteen years ago. Professional bodies (e.g., Royal College of Speech and Language Therapists, 2009) and my employer (Health Service Executive, 2018) emphasised the importance of parental involvement in intervention, recommending that I foster collaborative partnerships with parents. Yet the circumstances of my clinical practice often dictated exactly how, where and when parents could be involved. Standardised pathways of care meant that any parent with a child under 3 years would receive parent-mediated intervention in a group, for example. Restrictions on the number of appointments I could offer families, limited how long I could spend engaging clients in discussions regarding goal-setting. Additionally, as I saw it at the time, some families did not want to be involved. They didn't do the "homework" or programmes I gave them. They voiced frustration about the amount and type of therapy offered. I "knew" parent involvement was essential but was uncertain about what parent role I was seeking, and could seek from parents within a resource-constrained service, that was increasingly called upon to be more accountable and evidence-based. With hindsight, I recognise that I might have "known" that I was supposed to think parent involvement was

essential, without fully understanding why or what I expected of parents. Furthermore, change was coming. Therapy services were being reconfigured nationally and the discourse around this increasingly seemed to me to be pushing therapists to move away from traditional, therapist led, child focused interventions to ones based exclusively on parent training. I was confused about how I felt about this. Surely increased parent involvement would be beneficial to all, so why did part of me wonder if and how this could work, as well as querying the ethics of this shift? A review of the literature did little to address my confusion. Few studies had specifically addressed the parent role in therapies, let alone in [SLT](#), or in an Irish context, suggesting that the profession still had much to learn about the preferences, expectations and understandings of its “partner” parents. This was the context in which I began a seven-year PhD journey exploring the role of parents in [SLT](#).

1.3 Aims and Scope

This research aims to increase understandings of the parent role in [SLT](#) in order to increase awareness of what this role may involve and how parent involvement in therapy can be supported. Owing to the sample involved, the research is focused on the experiences of mothers. Specifically, the research targets the following questions:

1. How do mothers of children on the autism spectrum perceive their role in [SLT](#) in Ireland? (i.e., what do they perceive their role to be)
2. How do mothers of children on the autism spectrum in Ireland make sense of their role in [SLT](#)?

1.4 Organisation of the Thesis

This main body of the thesis is presented over four parts, comprising eleven chapters.

1.4.1 Part One- Situating the Research in Context

Part one of the thesis encompasses chapters two and three and aims to situate the research in the context of the available literature. Chapter two introduces the reader to

autism and discusses my decision-making regarding terminology relating to autism. It presents a review of the literature regarding parenting a child on the autism spectrum and seeks to familiarise the reader with [SLT](#) service provision for children with disabilities in Ireland. Chapter three reviews the available literature regarding parental involvement in [SLT](#) and parental perceptions of therapy roles. It also introduces the reader to the theoretical context from which this thesis draws – Role Theory and theories of Health Behaviours.

1.4.2 Part Two – Methodology

Part two incorporates chapters four and five. The core study of this thesis involved an Interpretative Phenomenological Analysis ([IPA](#)) study. An overview of the design of the whole research project and the methodology relating to the core [IPA](#) study is presented in chapter four. I also completed two survey studies to contextualise the [IPA](#) findings. The design of these survey studies is presented in chapter five.

1.4.3 Part 3 – Findings

The findings of the study are discussed over the next five chapters. Chapter six presents the findings of both survey studies. Chapter seven introduces the reader to the [IPA](#) participants and presents an overview of the superordinate themes constructed. Chapters eight, nine and ten discuss the [IPA](#) findings with a focus on the superordinate themes of “Understandings and Expectations of Autism and [SLT](#)” “*Therapy-Mother*” and “A Game of Survival.”

1.4.4 Part 4 – Discussion and Conclusions

Chapter eleven presents a discussion of my interpretation of the significance of the findings to practice and theory. The thesis is brought to a close in chapter twelve, with a summary of the main findings and conclusions and a critique of the study.

In an effort to honour my constructionist leanings and my chosen methodology, reflective and reflexive commentary is intertwined regularly throughout the thesis.

1.5 Summary

This chapter introduced the reader to the research aims and scope and the personal background context of the study. It also orientated the reader to the organisation of the thesis. The next chapter provides an overview of literature relating to the experience of parenting a child with autism.

Chapter 2: Understanding Parenting in the Context of Autism in Ireland

2.1 Introduction

This chapter introduces readers to the background context of the study and opens with a discussion of autism, including the terminology used in the thesis. It then presents a review of literature regarding the experience of parenting children on the autism spectrum. This is followed by a description of service provision for children with autism and their families in Ireland. The chapter concludes with a reflective and reflexive commentary.

2.2 The Autism Spectrum

It is estimated that approximately 1.0% of children in Ireland have a diagnosis of Autism Spectrum Disorders (ASD; henceforth “autism”) (Sweeney et al., 2016). Despite the prevalence of autism and the research attention it attracts, controversy persists regarding how autism should be understood and spoken about (Bury et al., 2020). Diagnosticians often use the term “Autism Spectrum Disorders” (ASD) to describe a group of lifelong, neurodevelopmental disorders of no clear aetiology (Stewart et al., 2017). A diagnosis of ASD is given when a person presents with “impairments” in social communication skills, in addition to the presence of restricted and repetitive behaviours, interests or activities that are evident from early childhood (APA, 2013). The reference to “spectrum” signals the variability in manifestation of autism. The social communication difficulties associated with autism can vary, for example, from difficulties with turn-taking in a conversation to more pronounced difficulties interacting for any reason other than to request desired objects and activities. Similarly, restricted and repetitive behaviours may present as an inflexibility in the walking to school, for example, but the consequences of changing this route may vary from mild anxiety in one person to severe distress and fear in another.

Academics and advocates (e.g., Bottema-Beutel et al., 2020) aligned with the neurodiversity movement, reject an impairment-based conceptualization of autism as reductionist and negative. The neurodiversity movement celebrates autism as both a difference and a disability (Vivanti, 2020). Viewing autism through this lens illuminates how many traits often associated with an individual's autism can act as strengths rather than "impairments." The neurodiversity movement underscores the role that autism plays in identity construction, at an individual and collective level, with people viewing themselves as part of an autism community (Andrews et al., 2019). Additionally, the movement highlights society's influence on the experience of disability, for example, through expectations of acceptable behaviours and a lack of flexibility in societal practices in measuring academic progress. The lived experience of autism is proposed to result from the "transaction between inherent weaknesses of autism and the social environment," (Bottema-Beutel et al., 2020, p. 4).

The neurodiversity movement is often critiqued as downplaying the negative impact that autism can have on some individuals, particularly those with co-occurring learning disabilities or severe communication difficulties (Vivanti, 2020). Children on the autism spectrum commonly present with seizures, attention difficulties, gastrointestinal concerns or difficulties with sleep, feeding, and/ or emotional regulation (Kuhlthau et al., 2014; Matson & Burns, 2019). Some children also present with challenging behaviours including aggression and self-injurious behaviours (Stewart et al., 2017). Autism also commonly co-occurs with other disabilities (Matson & Burns, 2019). Simonoff et al. (2008) found that 70% of their sample of 112 children (aged 10 to 14 years) had at least one co-occurring clinical difficulty. Studies (e.g., Baio et al., 2018) suggest that approximately a third of people on the autism spectrum also have a learning disability. Higher rates of depression, anxiety and suicidal ideation are reported in children on the autism spectrum compared to

typically developing peers (Dickerson Mayes et al., 2013; Hurtig et al., 2009). While each child on the autism spectrum has unique qualities, talents and strengths that contribute positively to family life, the challenges associated with their autism and/or any co-occurring difficulties may significantly impact on the quality of life of the child and their family (NICE, 2013). Thus, for the purposes of this study, I take the position that autism is neither entirely negative nor entirely positive and that its meaning and impact will vary both from person to person and across an individual's lifespan.

2.3 Terminology and Language

The differing philosophies of varied stakeholders and movements is reflected in how autism is referred to. Person-first language, (i.e., "person with an autism spectrum disorder" rather than "autistic person") is frequently used in the education of health professionals and in research publications (Crocker & Smith, 2019). Person-first language originated in the 1970's and was designed to reaffirm the humanity of people with disabilities, as 'a person first' who deserved the same rights and opportunities as those without disabilities (Vivanti, 2020). However, many neurodiversity advocates, such as Sinclair (2013) reject person-first language as medicalizing autism and presenting it negatively as both a disorder and an entity that is separate to the individual, rather than part of their identity. Such advocates often favour identity-first language, such as "autistic person," which they argue captures how autism is integral to one's identity (Bottema-Beutel et al., 2020). The limited studies to date (e.g., Bury et al., 2020; Kenny et al., 2016) indicate a lack of consensus both among and between adults with autism and other stakeholders such as family members and health professionals. Nevertheless, there appears to be an increasing awareness (e.g., Vivanti, 2020) that terminology is important and that a lack of care regarding language choices can contribute to stigma, feelings of isolation and negative self-beliefs among the people whom the label describes (Bottema-

Beutel et al., 2020). In an effort to write with sensitivity to both the participants of my study and their children, I have chosen to use the term “person on the autism spectrum” throughout this thesis, which preliminary evidence (Bury et al., 2020) suggests is acceptable to many adults in the autism community. Bury et al. found that adults who reported having an autism diagnosis showed preference for this term and that additionally, few participants rated this term as offensive. This level of acceptability is in contrast to the term “autistic”, which although ranked highly preferable by many, was ranked as highly offensive by many others. Bury et al. (2020) noted that the omission of the word “disorder” likely helps to reduce concerns of presenting autism as wholly negative. The use of “on” rather than “with” may also help to capture the voices of those who view autism as part of their identity (Bury et al., 2020). Additionally, this term is proposed as more acceptable to researchers, health professionals and family members as it provides both a clear and accurate label to describe all individuals on the autism spectrum, rather than just those who align with the neurodiversity movement, (Bottema-Beutel et al., 2020), while also allowing flexibility as to what extent autism forms part of that person’s identity.

2.4 Motherhood and Autism

The research presented in this thesis relates to mothers of children who are on the autism spectrum. A large body of literature relating to the experience of mothers of children with developmental disabilities, including autism, is found in studies of ‘parents’ and ‘parenting’ in this field. This literature points to the experience of parenting a child on the autism spectrum as being paradoxically both unique and shared, while also dynamic (Ryan & Runswick-Cole, 2008). Parenting a child with a disability can be both rewarding and joyful, while also extremely challenging at times (Tabatabai, 2020).

Parenting in the context of autism may be associated with difficult emotional and psychological parental experiences, particularly around the time of diagnosis and at other transition points during the child's life (e.g., commencement of school) (McGrew & Keyes, 2014). Parents of children on the autism spectrum have been found to have higher rates of depressive disorders (e.g., Charnsil & Bathia, 2010) compared to the general population and higher rates of stress (e.g., Hayes & Watson, 2013), anxiety and depression (Dumas et al., 1991; Firat et al., 2002) compared to parents of children with other developmental disabilities. The social impact of parenting a child on the autism spectrum is also frequently discussed in the literature, with many parents reporting experiences of isolation from their wider family and/or general society (e.g., Woodgate et al., 2008) and perceived reductions in the quality of their relationships with partners and other children in the family (e.g., Kuhlthau et al., 2014).

Parents may also experience further social and emotional difficulties relating to their beliefs about their ability to parent and relate with their child on the autism spectrum (Del Bianco et al., 2018; Taylor et al., 2021). These difficulties may stem from their perceptions of their child's social communication difficulties (Taylor et al., 2021). Early social communication difficulties in young children on the autism spectrum include less use of gesture and pointing than typically developing peers, differences in eye-contact and reduced or delayed responses to sensory stimuli in their environment (Kinard & Watson, 2021). Additionally, children may exhibit behaviours such as wandering, intense focus on a single toy, unusual and less functional play (for example, close visual inspection or spinning), and high or low activity levels (Kinard & Watson, 2021; Watson, 1998). As a result, parents' ability to recognise and interpret their child's communication attempts, join in play and engage in shared interaction experiences may be challenged (Kinard & Watson, 2021). This in turn may impact on parent-child relationships (Del Bianco et al.,

2018). Early reciprocal parent-child communication exchanges are considered significant to reinforcing the parent-child relationship, both facilitating secure attachment for the child and acting as a reward for parents as they navigate the many challenges of parenting a young child, including sleep deprivation, loss of freedom, managing tantrums and emotional outbursts (Harris & Butterworth, 2002). Thus, in the context of autism, parents may be afforded less frequent social exchanges with their child and thus sometimes less opportunities to access the rewarding interactions which serve to re-energise parents as they face the daily stresses of parenting. Potentially compounding these interaction difficulties further, many children on the autism spectrum also experience difficulties with speech and using or understanding spoken language (Kim et al., 2014). In response to their concerns about their child's communication development and other difficulties related difficulties, many parents seek interventions such as speech and language therapy.

While interventions are typically designed to help children and families, involvement with different professionals and services can involve additional work and pressures. Many parents depict feeling an urgency and pressure to access multiple interventions for their child as soon as possible in order to secure the best outcomes (Gentles et al., 2019). Studies (e.g., Hoogsteen & Woodgate, 2013; Sarrett, 2015) report that parents of children on the autism spectrum often note the additional time expended in advocating for services, attending appointments and completing therapy work at home. This temporal dimension can act as a source of considerable guilt. Some parents report beliefs that they are neglecting their other children, while simultaneously depicting themselves as not dedicating enough time to their child on the autism spectrum (e.g., Kuhlthau et al., 2014). Involvement with therapies and professionals may also impact financially on a family. Families in Ireland have been found to spend a mean figure of

€9,489.60 per year to address their child's autism-specific needs (Roddy & O'Neill, 2019), with many incurring debt in the process (Roddy & O'Neill, 2020).

The life-long nature of autism may also contribute to a different parent trajectory than when parenting a typically developing child. Parents of typically developing children often regain some personal time when their child turns nine years of age, as children of this age have usually developed basic independent skills, (e.g., dressing themselves), can assist with simple chores, and engage in leisure time with less adult assistance and supervision (Mayall, 2002). Conversely parents of children with developmental disabilities, including autism, can have less personal time at this age, as gaps between children and their typically developing peers widen, friendships are harder to maintain, and parents play an enhanced role in occupying their child's free time (Ytterhus et al., 2008). For some families, additional demands on a parent's time and energy may be life-long, as they may remain the primary care-giver for their adult-child (Piven & Rabins, 2011). Such parenting experiences may be associated with high levels of caregiver burden and reduced quality of life (Marsack-Topolewski & Church, 2019).

The large volume of research focused on the challenges associated with having a child on the autism spectrum indicates the intensity with which these difficulties can be experienced and subsequently voiced. However, changing attitudes to disability and the rise in influence of the Positive Psychology movement have helped to increase interest in the positive aspects of parenting (Meleady, Clyne, et al., 2020). The limited research available has found that some parents of children with developmental disabilities, including autism, report increased resilience, healthier perspectives toward life priorities, stronger relationships and also in some cases increased spirituality, as a result of having a child with a disability (Beighton & Wills, 2017). Figure 2.1 shows an overview of the reported rewards and challenges associated with parenting a child on the autism spectrum. When

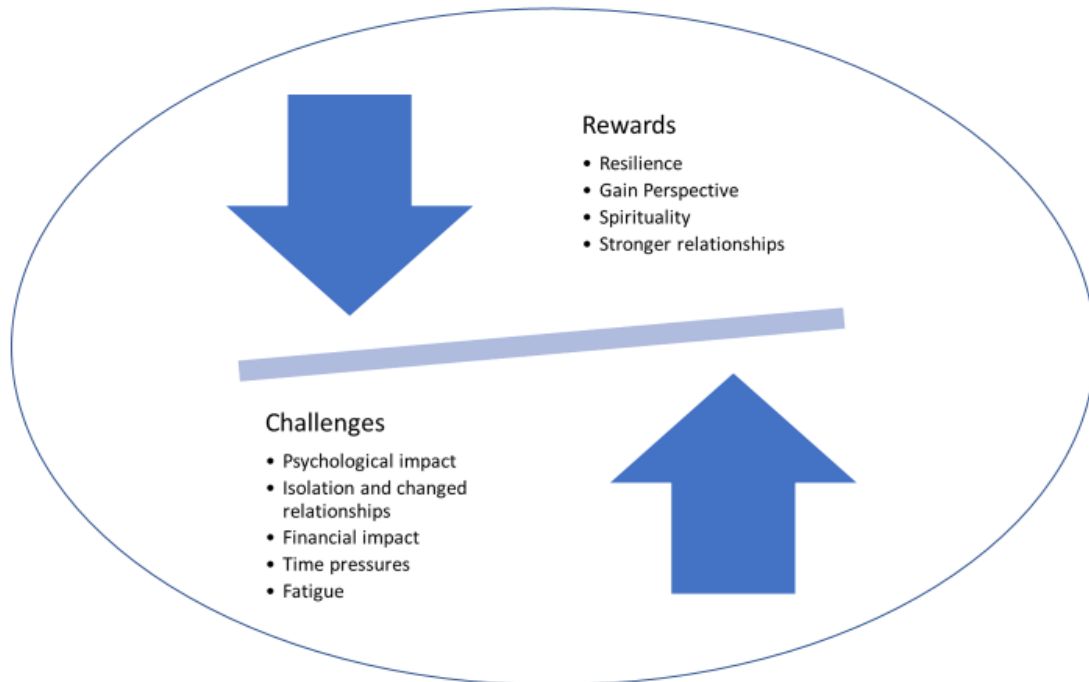


Figure 2.1 Graphic depicting the dynamic personal circumstances in which parents may be engaging with therapies and therapists.

contrasted with the large number, and range, of negative consequences of having a child on the autism spectrum discussed in the literature, the potential for a rewarding parenting experience may appear slim. However, it should be noted that studies of the positive aspects of parenting are in their infancy. For example, a systematic review by Meleady, Clyne et al. (2020) of the positive consequences of having a child on the autism spectrum included just 26 studies, with 75% of these published only in the previous ten years, despite there being no date restrictions included. Furthermore, many researchers (e.g., Lim & Chong, 2017; Meleady, Clyne, et al., 2020) have begun to acknowledge that parenting a child on the autism spectrum is not a binary experience and is best understood as simultaneously challenging and rewarding. It also appears reasonable to assume that like any experience that occurs over many years, a parent's experience may be dynamic. Nevertheless, an awareness of the potential challenges that parents may be experiencing

is pertinent to understanding the context in which many may engage with services and attempt to adopt a role in intervention.

2.5 A Specific Focus on Mothers

As it stands, much of the existing literature relating to “parenting” and autism stems from data dominated by female participants (Kingston, 2007). While understanding the ‘parent’ experience is helpful when considering mothers of children on the autism spectrum, a number of researchers (e.g., Rafferty et al., 2020; Rios et al., 2020) have begun to specify their research focus to that of either mothers or fathers, rather than parents in general. This likely reflects an understanding that despite social and political shifts in developed countries, the social construct of the role of a mother remains considerably different to that of a father (Blum, 2007). Ciciolla and Luthar (2019, p. 468) found that mothers of typically developing children feel compelled to adopt the role of “captain of the ship,” acting as both managers to the home and family life, even while in full time paid employment. Indeed, preliminary evidence suggests that some differences exist in maternal and paternal experiences of parenting children on the autism spectrum. A systematic review (Vasilopoulou & Nisbet, 2016) of quality of life in parents of children on the autism spectrum found mothers demonstrated significantly lower quality of life scores than fathers. Mothers of children on the autism spectrum have been found to experience higher rates of stress and depression than fathers (Dabrowska & Pisula, 2010; Foody et al., 2015). Researchers (e.g., Vasilopoulou & Nisbet, 2016) often point to mothers being the primary carer when hypothesizing the causes for these differences in quality of life and mental health measures. However, some authors (e.g., Ang & Loh, 2019) have begun to question if societal beliefs and expectations may also be influential.

Feminist scholars (e.g., Blum, 2007) contend that the role of mother is held as a binary social construct, with mothers categorized as either “good” or “bad” (DeGroot & Vik,

2019). Blum (2007) suggests that women remain both controlled by societal beliefs and police themselves out of fear of being judged as a 'bad' mother. 'Good' mothers are defined by their selflessness and sacrifices (DeGroot & Vik, 2019) and informed by societal beliefs that the "measure of a mother is her child," (Carpenter & Austin, 2007, p. 660). This may be a factor in why mothers, more than fathers, act as the primary carer to children on the autism spectrum and often report reluctantly leaving the workforce to do so, citing feelings of maternal obligation (Ang & Loh, 2019). The emphasis on selflessness in motherhood has also been proposed to explain the intensified workload (Blum, 2007) that many mothers of children with disabilities engage in. This intensified workload involves, for example, the completion of home therapies, ongoing research of new treatment approaches, and regularly engaging in advocacy. Kingston (2007) notes that mothers of children with disabilities often prioritize this intensified work over meeting their own needs and report feeling a maternal duty to conduct this work independently despite having supportive partners. You and McGraw (2011) argue that societal and internal pressures to be a 'good' mother contribute to the feelings of failure and self-blame reported among mothers of children on the autism spectrum, who sometimes depict themselves as not selfless enough, not hard working enough, and not sufficiently nurturing. Thus, while the literature relating to the impact of gender on the experience of parenting a child on the autism spectrum currently encompasses a relatively small body of work, it provides a preliminary evidence base which may illuminate different dimensions of the lived experiences of mothers of children on the autism spectrum.

2.6 Understanding Overall Parental Experiences

A number of factors beyond gender may also influence mothers' experiences of parenting a child with a disability (Meleady, Nearchou, et al., 2020). These include factors specific to the child, the parents and the environment. Reports of high parental burden have been

consistently associated with parental reliance on passive-avoidance coping mechanisms (e.g., Yu et al., 2018). Additionally numerous studies (e.g., Meleady, Nearchou, et al., 2020) suggest that the presence of challenging behaviours may negatively impact on parents' and the family unit's quality of life. However, parental optimism (Ekas et al., 2010), parenting efficacy (Wong et al., 2020), and parental perceptions regarding levels of social support (Drogomyretska et al., 2020) have been found to be predictive of positive outcomes for parents of children on the autism spectrum, using measures of depression and stress. Additionally, maternal wellbeing has been found to relate to service factors, including continuity of service provision and number of professionals involved (Hodgetts et al., 2013). However, many researchers (e.g., Meleady, Nearchou, et al., 2020) increasingly espouse multifactorial models of family adaptation in a disability context. For example, Meleady, Nearchou et al. argued for the application of a modified form of McCubbin and Patterson's (1983) double ABCX model to explain family experiences in the context of autism. Their modified model, shown in Figure 2.2 below, proposes that no single factor can predict outcomes such as quality of life and satisfaction with life, and instead these outcomes likely stem from the interaction of a number of variables whose values change over time, including support, perceptions and evaluations of autism and coping strategies,

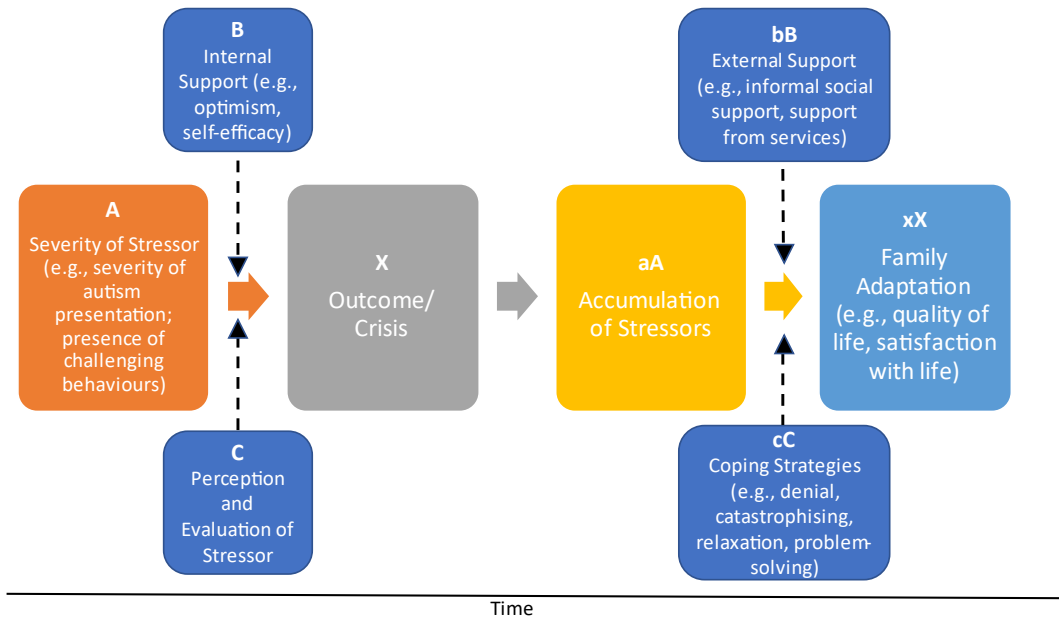


Figure 2.2 Graphic depicting Meleady, Nearchou et al. (2020)'s adapted Double ABCx Model

2.7 Therapeutic Service Provision for Children on the Autism Spectrum in Ireland

Multifactorial models, such as the double ABCx model (McCubbin & Patterson, 1983), that are designed to predict and explain family adaptation, often include access to formal social support, like therapy services, as an influential factor. Currently in Ireland public services for children on the autism spectrum are either provided directly by different agencies within the state-funded Health Service Executive ([HSE](#)) or by voluntary bodies who are funded primarily by the [HSE](#) (HSE, 2020). Services typically vary geographically in terms of service provider, whether the service is autism-specific, disability-specific or universal, and whether the service is for a particular age range or for across the lifespan. Often children with less significant needs are seen in Primary Care which offers uni-disciplinary service provision. Children in autism-specific or disability-specific services more typically have access to a team of professionals but the range of professionals on these teams and the

model of team-working differs from service to service. At an inter-agency level, there are often no transfer agreements in place, resulting in some children being discharged from one service and placed on a lengthy waiting list for an initial assessment with another service (HSE, 2018). Considerable variability can exist in how services manage waiting lists and determine prioritisation, as well as in staffing and resource levels.

The Irish government is bound by Irish and European law to protect the rights of children and the right of its citizens to healthcare (OCO, 2020). Yet a 2020 report by the Office of the Ombudsman for Children in Ireland found that many children wait periods of one to three years before being offered diagnostic assessments. This delay in diagnostic assessments is significant when many therapy services in Ireland remain diagnosis driven, meaning that without a diagnosis a child cannot be referred to the service and will not be eligible for referral to a special class or school. Indeed, even when a child's case has been opened by a service, many families experience long waiting times between therapy episodes resulting in unmet needs. An Irish study by Roddy and O'Neil (2020) of 195 parents of 222 children on the autism spectrum in Ireland found high levels of parent reported unmet therapy needs for their children. More than half of the children included were reported to be on waiting lists for further therapy from current service providers, while 61% of the children had identified needs in a particular area but no eligible service available to meet these needs. In relation to [SLT](#), 88% of children aged 2–4 years had unmet needs, reducing to 57% for children aged 5–12, and 48% for those aged 13 – 18 years.

In recognition of the problems inherent in how disability services in Ireland are organized and delivered, the Irish government introduced the programme for “Progressing Disability Services ([PDS](#)) for Children and Young People,” in 2010 (HSE, 2012). The programme aims to reconfigure service provision in Ireland, by disbanding existing

services that historically provided therapies to children with a specific diagnosis only, such as autism or learning disabilities. Children with less severe needs will be seen in Primary Care services, while those with more complex needs will access services from local teams called Children's Disability Network Teams that operate in an interdisciplinary manner (HSE, 2020). The aim of this reconfiguration is to provide services nationally that are more equitable and offer clearer pathways of care (HSE, 2020). Services that are reconfigured will adopt family-centred models of care and practices which the [HSE](#) (2020, p. 10) advises will represent a "seismic shift" particularly in relation to decision-making practices for professionals and families. The roll out of [PDS](#) has been slow. Although it commenced in 2010, many areas of the country remain at the planning stage of development (see Figure 2.2 below). It appears reasonable to assume that knowledge of this pending reconfiguration of services may add to families' feelings of uncertainty as they may be aware that the professionals, teams and service that they are currently utilising will ultimately change entirely once this reconfiguration is complete.

One of the stated aims of [PDS](#) is to support children to reach their full potential, while another aim is to utilise resources more effectively (HSE, 2020). Roddy and O'Neil (2020) note that in settings with insufficient funding, interventions that take the form of parent trainings, designed to teach parents strategies to improve children's communication, behaviour, social interaction and daily living skills are increasingly popular. Roddy and O'Neil (2020, p. 323) caution that, in the absence of investment into greater access to health, education and social supports for families with children on the autism spectrum, an over-reliance on such an approach "could be construed as simply deflecting responsibility from the State and toward parents who are already carrying a significant burden of a both financial and non-financial nature." Roddy and O'Neil also highlight that a lack of meaningful investment into children's disability services is short-sighted and fails to

recognise the financial and social benefits to society, as well as the potential personal gains for individual households associated with providing adequate health, educational and social supports to children at a younger age. However, it remains to be seen how the aspirations of [PDS](#) will translate into practice. Those involved in its roll out undoubtedly hope that [PDS](#) will lead to improvements in the lives of people with disabilities and their families. However, pertinent to this study, questions remain as to what type and level of parental involvement [PDS](#) will invite, expect or perhaps demand in practice and what this potential shift in role will mean for parents and families.

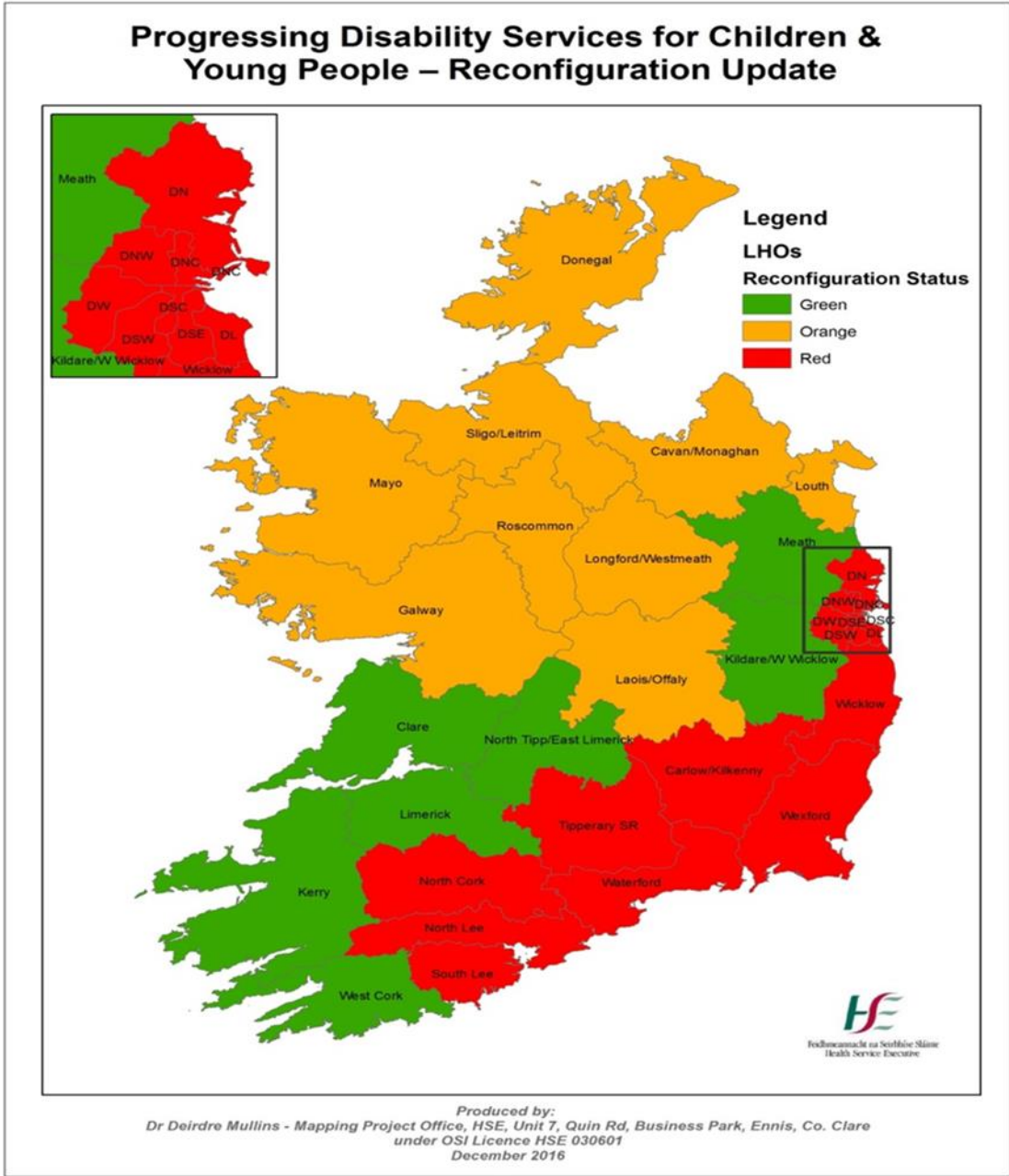


Figure 2.3 Image taken from a [HSE](#) document (HSE, 2020, p 12) showing the various stages of [PDS](#) roll-out in February 2020. Green represents the parts of Ireland with full teams in place. Orange shows areas with only Early Intervention Teams in operation. Red shows areas with no teams currently configured into [PDS](#) structures.

2.8 Reflective and Reflexive Commentary

Researching terminology in relation to autism contributed to some challenging internal debates about how I perceived autism. I wondered what my initial reactions to the

literature said about me as a person and a clinician. While I agreed with the argument that the community involved should choose the language used to describe them, I found even reading the word “autistic” uncomfortable. I had spent years being trained about the importance of person first language. I struggled with the idea of using alternative terminology. The irony of this struggle wasn’t lost on me. Prior to the PhD, while I used person-first language, I also paradoxically dismissed language as being of limited power. Pre-PhD me viewed language as a tool. Peri-PhD me, having spent months analysing participants’ vocabulary, pronouns, and use of metaphors and similes, saw language differently. Language both reflected and forged realities. If I labelled someone as autistic, was I not signalling to the world that I defined them by their diagnosis? I understood the arguments against the term ASD but considered how readily I had used this term as a clinician. I reflected on my understandings of autism. Did I see autism as difference or disorder? If it was a difference, as I claimed, then what business did I have in being a therapist? Surely being a therapist signalled to the world that I thought autism was something requiring “treatment.” Eventually, by comparing my work in autism to my work with clients who stammer, I was able to reconcile my identity as a therapist. I was very confident of my stance that stammering was a difference, but that many people who stammer benefit from [SLT](#) focused on their participation in life. When I did therapy with clients who had a stammer, I was never trying to “fix” their stammer but I was doing therapy. I considered that the same position could apply to my work with children on the autism spectrum. I recognised their autism as difference, but also perceived therapy targeting enhanced participation in life as beneficial and aligned with such a stance.

2.9 Summary

This chapter provided an introduction to autism and the terminology relating to autism used in the thesis. The available literature relating to parenting and autism was then

discussed. Much of this literature is based on research primarily involving mothers. Indeed, some authors (e.g., Ang & Loh, 2019) propose that there is a gender-specific socio-political dimension to the experiences of mothers of children with developmental disabilities. Literature regarding the experience of parenting a child on the autism spectrum suggests that it can be both unique and shared, while also dynamic, involving both challenges and joy. The context of service provision in Ireland is also complex and dynamic. While service provision is provided free of charge, it can involve long waiting times and gaps in services. In an effort to improve service provision, the Irish government has begun a phased programme of reconfiguration of disability services, giving rise to considerable change, and arguably uncertainty for families accessing services. This is the context in which parents in Ireland are engaged in [SLT](#). The next chapter discusses literature pertaining to parental involvement in [SLT](#) and theories relating to both roles in general and client involvement in healthcare.

Chapter 3: Understanding Roles in a Healthcare Context

3.1 Introduction

This chapter introduces the reader to literature relating to roles and sense-making of roles in healthcare. The chapter is divided into four parts.

- Part one seeks to orient the reader to the topic of roles. It briefly introduces Role Theory and definitions of roles, before presenting a review of literature regarding parents' and therapists' perceptions of therapy roles.
- Part two focuses on familiarizing the reader to sense-making in the context of roles. It discusses different schools of Role Theory and how they approach role learning or construction. Literature regarding the field of Health Behaviours and factors considered influential to client behaviour in healthcare are then discussed.
- Part three aims to justify the study through a discussion of the topics of engagement and disengagement, and the potential relevance a better understanding of roles may make to this topic.
- The chapter concludes with a reflective and reflexive commentary.

PART ONE- THE CONCEPT OF ROLES

3.2 Definition of Roles

This thesis is concerned with roles, which are the primary focus of Role Theory. Role Theory is a field of academic interest broadly concerned with “patterns of human conduct” associated with roles (Biddle, 1979, p. ix). Role theorists are often interested in how roles develop or change. Historically, role theorists have been associated with a wide range of

academic backgrounds, including social psychology, anthropology and sociology, and espoused different philosophical leanings. This has contributed to differing conceptualisations and definitions of roles. One point of consensus among role theorists is that at a minimum the concept of a role refers to a cluster of behaviours that are characteristic of a set of persons or positions associated with a specific context (Biddle, 1979). However, some role theorists, such as Turner (2001) utilize a definition of roles that includes attitudes in addition to behaviours. A focus solely on behaviours may be useful in differentiating some occupational roles such as a teacher versus a mechanic, but its usefulness when applied to roles such as mother or hero has been questioned by authors such as Turner (2001). If the role of a mother of a young baby is exclusively defined in terms of the child-care tasks that the mother performs, then how can the role of mother be differentiated from that of a nanny? Furthermore, in some cases characteristic attitudes may be the only unifying feature of a role. For example, authors such as Hage and Powers (1992) note that women playing the role of mother may share attitudes and feelings such as unconditional love, but may demonstrate alternative sets of behavioural repertoires from one another. For the purposes of this study, I have adopted Turner's (2001, p. 234) conceptualization of roles as "a comprehensive pattern for behaviour and attitude that is linked to an identity, is socially identified more or less clearly as an entity, and is subject to being played recognizably by different individuals."

3.3 The Role of Parents in SLT- Frequently Celebrated but Less Often Defined

Given the debate between role theorists regarding how to define a role, inconsistency in approaches to defining the parent role in [SLT](#) may be understandable. Yet the available literature suggests that the parent role in [SLT](#) is more often celebrated than explored or defined in detail. Parental involvement in [SLT](#) is recommended by professional bodies

(e.g., Royal College of Speech and Language Therapists, 2009), and service providers (Health Service Executive, 2018) alike. It is argued to be essential in the provision of services to individuals who have lifelong diagnoses such as autism, and whose families represent a constant support in a context of changing service providers and professionals (Smith, Swallow, & Coyne, 2015). It is suggested to contribute to more meaningful outcomes for families (Espe-Sherwindt, 2008), to increase the efficiency and cost-effectiveness of therapy (e.g., Burrell & Borrego, 2012) and to facilitate the generalization of skills learned to natural environments (Steiner et al. 2012). Yet, few studies have attempted an in-depth exploration of how parents and other stakeholders perceive the parent role. When addressed in research, the parent role in intervention is more commonly included as part of descriptive studies of parents' general experiences of parenting children with disabilities (e.g., Kingston, 2007) or working with particular disciplines (e.g., Edwards, Brebner, McCormack, & MacDougall, 2016). However, interest in this topic has increased in recent years, particularly in studies of parent engagement (e.g., Melvin et al., 2019). The literature relating to what roles are expected of and enacted by parents in [SLT](#) broadly encompasses two categories:

- 1) Models of Parent-Professional Working Relationships
- 2) Different Stakeholder Perspectives on the Parent Role

3.4 Models of Parent-Professional Working Relationships

Watts-Pappas et al. (2009) note that the profession of [SLT](#) is associated with three models of parent – professional working relationships. These models are largely focused on behaviours relating to planning and implementing therapy, as well as decision-making. The three models are discussed below.

3.4.1 Therapist-Centred Models of Parent – Professional Working Relationships

Historically healthcare has been dominated by the medical model of disease or disorder. A central philosophy of the medical model relates to a conceptualisation of disease or disorder as a purely biological impairment (World Health Organization, 2002). Under the medical model, the function of intervention is to reduce or remove impairment. This is considered dependent on the diagnostic and intervention skills of expert professionals (Kaba & Sooriakumaran, 2007). The model is associated with promoting an expert-led approach to working with clients (Swaine, 2011). In the context of therapeutic professions, such as [SLT](#), this type of model is known as a Therapist-Centred Model. As the skilled expert, the professional holds the ultimate responsibility for decision-making, planning and implementing therapy (Watts-Pappas et al., 2009). Owing to its connections to the medical model, which assumes impairment to reside within the patient alone, the Therapist-Centred Model considers the child, and not the family, to be both the client and target of intervention (Barnes & Mercer, 2010). The child as the “client” is expected to faithfully follow the expert professional’s recommendations (Parsons, 1991). The parent’s role in this model of working primarily involves bringing the child to appointments and answering the professional’s questions during assessments (Watts-Pappas et al., 2009).

Expert led approaches, such as the Therapist- Centred Model may be favoured by some professionals concerned with their ethical responsibility to do no harm (Kaba & Sooriakumaran, 2007). Some professionals may assume that they have a greater understanding of disorders, treatments and prognosis than the family, and are thus better placed to make decisions, and to plan and implement intervention. It is also plausible that the Therapist-Centred Model may be attractive to some parents who have greater confidence in the skills of ‘experts than in their own abilities to help their children. However, this is also a source of criticism for the model, as it is argued that this form of working does little to empower parents, and instead promotes dependence on

professionals (Watts-Pappas et al., 2009). The model is criticised for ignoring the unique expertise of parents, who hold detailed knowledge and experience of their specific child (Hanna & Rodger, 2002). Furthermore, many authors (e.g., Gibbard, 1998) argue that the meaningful impact of therapy is restricted greatly when parents are not involved, and professionals work in isolation.

3.4.2 Parent as Therapist - Aide Models of Parent – Professional Working Relationships

The 1960's onwards saw the rise of the disability rights movement. A key focus of this movement related to the right to autonomy for people with disabilities. The social model of disability emerged from this movement. It asserts that disability is a social construct and interventions should focus on the removal of structural and attitudinal barriers in the environments of people with disabilities (Howson, 2021). This broadening discourse surrounding disability interventions and autonomy provided the background context from which many parent advocacy groups emerged in Western countries in the 1970s and 1980s. These groups sought increased involvement in their children's intervention (Watts-Pappas et al., 2009). In countries such as the United States of America (USA), these groups successfully lobbied for legislative change, contributing to new models of working between therapists and families (Hanna & Rodger, 2002).

The Parent as Therapist-Aide Model emerged from this context (Watts-Pappas et al., 2009). In this model, therapists consult with parents to plan intervention and make decisions, but the therapist is the primary decision maker (Watts-Pappas et al., 2009). The child remains the client and focus of intervention, rather than the family (Watts-Pappas et al., 2009). Parents are involved in the implementation of therapy under the direction of the therapist (Watts-Pappas et al., 2009). For example, parents may complete prescribed therapy exercises as instructed by therapists. Involving parents in the

implementation of therapy at home has been argued to offer a potentially cost-saving means to increase treatment intensity (Dodd & Barker, 1990), while also potentially targeting the generalisation of skills to the child's natural environment (Burrell & Borrego, 2012). Yet, Hanna and Rodger (2002) note that parental involvement in implementation, in the absence of their inclusion in planning and decision-making, carries some risk. They argue that capacity among parents varies. Directing parents to implement therapy at home may overburden some parents and increase their stress (Hanna & Rodger, 2002). Parents who cannot take this implementation role may be labelled as "non-compliant" (Hanna & Rodger, 2002, p. 15), potentially straining the therapeutic relationship. While the model offers greater opportunities for parental involvement than the Therapist-Centred Model, it still represents a power imbalance with the therapist retaining ultimate decision-making power. Indeed, authors such as Turnbull, Turbiville and Turnbull (2000) note that not all parents want to be involved in the implementation of therapy. The model offers little scope to address the preferences of such parents.

3.4.3 Family-Centred Models of Parent – Professional Working Relationships

In the 1990s, the continued advocacy of disability rights groups and parent groups contributed to further legislative changes in the USA, as well as policy changes in countries such as the United Kingdom (Watts-Pappas et al., 2009). These changes reconceptualised 'the client' as the family unit, rather than the child alone (Hanna & Rodger, 2002) and called for increased parental involvement in decision-making in therapy. During this period, the Family-Centred Model of service provision became increasingly recommended by researchers and by policy makers (Watts-Pappas et al., 2009). The Family-Centred Model represents a philosophy of general service provision, with much emphasis placed on the relationship between therapists and parents. This model is focused on the needs of the family as a whole and takes a position that parents are experts on their child and thus should have ultimate decision-making powers. This

model promotes service provision that is flexible and individualised to each family (Watts-Pappas et al., 2009). It is strongly influenced by Bronfenbrenner's (1979), Human Ecological Theory, which stresses the influences of a child's various environments (e.g., home, school, wider society) on a child's development. The Family-Centred Model draws from this theory, taking the position that changes to the environment will affect the child, and thus changes to other family members' skills or well-being, etc., will impact on the child (Watts-Pappas et al., 2009).

Under this model, parents, not professionals, are the primary decision-makers. The [SLT](#) is responsible for supporting parents in decision making by consulting with them and providing information (Watts-Pappas et al., 2009). Parents' decisions, when within the bounds of law and ethical codes of practice, are ultimately final and should be accepted by professionals, regardless of whether the professionals agree with them or not (Hanna & Rodger, 2002). This includes parental decision-making regarding how much involvement (if any) they wish to have in their child's intervention (Watts-Pappas et al., 2009). The model emphasises the importance of empowering parents and enhancing their competencies through a strengths focused approach (Hanna & Rodger, 2002). This often translates into interventions involving parent coaching. The model is celebrated for recognizing the expertise of parents and promoting interventions designed to bring meaningful improvement to the lives of families (Espe-Sherwindt, 2008). The model is not without criticism. Some authors (e.g., Allen & Hudd, 1987) question the ethics of professionals' delivering services in the manner that a family may prefer but professionals consider inappropriate. Furthermore, it appears reasonable to question how readily the model can be applied to resource-constrained services which may struggle to offer all the different types of interventions that families may favour, particularly those involving high intensity treatment dosages. Yet many services claim to provide care using the Family-

Centred Model, suggesting that services value this model.

3.4.4 Summary of Models of Parent – Professional Working Relationships

The three models discussed above emerged sequentially reflecting broadening discourses about disability and wider socio-political shifts, particularly with regard to autonomy. The parent roles in these models are depicted exclusively in terms of behaviours and are often considered to operate along a continuum of “passive” to “active” parent roles (e.g., Smith & Samuels, 2021). Figure 3.1 below shows an overview of the models. The models are informative about the different parent roles presented at a philosophical and theoretical level. The next section attempts to explore roles at a more applied level, by discussing literature regarding how parents, therapists and services perceive the parent role.

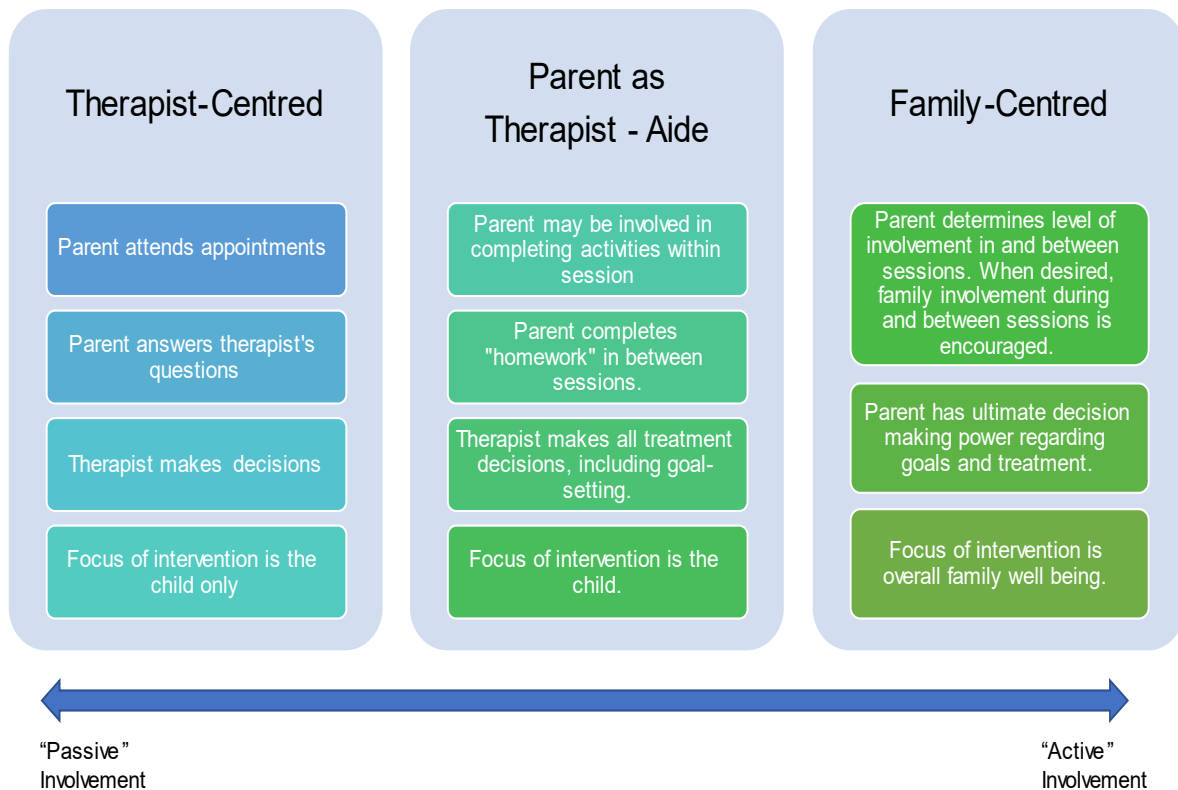


Figure 3.1 My understandings of the different models of parent - professional working relationships.

3.5 Parents' Perceptions of the Parent Role in SLT

The literature relating to parents' perceptions of their role in [SLT](#) is small but growing. There is some preliminary evidence (e.g., Davies et al., 2017) that small numbers of parents understand their role primarily in terms of attendance at therapy sessions only. However, most of the literature available (e.g., Piggot et al., 2003) suggests that most parents share a conceptualisation of their role that broadly aligns with the Parent as Therapist-Aide Model. Many parents expect the [SLT](#) to act as an expert and teacher and describe the parent role primarily in terms of the completion of prescribed exercises and homework (e.g., Watts-Pappas et al., 2016). A small number of studies (e.g., Phoenix et al., 2019) have found that parents expect to be involved in therapy activities within sessions, under the direction of therapists. However, most studies (e.g., Skeat & Roddam, 2019) suggest that parents expect their involvement within sessions to involve learning by observing therapists, being shown new approaches and activities and given direction on what to do with their child. Further tentative evidence of an understanding of roles that aligns with the Parent as Therapist-Aide Model may be derived from studies (e.g., Baxendale et al., 2001) that suggest that parents commonly understand therapy in terms of direct intervention, where a therapist works face to face with a child using therapy exercises and activities. This traditional understanding of intervention perhaps hints at an expectation that therapy will primarily involve an 'expert' therapist directing therapy, and that parental involvement within sessions relates to a secondary, non-leading role.

The Parent as Therapist-Aide Model involves therapists having primary decision-making power. The literature regarding parental expectations and preferences for involvement in decision-making less conclusively aligns with the Parent as Therapist-Aide Model. Some studies (e.g., Glogowska & Campbell, 2000) suggest that many parents expect the [SLT](#) to direct decision-making about when a child requires intervention and can be discharged, and how best to intervene. However other studies (e.g., Reeder & Morris,

2020) have found that parents desire greater input, and a shared approach to decision-making. It seems plausible that different parents have different preferences and expectations regarding their role in decision-making. For example, an online survey study of 100 parents of children with communication difficulties found that, in relation to involvement in goal-setting, 38% were satisfied, 25% were dissatisfied and 37% reported being content but interested in also being more involved (Roulstone et al., 2016). Furthermore some authors (e.g., Reeder & Morris, 2020) contend that the role taken by parents in decision-making is changeable and influenced by parent, therapist and parent-therapist relationship factors.

Indeed, there is some evidence to suggest that parents' role conceptions can shift, and some parents may develop conceptualisations which include taking a lead role in implementing and planning therapy. A study by Davies et al. (2017) analysed interview data from 14 parents of preschool children with [SLT](#) needs who were receiving indirect intervention. Indirect intervention involves the therapist only working with adults familiar to the child, such as the parent. It often involves parent training or coaching and is widely used in [SLT](#) (Pring et al., 2012). A subset of the parents in Davies et al.'s study identified as an "intervenor" (2017, p. 181). This role involved engaging in learning during therapy, and integrating this learning into practice at home independently, rather than with direction from the therapist. However not all parents in this study demonstrated a shift in role conceptualisation. James (2011) proposes that a number of different factors including therapists' skills and practices in fostering collaborative partnerships may explain why some parents experience a shift but others do not. Skeat and Roddam (2019) queried if there may be also be a ceiling effect, related to practical barriers in parents' personal circumstances, that inhibits their capacity to adopt roles like the "intervenor".

One role not found in the literature relating to models of working relationships, but discussed frequently in the empirical research relates to advocacy. A number of studies

focused specifically on [SLT](#) (e.g., McAllister et al., 2011) but also on autism and other developmental disabilities (e.g., Ryan & Quinlan, 2018) have shown that parents routinely adopt the role of advocate and have a concrete understanding of this role (Davies et al., 2017). The behaviours associated with this role commonly include researching services, seeking referrals, attempting to access more services from a current provider, and highlighting concerns about the child (Boshoff et al., 2016). Some studies also include communicating with professionals frequently and coordinating communication between services, when describing parents' experiences of advocacy (Sugden et al., 2019). Sometimes the role of advocate may extend into activism, involving organised, collective action on behalf of a community of parents and children (Ryan & Cole, 2009). Many of the studies regarding advocacy report on a subset of participants who describe advocating forcefully, and who use language including "fight" (Woodgate et al., 2008), "battle" (Ryan & Cole, 2009), and becoming "pushy," (Goldbart & Marshall, 2004) to describe their advocacy. Such participants tend to report feeling compelled to take this approach, believing it to be the only way to secure the services needed by their child (Ryan & Quinlan, 2018).

When considered together, the limited literature available provides a preliminary base to understand how parents may perceive the behaviours associated with their role in [SLT](#). Little is reported regarding parental perceptions of the attitudinal components of their role. The available evidence suggests that many parents have firm understandings of their role as advocates, while also holding concrete but relatively traditional ideas of having a role in therapy that largely aligns with the Parent as Therapist-Aide model. Nonetheless many parents appear to experience uncertainty and differing preferences, particularly about their role during sessions and in decision-making (see Figure 3.2). Thus the available literature suggests that parents' role conceptions do not neatly correspond with

those depicted in the models of working relationships, highlighting the need to better understand parents' roles and the factors that influence them.

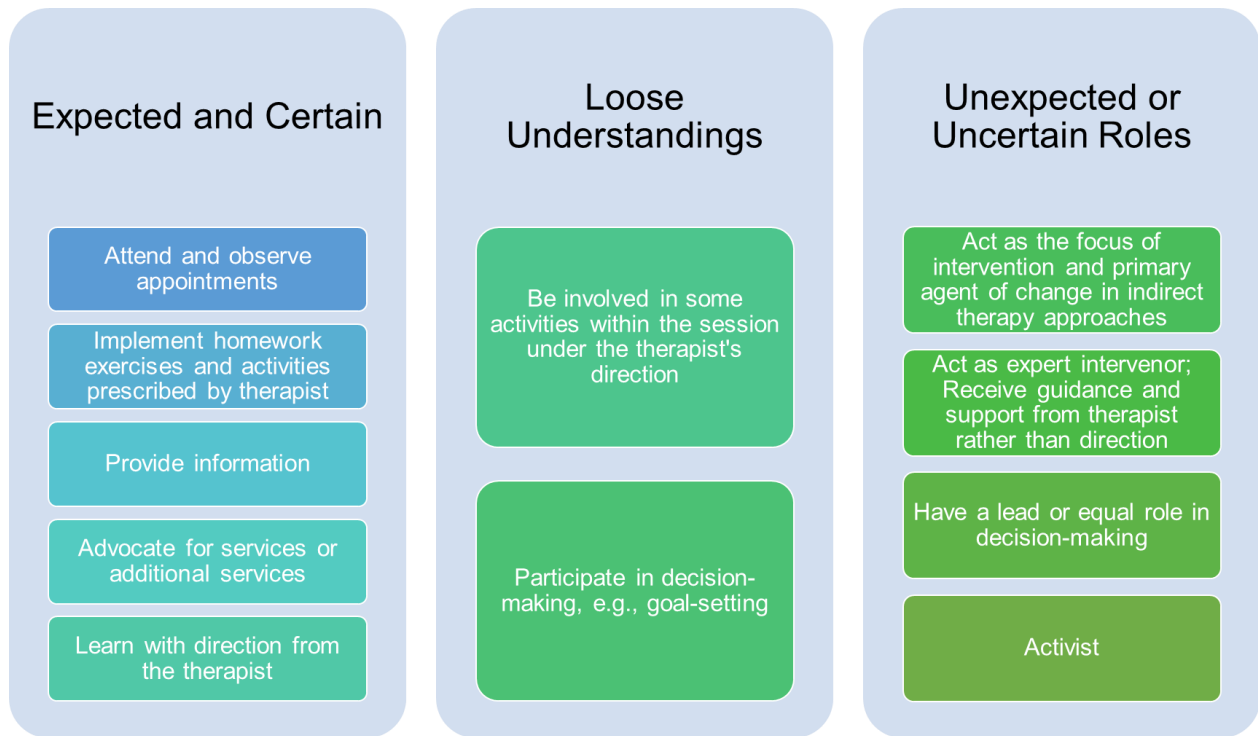


Figure 3.2 Overview of parental role expectations as suggested in the literature

3.6 Therapists' Perceptions of the Parent Role in SLT

It appears reasonable that as parents report feeling confused and uncertain about their role prior to entering intervention (Davies et al., 2017), they may look to therapists when seeking to define roles. Similar to the parent-based literature, much of the literature relating to therapists' perceptions and experiences of parent roles pertains to decision-making, attendance, and behaviours within and in between therapy sessions. However, my search of the literature revealed one parent role discussed by therapists but not parents. This role relates to recognizing and celebrating positive gains. Melvin, Meyer and

Scarinci (2020) found that [SLTs](#) valued the importance of parental involvement in noticing and celebrating progress, in maintaining motivation and gaining confidence. Indeed, therapists who draw from Solution-Focused Intervention approaches routinely employ coaching techniques that are designed to promote parents' recognition of incremental positive gains with a view to augmenting and maintaining motivation in therapy (Schwellnus et al., 2020). An unpublished doctoral thesis by Davies (2014) found that parents reported that observing progress in their child acted as a contributing factor in their adoption of more active roles in therapy. However, I found no other studies of parental perceptions of their role that discussed this type of involvement. It is possible that the absence of any discussion of this in parent-based studies may imply an understanding that noticing and celebrating gains is part of a more general parent role than a therapy-specific role. Alternatively, it may suggest that parents are not aware of the potential significance of this type of involvement or may feel less confident in it.

When considered in isolation, studies of therapists' practices point to a parent role akin to that described in the Parent as Therapist-Aide Model. Therapists largely depict parental involvement in terms of attending and observing appointments, doing prescribed homework activities and sometimes participating in therapy activities within sessions (Davies et al., 2019; Watts-Pappas et al., 2008). There is some evidence (Davies et al., 2019) that [SLTs](#) perceive parents to adopt a learner role that involves the parent learning to act as a technician, competent in applying a specific programme with ongoing direction from the therapist. Therapists' reported practices suggest that they frequently do not expect parents to adopt a lead role in decision-making. Some studies point to an understanding by therapists that parents' perspectives should inform decision making (Watts-Pappas et al., 2008), while others (e.g., McCurtin & Clifford, 2015) suggest that client preferences are seldom considered when making decisions. The findings relating to therapists' practices should suggest that parents' and therapists' views of the parent role

are relatively compatible, when compared to the literature regarding parents' perspectives described above. Yet preliminary evidence suggests that many therapists are not satisfied with the role adopted by parents in therapy (e.g., Watts-Pappas et al., 2008) and may evaluate a parent as being too involved or too little involved (Bezdek et al., 2010).

Some of this dissatisfaction among professionals may stem from a conflict between therapists' philosophies of intervention and their practices. Research suggests that professionals, including [SLTs](#), typically value family-centred philosophies of care, and view themselves as seeking to work in collaborative partnerships that empower parents (Bezdek et al., 2010; Watts-Pappas et al., 2008). Melvin, Meyer and Scarinci (2020) found that [SLTs](#) valued a parent role involving engagement in both decision-making and implementation, and an autonomous, empowered parent role characterized by parents understanding intervention, taking initiative and committing to bringing intervention strategies into home life. However, a number of studies (Bezdek et al., 2010; Smith et al., 2015; Watts-Pappas et al., 2008) have found that while professionals may align themselves with philosophies of intervention related to Family Centred models of care, this philosophy rarely translates consistently into practice. For example, Bezdek et al. (2010) found that more than 90% of those interviewed used language in their interviews that showed an awareness of the importance of collaborative working with parents. However, the authors noted that almost all of the same professionals described behaviours and actions in their clinical practice that were not well-matched with collaborative working (see Figure 3.3).

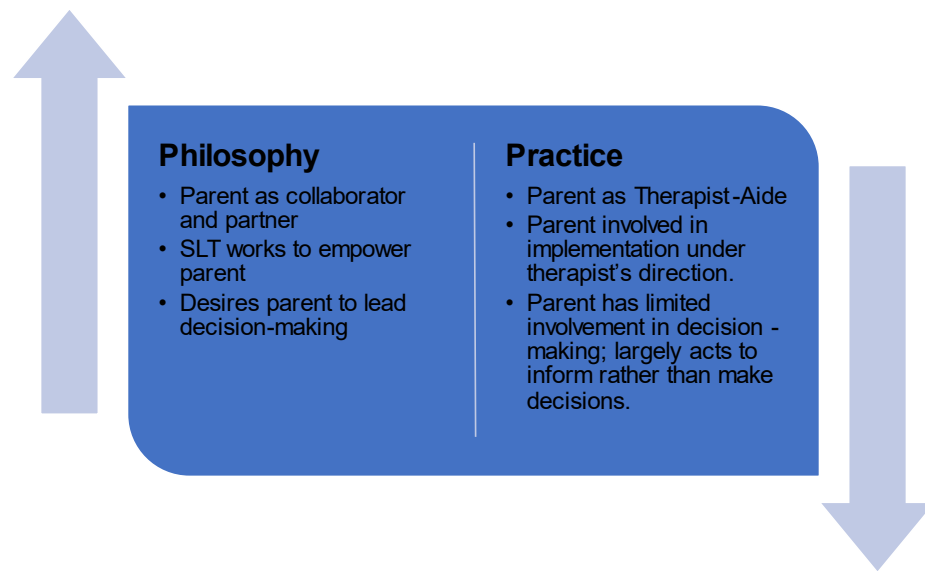


Figure 3.3 Graphic depicting the potential tension between the parent role promoted by therapists' practices and the parent role involved in therapists' espoused philosophies of intervention.

This mismatch between philosophy and practice may be intentional or unintentional (Klatte et al., 2020). If intentional, it may suggest a reluctance on the part of the professional to enter into a more collaborative partnership, perhaps due to concerns about professional identity and power (Davies et al., 2019), concerns about accountability and litigation (Reeder & Morris, 2020) or more pragmatic issues such as beliefs about time and organizational constraints (Klatte et al., 2020). If unintentional, it may suggest differing understandings of concepts such as collaboration and shared decision-making, or a lack of insight into the potential influences of therapists on the role adopted by parents (Klatte et al., 2020). Whether intentional or unintentional, this mismatch may complicate parental attempts to understand their role in therapy.

It is reasonable to assume, that not all therapists experience a mismatch between their practices and their philosophy. Indeed, there is evidence indicating that some

therapists engage in practices which promote parents to become more independent in implementing therapy or to lead decision-making. For example, Davies et al. (2019) describe a small subset of [SLTs](#) within their study who viewed parents as agents of change capable of working independently as intervenors. These therapists described adopting coaching-style approaches rather than directive approaches in intervention (Davies et al., 2019). Additionally, 38% of therapists studied by Watts-Pappas et al. (2008) reported that they facilitated parents in having ultimate decision-making power regarding therapy goals. However, I found no study in which the majority of therapists reported practices that reflected a view of parents as empowered collaborators working in equal partnership with therapists. These findings indicate that it is plausible that parents may encounter different therapists over time who each encourage different types of roles through their practices. For parents who are uncertain about their role, these varied experiences may create confusion about what role they understand therapists to expect from them.

Overall, the literature relating to therapists' perceptions of the parent role in [SLT](#) suggests that therapists' role conceptions can be complex and varied and sometimes paradoxical, which may potentially challenge parents in developing more concrete role conceptualizations.

3.7 The Parent Role Promoted by Service Organisations

Healthcare service organisations often take care to write mission statements outlining the principles underpinning service operations. These statements typically specify the model of working parent-professional relationship employed, or core values, such as shared decision-making, or person-centredness. As such, these statements illustrate that services can adopt differing positions regarding the parent role in therapies. These positions may influence how parents understand and experience their role. Indeed, in their seminal paper

on the changing role of patients with chronic disease, May et al. (2014) stress that changes to how service organisations perceive the patient role have contributed to changes in physicians' practices and the role assigned to patients. May et al. (2014) note that societal, scientific and economic shifts have contributed to changes in healthcare service provision. The authors state that with scientific advances, people are living longer and often with more complex healthcare needs. Consequently, more people attempt to access healthcare services and often require longer episodes of care. The authors also argue that political shifts have led to an increased emphasis on accountability and value for money in healthcare (May et al., 2014). They contend that healthcare activities have intensified as services "seek to do more work, with fewer people, in less time, at lower costs. In turn this leads to stricter patterns of corporate controls on practice for professionals and patients and thus reshapes the opportunity afforded to patients to engage with health services," (2014, p. 283). May et al. propose that in this changed healthcare landscape, the role of the patient has been "re-engineered" to absorb increased accountability. They suggest that increasingly organisations are structured to encourage clinicians to delegate work to clients and their families, often by relying heavily on client training and education. In theory, this delegation of work should also be accompanied by shared decision-making and the upskilling of clients so they have greater understanding of their disorder and treatment. Such an approach aims to empower clients and utilise resources more efficiently. Nonetheless, the responsibilities and volume of work involved in this new client role may be surprising and perhaps undesirable for some clients and create a difficult context in which to develop an understanding of roles.

While the work of May et al. (2014) relates to chronic disease, parallels may be drawn to service organisations working with children with disabilities. As discussed in Chapter two, paediatric disability services in Ireland are being re-configured under the [PDS](#) programme. [PDS](#) is being driven by factors similar to those that May et al. cite as the

driving forces behind changes to the care of patients with chronic disease. More cost-effective use of resources, the provision of “clear pathways,” and the movement of all services to a Family-Centred model of care (HSE, 2020, p. 3), are among the core aims of [PDS](#). It seems reasonable that just as in the case of chronic disease, [PDS](#) will involve attempts to standardise service delivery and pathways of care, emphasising therapy approaches that are both effective and cost-efficient. It is plausible that this drive for increased efficiency may lead to an increased reliance on parent-mediated therapy approaches, particularly those delivered through groups, and potentially reduce the availability of direct intervention. This shift may be challenging for many parents and therapists alike. The literature discussed above relating to stakeholder perspectives of therapy roles, suggests that many parents understand therapy as involving direct intervention and expect the therapist to lead decision-making, while many therapists currently deliver services in a manner similar to the Parent as Therapist-Aide Model. Thus, the role promoted by services, once reconfigured, may be distant from the role parents anticipate and therapists may also be unfamiliar and uncertain of their role and what they expect of parents. This suggests that [PDS](#) may further complicate parental attempts to navigate their role.

3.8 Summary of Literature Regarding Role Perceptions in Therapy

Literature relating to how parents perceive their role in [SLT](#) is relatively limited and almost entirely focused on the behaviours associated with the parent role, with attitudinal components rarely discussed. The behaviours discussed largely involve those within and between therapy sessions, and those related to decision-making and advocacy. There appears to be variability in how the parent role is understood by parents (Davies, Marshall, Brown, & Goldbart, 2017) and professionals (e.g., Davies, Marshall, Brown, & Goldbart,

2019). However, when considered together, the available literature suggests that many parents' understandings of their role align best with the Parent as Therapist-Aide Model. This may be problematic given that services appear to be promoting the Family-Centred Model, and the literature suggests many therapists hold complex, sometimes paradoxical conceptions of the parent role. The available literature points to a complex context in which parents attempt to construct and navigate roles (see Figure 3.4). Given this complexity, it appears important to gain a more detailed understanding of both how parents understand their role, as well as how they make sense of their role.

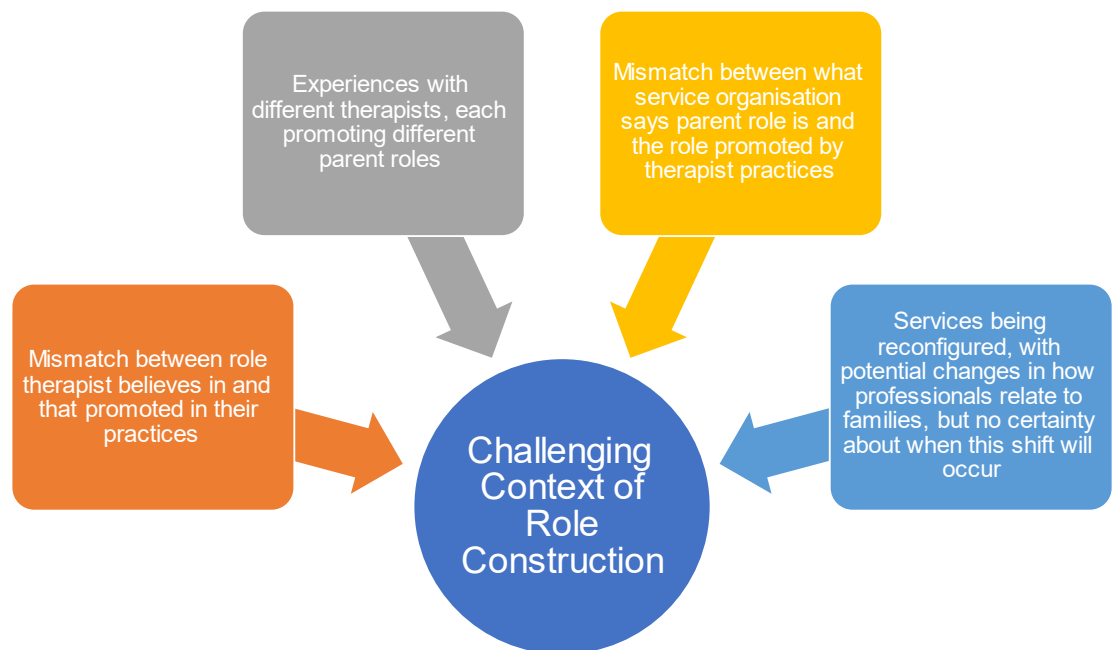


Figure 3.4 Graphic depicting the challenges parents may experience while attempting to construct their role.

PART TWO- SENSE-MAKING OF ROLES

The second research question driving this PhD regards how parents make sense of their roles in [SLT](#). My review of the literature relating to this question involves two strands: (i) how roles in general are constructed or learned from a Role Theory perspective; and (ii) roles in healthcare, and the factors that influence health behaviours.

3.9 Schools of Role Theory

There are two major schools of thought within Role Theory - Structural Role Theory and Interactional Role Theory (Turner, 2001). Both schools propose that most roles exist and develop out of pairs, for example, teacher – student; [SLT](#) – client (Turner, 2001). However, the schools differ with regard to their understanding as to whether roles are simply played or made (Biddle, 1979). Structural Role Theory emphasizes society, social structures and social systems as determinants of roles (Brookes et al., 2007), while Interactional Role Theory highlights the influence of individuals engaging in interactions within society as the driving force behind how roles are constructed (Turner, 2001). Figure 3.5 shows my interpretation of the major differences between these theoretical positions.

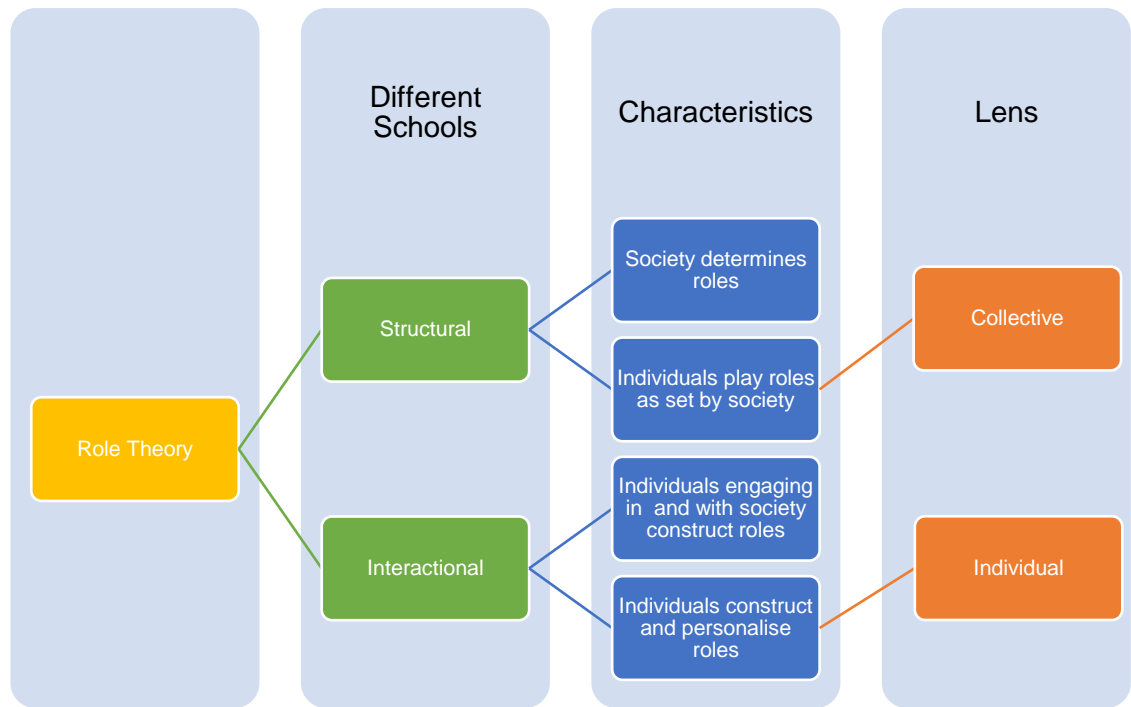


Figure 3.5 Chart displaying my interpretations of the core differences between Interactional and Structural Role Theories.

3.9.1 Structural Role Theory

Structural Role theory is commonly used to understand roles associated with prescribed statuses or power relationships, for example roles within organisations and institutions, some of which (such as the client or patient role) may be adopted out of necessity rather than choice (Turner, 2001). The metaphor of theatre and of actors simply following scripts written by society is often evoked to describe Structural Role Theory (Stryker, 2001).

Structural Role Theory proposes that society supersedes the role and that a person attempts to perform a role as society has determined it should be played (Stryker, 2001).

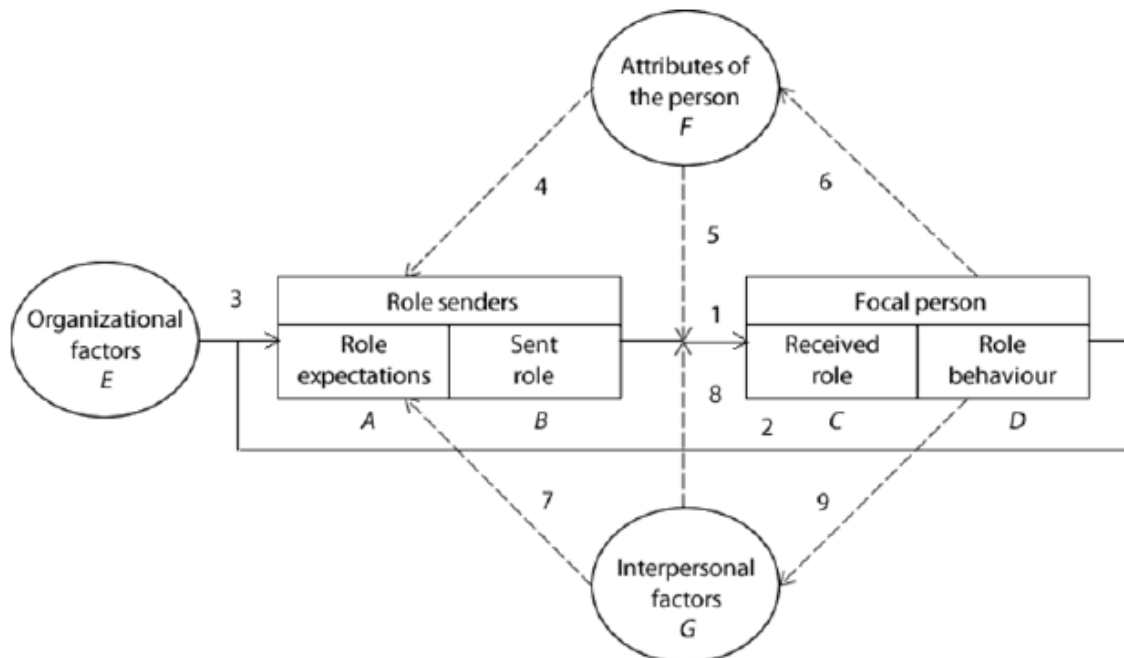
Stryker (2001) notes that influential Structural Role theorists such as Talcott Parsons and Ralph Linton construed roles as societal norms that people had a duty to conform to in order to maintain a smoothly functioning society. According to this view, role occupants, such as a doctor and patient, must recognize, respect and adhere to their social status and

the balance of power, and perform their roles as scripted by society for society to function. (Jackson, 1998).

Katz and Kahn's (1978) Role Episode Model

Structural Role Theories heavily emphasise the influence of society and societal norms on role learning (Turner, 2001). One influential Structural Role Theory of role learning within organisations is Katz and Kahn's (1978) Role Episode Model (see Figure 3.6 below), which was designed to explain the process of role learning (and breakdowns in role learning) in the context of organisations. Katz and Kahn hypothesise that in organisations, the organisation (shown in circle E below) acts as a form of local society, with norms and expectations regarding the division of labour that inform the prescribed roles within the organisation (Frink & Klimoski, 2004). These expectations are communicated overtly and covertly by management and other members of the organisation and form part of its culture. Katz and Kahn (1978) assert that roles are learned through pairs, with one person

Figure 3.6 Katz and Kahn's (1978, p 196) Role Episode Model.



in the pair acting as a “role sender.” The role sender is typically experienced in performing their role as prescribed by the organisation, and holds a greater status than their role counterpart. The role sender holds expectations (rectangle A) for their own role and the role of their counterpart, which are heavily influenced by the organisation. These expectations shape how they behave and interact with the focal person (rectangle B). Through their interactions, the role sender communicates what the prescribed role of their role counterpart or “focal person” is. For example, when applied to an [SLT](#) context, the organisation might be considered to be a named disability service. This service may have a mission statement, unofficial normed practices, as well as official policies. These act in combination to define expectations of roles within the organisation. Therapists then act as role senders communicating overtly or covertly to the parent about how they should behave. The focal person must then interpret these communications (rectangle C) and attempt to enact the role (rectangle D). The role sender’s responses to the focal person’s behaviours act as either a reinforcement or deterrent. When successful, this process allows the role sender to shape the focal person’s behaviours closer towards the normed role of the organisation.

Unusually for a Structural Role Theory, Katz and Kahn’s (1978) model also includes personality (attributes of the person) and interpersonal factors as influential to the role learning process. The focal person’s personality is considered to influence how they perceive communications regarding role expectations (arrow 5) and how they react to expectations, for example with stress or enthusiasm. The focal person’s personality may also trigger different responses in the role sender (arrow 4), potentially impacting how they behave and communicate towards the focal person. For example, a friendly focal person may induce more friendly behaviours from the role sender. Additionally, enacting the role may eventually impact on the person’s personality (arrow 6). For example, a role involving public speaking may lead to increased confidence and more extroverted behaviours. The

patterns of interpersonal relations between the role sender and focal person are also considered an influential factor. This factor can encompass a multitude of variables including perceptions of trust, power and competence. These variables may influence how communications are interpreted (arrow 8), as well as evaluations of the relationship between both parties (arrows 7 and 9).

The inclusion of personality and interpersonal factors is unusual for a Structural Role Theory. Nonetheless, in Katz and Kahn's (1978) model, the organisation is considered a powerful factor in determining roles. The organisation is viewed as an antecedent to all role expectations and the role learning process. Furthermore, the focus of the model is on learning to "take" roles rather than "make" roles, with an emphasis on the power of status figures to shape roles to be more compatible with the norms of the organisation. As such, the model represents a Structural Role Theory approach to role learning.

Critique of Structural Role Theory

Structural Role Theory offers an insight into the potential power of society and culture on roles. Its use may be particularly informative when applied to settings involving power hierarchies, for example understanding categories of employee roles within a business. Structural Role Theory's emphasis on norms may help to explain how roles tend to be readily identifiable and enacted by many different people in a similar way. However, this emphasis on norms also acts as the source of much criticism (e.g., Jackson, 1998). Structural Role Theory is associated with the stance that conforming to norms facilitates the functioning of society and it presents those who enact their role differently from the norm as 'deviant' (Stryker, 2001). This arguably promotes the position that there is a single, correct way to perform a role, potentially reinforcing the status quo and acting as a

barrier to change. For example, under Structural Role Theory, the shift of the role of women in society from mothers and home-makers to also include paid workers outside of the home, could potentially be labelled as “deviant” behaviour, rather than societal advancement. The theory could be interpreted as encouraging role conformity at all costs. In doing so, it lends itself less readily to enhancing understandings of situations involving changes to role configurations. The other key criticism of Structural Role Theory relates to individualism. Structural Role Theory adopts a general view of roles as they occur within collective society and it is thus sometimes criticized for overlooking human agency (Jackson, 1998). Different actors and directors can take the same script and produce different performances. Indeed, the same role can be enacted many different ways over the course of a person’s life. For example, how an individual enacts their role as a mother may change as their child increases in age, and may differ with each subsequent child. Thus, while Structural Role Theory may provide a useful bird’s-eye view of roles, it may be less useful in understanding how a particular person perceives and constructs their individual interpretation of a role.

3.9.2 Interactional Role Theory

The second major School of Role Theory is Interactional Role Theory. Interactional Role Theory views roles as constructed and negotiated primarily through social interactions between individuals who are members of a wider society (Stryker, 2001). Human agency and creativity are recognised in how individuals are involved in making rather than simply performing roles (Biddle, 1979). Under Interactional Role Theory “society, as a web of interaction, creates persons; but the actions of persons create, through interaction, society. Society and person are two sides of the same coin; neither exist except as they relate to one another,” (Stryker, 2001, p. 213). Rather than simply performing a role scripted by society, Interactional Role Theory proposes that individuals are both actors and reactors,

to varying degrees, performing a role, but also creatively reshaping that role in response to their interactions with others and their interactions with society (Stryker, 2001).

Role Construction

Interactional Role Theory's stance on roles as constructed through social interaction is heavily influenced by the philosophy of George Herbert Mead (1934). Mead viewed individuals as reflexive and engaged in perspective taking. Interactional Role Theory posits that individuals engage in perspective taking with the goal of achieving a successful interaction. Thus, in the process of constructing an understanding of a role, a person engages in the activity of imagining what the role of their counterpart is. The individual then shapes their conception of their own role in order to interact most effectively.

Ultimately how the individual defines a successful interaction will be highly influential in how they enact their role (Stryker, 2001). Hence, what the person hopes to achieve will influence the role enacted. Furthermore, Interactional Role Theory proposes that individuals mould their enactment of their role, to some degree, in response to how their counterpart interacts with them. For example, a student therapist's role will be impacted both by the student's expectations of their supervisor, as well as their personal motivations and how they interpret the supervisor to be reacting to them. The student may enact their role differently depending on whether they perceive their supervisor as a teacher figure or a mentor. The student who is motivated to get a high grade may enact their role differently from the student who hopes to pass. Additionally, the student may change their behaviour, for example, changing the frequency with which they ask questions, depending on how they perceive their supervisor's reactions to this behaviour. While Interactional Role Theory views individuals as both actors and reactors in the construction of their own roles, it notes that often role construction can involve choosing to conform to norms. This may occur if the individual involved perceives role conformity to facilitate their achievement of

their personal definition of a successful interaction (Turner, 2001). Figure 3.7 provides a graphical overview of my interpretation of Interactional Role Theory's stance on role construction.

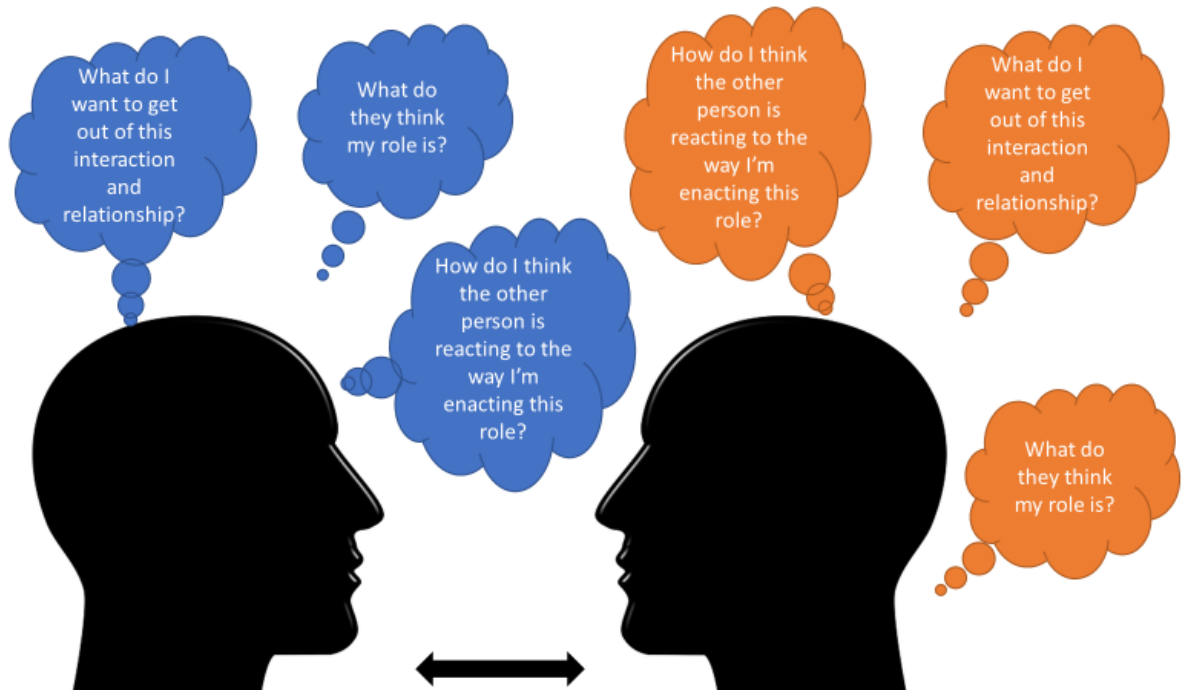


Figure 3.7 Graphic depicting my interpretation of Interactional Role Theory's approach to role construction.

Thornton and Nardi's (1975) Stages of Role Construction

Given Interactional Role Theory's stance on interaction, it is perhaps unsurprising that theorists affiliated with this School offer a detailed hypothesis of how roles are constructed through interaction. Thornton and Nardi (1975) propose that successful role construction occurs in four stages (Figure 3.8). Breakdowns may occur at any of these stages stalling further developments in the process, but moving through all four stages is considered important for achieving optimal outcomes for the parties involved. Rather than viewing the interaction as a means of behaviour reinforcement, as depicted in Structural Role Theory, Thornton and Nardi present the interaction between the role counterparts as a complex,

reciprocal process of role negotiation (Turner, 2001). Each of the stages are outlined below.

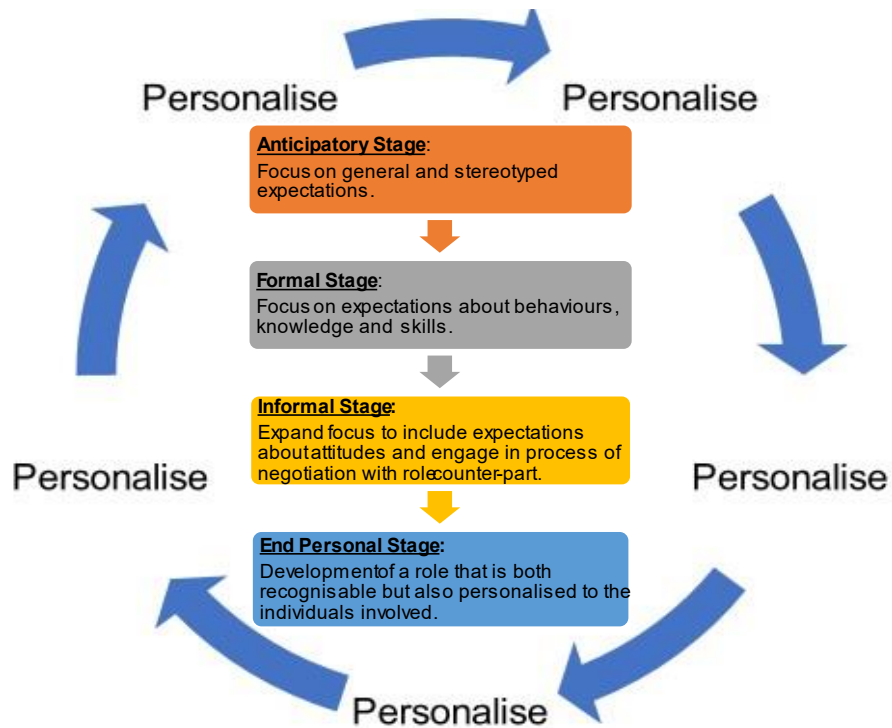


Figure 3.8 Graphic depicting Thornton and Nardi's (1975) stages of role construction.

Stage 1: Anticipatory Stage

Stage one involves the person collating information that they have already collected consciously and unconsciously through media exposure and knowledge of others who have held this or similar roles. Thornton and Nardi (1975) note that during this stage, role constructs are often incomplete and idealised, and more closely relate to what a person wants and needs a role to involve, rather than what the role realistically will involve. They cite a number of studies (e.g., Wright, 1967) that suggest that the anticipatory stage is helpful in adopting roles when a person's expectations are aligned with the role that is later negotiated. If there is too great a distance between a person's anticipated role and the

perceived reality of the role, then role enactment may be challenging and require the person to 'unlearn' the anticipated role.

Stage 2: Formal Stage

The formal stage occurs when a person first attempts to enact the new role. The person develops new expectations of their role through their interaction with the individual in the counter-role. These expectations are shaped by the counterpart's perceived expectations and to some degree by the individual's own response to their counterpart's expectations. At this stage these formalised expectations tend to focus on the behaviours, knowledge and skills associated with the role, rather than attitudes (see Figure 3.9). Thornton and Nardi (1975) note that during the formal stage, individuals are likely to conform to the perceived expectations of their more powerful, experienced or socially significant role counterpart. They contend that this is because the person is trialling the new role and gathering information about the new situation and context. During this stage individuals may postpone their own expectations of the role. Thornton and Nardi note conforming likely occurs because the role expected of them may feel more standardised and thought through. Additionally in the case of organisations, like healthcare systems, individuals may perceive there to be power hierarchies which must be adhered to. During this stage the person may be "playing at roles rather than truly enacting them," (Thornton & Nardi, 1975, pp. 877 - 878). Thus, it may appear to their role counterpart that a mutual and satisfactory understanding of each other's roles has been achieved.

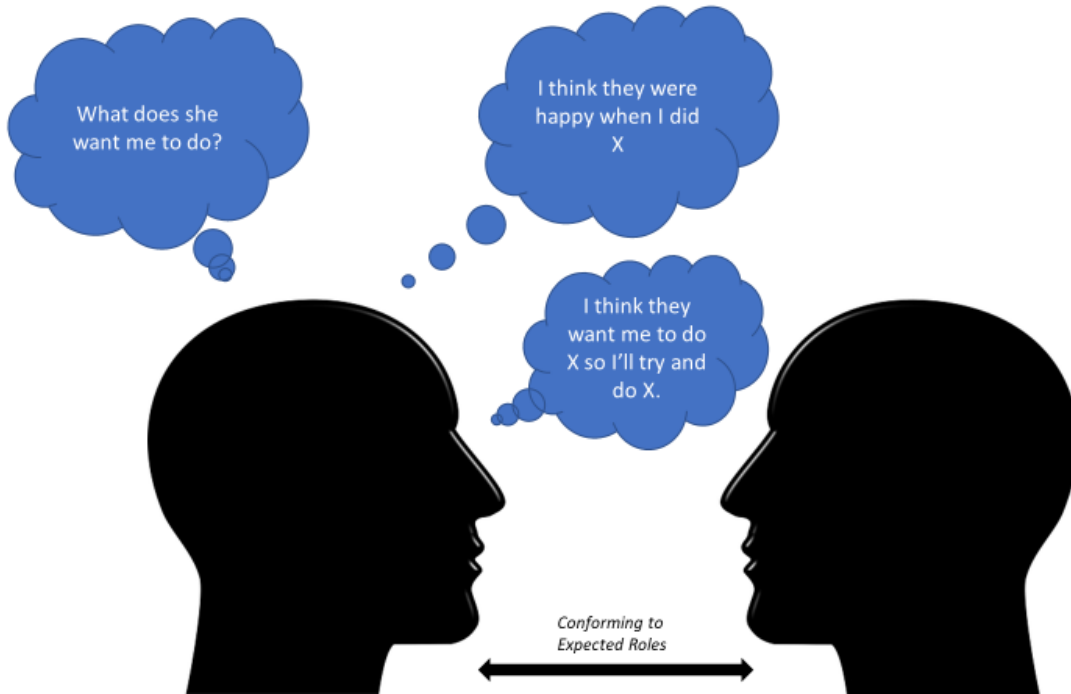


Figure 3.9 Graphic depicting my interpretation of Thornton and Nardi's (1975) Formal Stage of role construction.

Stage 3: Informal Stage

During the informal stage, the individual constructs an understanding of their role that is more inclusive of attitudes and values and is more flexible (see Figure 3.10). The individual's understanding of the role loosens as they become aware of which aspects of their role are obligatory and which may be optional. Individuals reconstruct their understandings of their role through their interactions with other people playing the same role. For example, a mother of a school child may interact with other parents of children in the same school, leading to an understanding that her role can be enacted differently. She may then modify her role construct, for example, to include new attitudes towards how she manages homework. During this stage individuals begin to remould their construction of the role to better fit who they are as a person and their personal context and goals for the role. As this shift occurs, there may be some misalignment between how both individuals

in the role pair understand and expect roles to be enacted. This stage typically represents the beginning of role negotiation.

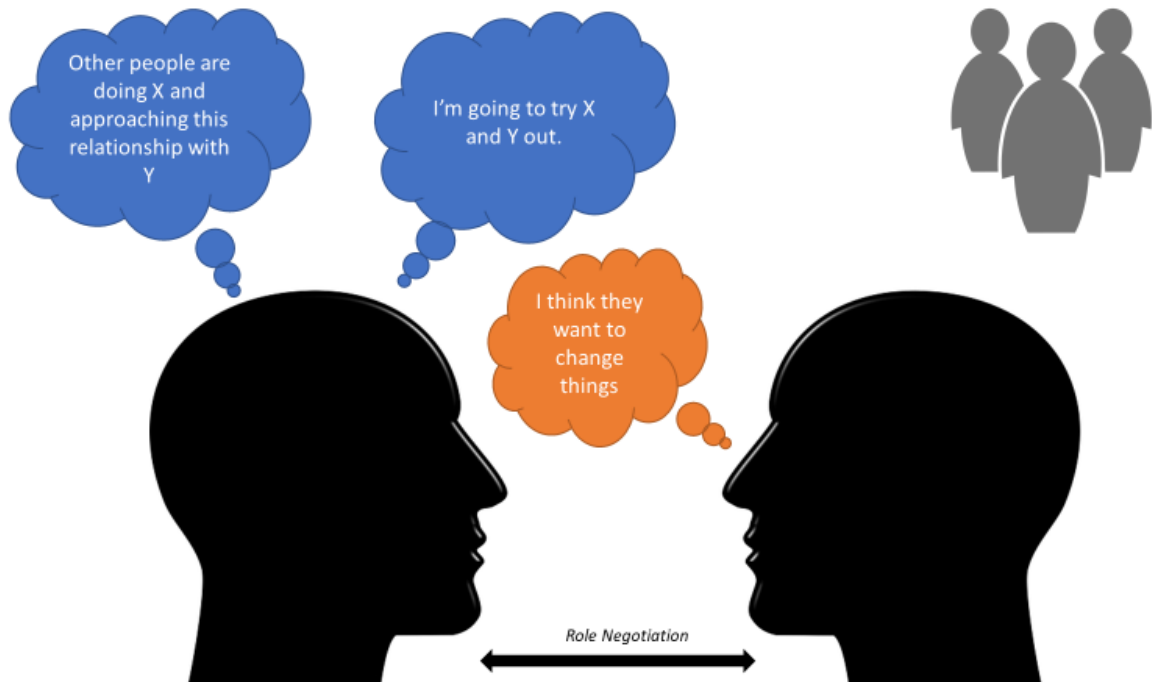


Figure 3.10 Graphic depicting my interpretation of Thornton and Nardi's (1975) Informal Stage of role construction.

Stage 4: Personal Stage

Rather than representing the next and final stage of role construction, the personal stage spans the duration of the role construction process. During stages one to three, the individual's personality and biography impacts on their role expectations to varying degrees. Thornton and Nardi (1975) propose that a person has to experience anticipatory, formal and informal expectations and only then will they adopt a fully personalised role. After stage three is complete, an individual will have more certainty about their understandings of the roles involved and what they hope to achieve in enacting their role (see Figure 3.11). The individual then attempts to negotiate a role that is recognisable to

others, but also reflects their personal style. For example, a student therapist who feels they learn best by observing and reflecting might negotiate a role with their supervisor that involves regular opportunities for critical reflection and observation, in addition to the mandated time spent doing assessments or intervention. Thornton and Nardi (1975) propose that at this stage, role expectations have been re-negotiated and have been re-constructed relatively successfully and both counterparts have made accommodations in order to maintain successful interactions.

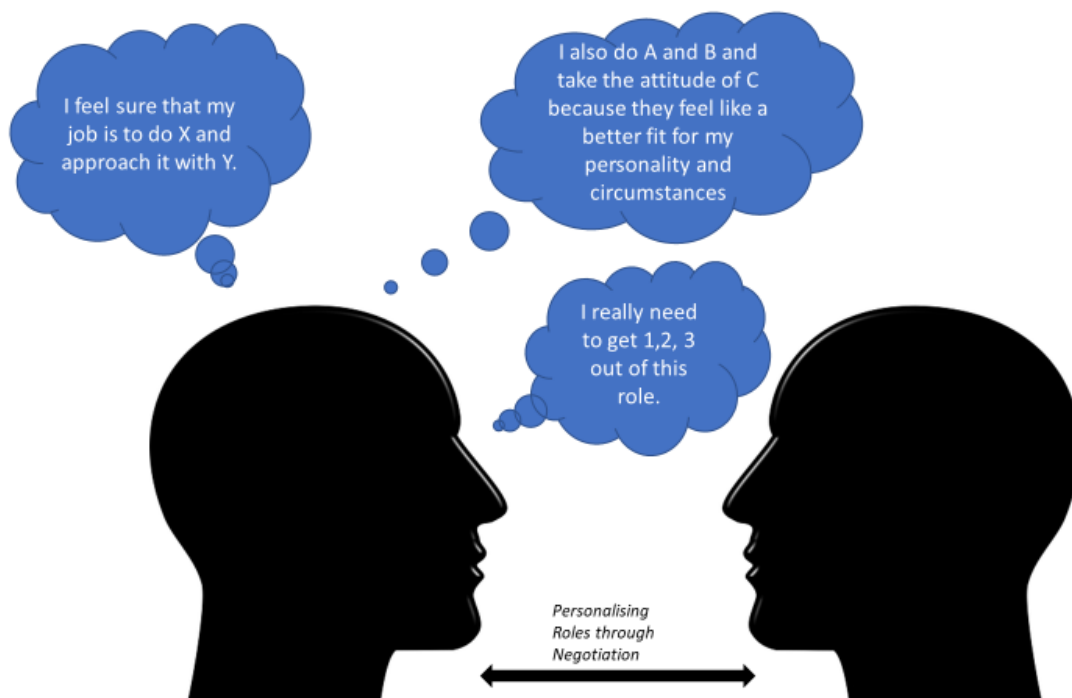


Figure 3.11 Graphic depicting my interpretation of Thornton and Nardi's (1975) **Personal Stage of role construction.**

Critique of Interactional Role Theory

Interactional Role Theory's recognition of human agency's influence on role construction helps to explain how roles can be enacted in a manner which is recognisable, but also personalised to the individual involved. By promoting a stance that individuals are involved in constructing their own roles, the theory arguably fosters acceptance that roles can be enacted in a range of ways. The theory positions roles as dynamic, thus offering a more

neutral stance towards role change than Structural Role Theory. Interactional Role Theory proposes that as roles are made and reconstructed through social interactions, new norms can also emerge from these collective social interactions (Turner, 2001). As the theory allows greater variety in the enactment of roles, norms are viewed descriptively rather than prescriptively (Hindin, 2007). Additionally, Interactional Role Theory's focus on interaction as the vehicle through which roles are constructed, appears to capture how the same role may be enacted differently depending on the individuals involved and the interactions involved. For example, the role of friend may involve differing levels of trust, openness and fun depending on the individuals involved and how they interact. Nonetheless, Interactional Role Theory has been argued (e.g., Wrong, 1961) to have some limitations with regard to its application to roles associated with organisations involving power hierarchies and rule governed structures and systems. It appears reasonable to assume that an individual's freedom to negotiate and personalise their roles in such a context may be restricted to some degree.

3.10 Role Theory in Relation to the Thesis

More recently, contemporary approaches to research regarding roles have drawn from aspects of both Structural and Interactional Schools. For example, Stryker (2001) discusses Social Structural Symbolic Interactionism which is influenced by both Structural and Interactional Role Theory. As I interpret them, both Schools offer useful but different lenses with which to understand roles. Structural Role Theory provides a collective lens to understand how society as a whole prescribes roles. Interactional Role Theory provides an individual lens to help understand how each person personally engages in role construction. Thus, for the purposes of this study, I have adopted a blended Role Theory approach.

I am, however, also aware of the limitations of Role Theory. It has been critiqued as reductionist, compartmentalizing people into a series of unrelated single roles (Jackson, 1998). This criticism appears understandable. While some Role Theorists have explored the impact of multiple roles in terms of overloading an individual (as discussed below), there is little literature in the area of Role Theory, to my knowledge, that explores in detail how prior and existing roles might influence how roles are constructed and enacted. Additionally, the research regarding roles and identity appears relatively limited. Turner (2001) notes that most Interactional Role Theorists agree that roles differ in depth and significance for each individual and are organised in a loose and dynamic hierarchy, arranged in terms of significance to the person's identity. He proposes that a person will value or emphasise the roles at the top of their hierarchy more and thus invest more time and/or energy into these roles. Yet, to my knowledge, Role Theory does not provide any detailed models of the relationship between roles and identity. Nonetheless Role Theory offers a valuable framework for examining how roles in general are constructed, albeit in a decontextualised manner.

3.11 Theories of Health Behaviours

Role Theory is concerned with roles in general. It appears reasonable to assume, however, that there may be certain processes and factors that are specific to how the client role is constructed and enacted. The field of Health Behaviour has attracted much theoretical and empirical study, and arguably offers further insights into how parents in [SLT](#) may make sense of their roles. Conner and Norman (2005, p. 2) define health behaviours as “any activity undertaken for the purpose of preventing, or detecting disease or for improving health and well-being.” The term is commonly used in relation to preventative behaviours, (e.g., cessation of smoking, getting vaccinated), however it also refers to behaviours that aim to improve functioning, such as a person with diabetes

modifying their diet, or a person taking prescribed medication (Conner & Norman, 2005). I propose that parent involvement in therapy could be considered a broad type of health behaviour. For example, the parent who chooses to work with their therapist to use Lamh signs (modified sign language) when speaking with their child at home, is taking an action that may improve their child's ability to understand and function better in the home. Additionally, the parent who chooses to bring their child to all therapy appointments, is completing an activity that may optimise their child's gains from therapy.

3.11.1 The Major Theorists' Model of Health Behaviours

A great number of theories of health behaviours have been proposed over the years. For example, Davis, Campbell, Hildon et al. (2015) conducted a scoping review and found 82 theories of behaviour and behaviour change. These include the Health Belief Model (Rosenstock et al., 1988), Social Cognitive Theory (Bandura, 1986) and Theory of Planned Behaviour (Ajzen, 1988). In 2001, five major theorists in the area of health behaviours (Bandura, Becker, Fishbein, Kanfer and Triandis) came together at a workshop organised by the National Institute of Mental Health Office on AIDS (Fishbein et al., 2001). At this workshop the theorists reached consensus on eight variables that they identified as primary determinants of health behaviours. This framework of health behaviours is referred to as the Major Theorists' Model. An overview of this framework is shown in Figure 3.12 below. The Major Theorists' Model proposes that for a specified health behaviour to occur, three factors are essential: a conducive environment, the necessary skills and the intent to carry out the behaviour (Fishbein et al., 2001). Each of these factors are discussed in greater detail below.

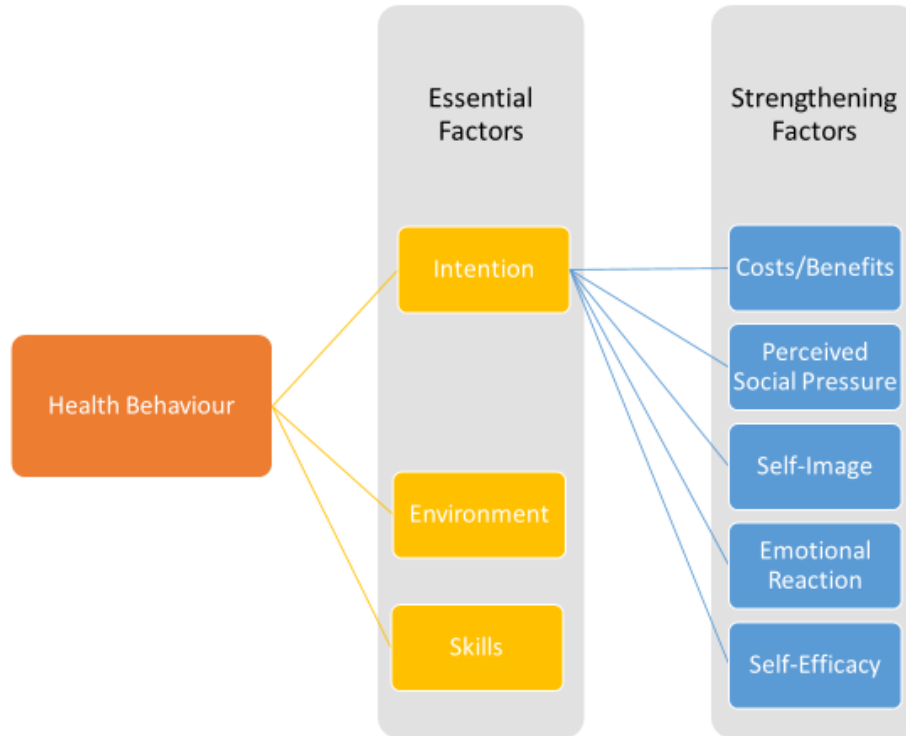


Figure 3.12 Graphic depicting Fishbein et al.'s (2001) Major Theorists' Model of Health Behaviours.

3.11.2 Environment

In order for a person to engage in a particular set of health behaviours, the person's environment must provide "a context of opportunity, or be free of constraints," (Fishbein et al., 2001, p. 5). Different theorists hold different understandings about what constitutes an environment. The broadest, but perhaps most detailed understanding of the environment may be derived from Social Ecological Models of Health Behaviour Change (Golden & Earp, 2012). The Social Ecological Model adopts a multitiered view of environments as shown in Figure 3.13 below. A person's environment may be construed as their home, their interpersonal environments or social support networks, the environment of the wider communities that the person belongs to (for example their local neighbourhood, church or sports club), organizational environments that involve rule-governed institutions such as a

disability service or school, as well as the wider political and legal systems of the society in which they live.



Figure 3.13 Graphic depicting the different types of environments as described by the Social Ecological Model (Golden & Earp, 2012).

The literature relating to the interaction between the environment and parental engagement in healthcare appears largely focused on the organizational environment alone. Service issues such as waiting times, level of met needs and ease or difficulty of accessing services are commonly discussed by parents in the literature (e.g., Crane et al., 2016; Nicholas et al., 2016). There is emerging evidence from studies related to paediatric mental health services that suggests an association between waiting times and parental involvement. Longer waiting times for initial appointments have been found to correlate with lower levels of engagement from families, as measured in number of appointments attended, and reduced service user satisfaction (Schraeder & Reid, 2015; Westin et al.,

2014). The [SLT](#) and other allied health literature discusses how staffing, funding, amounts of therapy offered and delivery models can be a source of pressure or support for parents and can impact on how they perceive their role (e.g., Marshall & Goldbart, 2008). A perceived lack of co-ordination between professionals and services, coupled with staff turnover are reported to cause frustration among some parents (Brotherson & Goldstein, 1992; MacKean et al., 2005) who note feeling expected to take on an enhanced communication role, to ensure all professionals are aware of their child's profile and history. Thus, the available evidence suggests that parents' perceptions of the organizational environment can act as a facilitator or barrier to their involvement in therapy.

3.11.3 Skills

The Major Theorists' Model (Fishbein et al., 2001) asserts that the person must have the necessary skills to carry out the behaviour. For example, the parent using Lamh must have the dexterity to make the signs, and the cognitive skills to learn and remember the signs. There is little discussion in the literature relating to [SLT](#) regarding skills as a factor in role performance; however, it appears reasonable to assume that this factor is fundamental in determining if and how well a person can perform their role.

3.11.4 Intention

A factor that may be potentially overlooked due to its simplicity is intent. The Major Theorists' Model (Fishbein et al., 2001) proposes that it is fundamental that a person holds intentions of performing the behaviour. The model asserts that the strength of this intent is impacted by five variables (see Figure 3.14). While intent is not overtly discussed in the allied health literature, a number of the variables proposed to influence the strength of intent are.

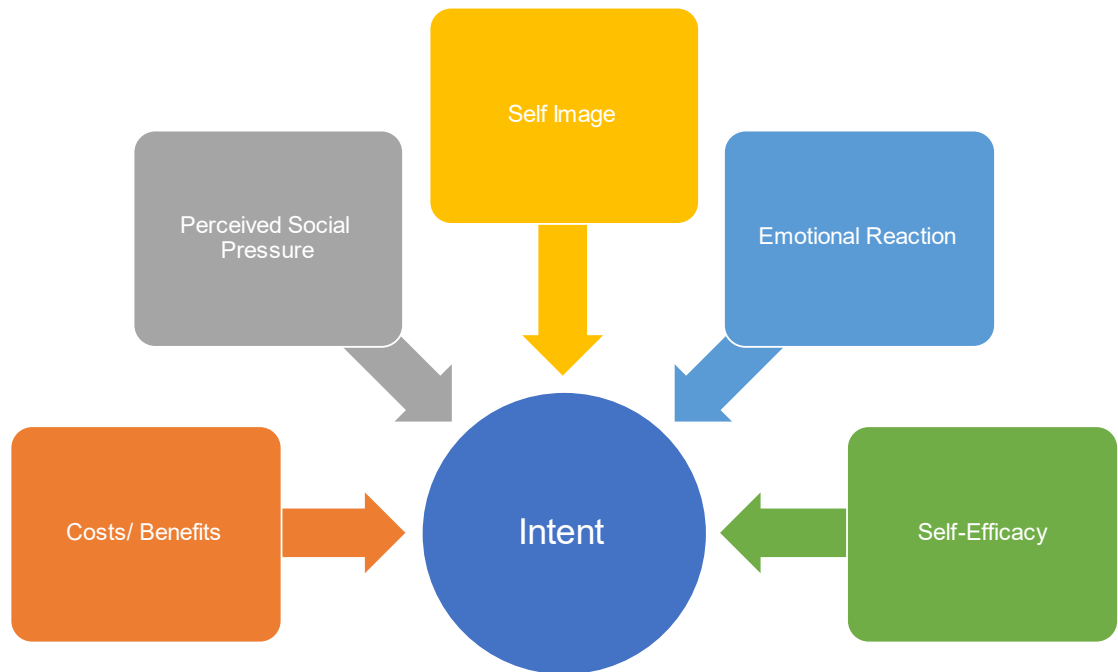


Figure 3.14 Graphic depicting the factors that influence strength of intent according to the Major Theorists' Model (Fishebein et al., 2001).

Costs/ Benefits

The Major Theorists' Model (Fishbein et al., 2001) asserts that the person must believe that the benefits and perceived outcomes of the health behaviour are positive enough to outweigh any perceived costs associated with the behaviour. The literature supports the stance that clients consider intervention to involve both costs and benefits. Studies of the influence of the perceived benefits of intervention on client participation in treatment has a long history, albeit primarily in the field of mental health. Outcome expectations encompass a client's "prognostic beliefs about the consequences of engaging in treatment," (Constantino et al., 2011, p. 354). They relate to clients' hopes and beliefs that positive outcomes or benefits can or will occur if they partake in intervention (Constantino et al., 2011). Positive outcome expectations have been found to be associated with greater

patient participation in a number of treatments including, for example, diabetes self-care (Reisi et al., 2016) and dialysis (Bogataj et al., 2020). Indeed, a number of systematic reviews relating to psychotherapy (Constantino et al., 2011), treatment for back pain (Iles et al., 2009), and total knee and total hip arthroplasty (Haanstra et al., 2012) have concluded that outcome expectations may also influence treatment outcomes. Additionally, there is some tentative evidence to support the influence of outcome expectations on parents' participation in [SLT](#). A study by Watts Pappas et al. (2016) found that some parents explained their commitment to involvement in therapy with their belief that their child's difficulties would resolve quickly with a small amount of therapy.

While the literature relating to the influence of the perceived benefits of intervention spans a number of decades, academic interest in the costs associated with intervention appears a more recent phenomenon. Shippee, Shah et al. (2012) conceptualise the costs associated with intervention as the "burden of treatment." All interventions are associated with some degree of costs or burden. Evidence of burden of treatment has largely been documented in relation to medical treatments, for example treatment of stroke (Gallacher et al., 2013), diabetes, chronic kidney disease and heart failure (Eton et al., 2013). Sav, Salehi, Mair and McMillan (2017) conducted a scoping review and proposed six dimensions of burden of treatment:

1. Financial: Costs associated with treatment, (e.g., purchasing private treatment, funding medications or the costs associated with travel or taking time off work.)
2. Medication: Organizing and managing medications, as well as performing other medical self-care tasks.
3. Administrative: Completing necessary paperwork, arranging appointments and assessments, recording relevant information related to self-monitoring.

4. Lifestyle: Social and relationship costs associated with treatments, (e.g., modifications in how the person socializes due to recommended changes in diet.)
5. Healthcare: Burdens primarily related to treatment including increased need to access and navigate health services according to the rules and policies of the institutions involved.
6. Time/travel: Time and travel involved in attending appointments and completing prescribed exercises etc.,

Similar to the Major Theorists' Model, Shippee et al. (2012) argue that if the burden of treatment outweighs the perceived benefits, patient engagement in treatment may reduce. In keeping with this assertion, some authors in the field of [SLT](#) (Glogowska et al., 2002; Watts Pappas & McLeod, 2009) have concluded that parents' decision-making regarding participation in therapy, involves a costs-benefits analysis. These authors propose that if the cost of involvement is perceived to be high in relation to the expected outcomes, parents' involvement in therapy may be reduced. Thus, when considered together, the available literature appears to support the assertion that clients understand intervention to involve both costs and benefits and their perceptions of costs and benefits may influence how they enact their role.

Perceived Social Pressure

Another factor hypothesized to influence the strength of an individual's intent relates to perceived social pressure (Fishbein et al., 2001). The person must sense that the wider society expects them to perform this behaviour. For example, society often emphasizes the importance of early intervention for children, potentially contributing to parents of young children feeling more compelled to partake in therapy than parents of adults with disabilities, who may not feel a comparable social pressure. The influence of perceived social pressure is commonly addressed in relation to traditional conceptualisations of

health behaviours, such as smoking (e.g., Li et al., 2003). The relevance of this domain to autism therapies and [SLT](#) appears unexplored.

Self-image

According to the Major Theorists' Model, the health behaviour involved must be consistent with the person's self-image and must "not violate personal standards that activate negative self-sanctions," (Fishbein et al., 2001, p. 5). Demain et al. (2015) conducted a systematic review of qualitative literature related to patients with a range of long-term chronic conditions, and concluded that participation in treatment may negatively impact on some people's self-image, particularly when the treatment is perceived to carry a stigma or to increase the visibility of the "disease." They also noted that disruptions to self-image can occur in terms of perceived loss of freedom stemming from treatment-related physical constraints (e.g., attachment to feeding machines) and existential constraints (e.g., the perception that life was no longer care-free and was instead bound by treatment regimens required constant planning.)

Similar impacts on self-image have been reported in paediatric disability studies. For example, Todd and Jones (2003) found that mothers of children with disabilities often engage with services with a heightened sensitivity about their identities as "good mothers." As such, they propose that mothers may have an unconscious agenda of affirming their identities as "good mothers," when engaging with services. This may manifest in a reluctance to engage with interventions that are perceived to target "parenting." Rather than perceiving interventions as implying judgements about identity, Brady et al. (2006) found that some mothers of children with Fragile X syndrome perceived their participation in therapy to threaten their identities as mothers. One mother noted, "It's kind of sad in a way because everything I do with him is like a therapy-type thing and there's a lot of times I don't want to be that. I just want to be a mom. So, it's hard for me sometimes to decipher

between the two of them,” (Brady et al., 2006, p. 359). Demain et al. (2015) argue that people seek intervention not just to address the presence of symptoms, but also because those symptoms curtail them in living as they want to live and from being the person they want to be. If their treatments act in a similar manner to a disease or disorder, cause different problems, and curtail them in living their life and being who they want to be, then the treatment can become as burdensome as the disorder. While the volume of studies relating to self-image and the client role is limited, it provides preliminary evidence supporting a relationship between self-image and participation in treatment.

Emotional Reaction

Fishbein et al. (2001) propose that a person’s feelings towards carrying out the health behaviour must be more positive than negative. For example, if the health behaviour of using Lamh signs generates feelings of embarrassment, the person’s intention will be reduced. Conversely if the behaviour triggers the parent to feel hopeful, their intention will be strengthened. There is evidence in the literature that participation in [SLT](#) can be associated with positive and negative emotional reactions. For example, parental feelings of blame, guilt and frustration associated with participation in intervention have been reported in both autism and [SLT](#) studies (Goldbart & Marshall, 2004; Kuhlthau et al., 2014; Marshall & Goldbart, 2008). Other studies have found that participation in parent-mediated interventions can be associated with improvements in parental mental health measures (e.g., Tonge et al., 2006). Few studies have specifically explored emotional reactions in relation to decisions regarding participation in [SLT](#), however there is some preliminary evidence supporting this. For example, Moorcroft, Scarinci and Meyer (2019) explored parents’ decisions to discontinue using Augmentative and Alternative Communication ([AAC](#).) They found that some parents reported a perception that they lacked adequate

emotional resilience to cope with their frustrations in using [AAC](#) and felt this was a factor in their abandonment of the [AAC](#) system.

Much of the literature regarding emotional reactions and involvement in therapy, relates to parents' emotional reactions to their child's diagnosis, rather than therapy itself. For example, in a grounded theory study involving interviews with 32 mothers of children on the autism spectrum and 9 professionals, Gentles et al (2019, p. 1) concluded that engagement in therapy was enmeshed in an adjustment process which generally followed a trajectory of "coming to understand their child has autism," "going into high gear," and "easing off." In the early stages of adjustment, different parents may display different levels of receptiveness to intervention. Some may be highly engaged as they remain optimistic that with intervention their child will make rapid gains. Others may avoid or devalue their involvement as they cope by engaging in the protective mechanism of denial. Others may feel overwhelmed by the diagnostic process and feel pessimistic about their role or intervention (Gentles et al., 2019). Indeed, other studies (e.g., MacKean et al., 2005) report similar findings regarding this early stage of adjustment with parents noting a history of taking a limited role in intervention in the early stages following their child's diagnosis, particularly in relation to decision-making, due to their emotional reaction to the diagnosis.

Gentles et al. (2019) concluded that as parents begin to adjust emotionally, their involvement in services and intervention increases and parents develop a more concrete understanding of their role. Typically, at this point, parental involvement moves into "high gear" (Gentles et al., 2019, p. 12), characterised by a highly motivated parent role, driven by a sense of urgency, and executed with an intensity and dedication of time, energy and resources that is ultimately unsustainable. The authors note this period may last months to years, and is often followed by a period of "easing off" that corresponded with parents' growing understanding of the life-long implications of their child's autism and that

involvement with services might continue into adulthood. This understanding can contribute to a shift in the intensity of parental involvement, as parents move to a “marathon instead of sprint pace,” (Gentles et al., 2019, p. 13). The authors stressed that these stages often followed this pattern, but can be flexible, with some parents reaching different stages in different orders or potentially not reaching some stages at all. Thus, with regard to emotional reaction, the available literature points to a possible relationship between parents’ emotional reactions to treatment and the role enacted, but more strongly supports a relationship between the reaction to a child’s diagnosis and the role enacted.

Self-efficacy

The final strengthening factor referred to in the Major Theorists’ Model (Fishbein et al., 2001) relates to self-efficacy. The model asserts that a person’s self-efficacy, or belief in their ability to perform the intervention behaviour across contexts, will influence their intention to complete the intervention in question. Self-efficacy has received considerable research attention, albeit primarily in relation to outcomes. It is commonly investigated as a potential outcome of intervention, rather than a mediator (e.g., Noyan Erbaş et al., 2020). Enhancing a person’s self-efficacy is considered to increase their sense of control over their life, and is thus argued to constitute a positive outcome (Brown et al., 2014). The relationship between self-efficacy and involvement in treatment has also received some attention. There is moderate evidence that self-efficacy may influence participation in treatments across a number of domains, including smoking cessation (e.g., Gwaltney et al., 2009), maintaining diets (Okpara et al., 2021) and adherence to HIV treatments (Traynor et al., 2021). The impact of self-efficacy on participation in allied health therapies is supported by a preliminary evidence base. For example, self-efficacy was found to be one factor that predicted client participation in voice therapy (van Leer & Connor, 2015). It has also been associated with parental promotion of children’s hearing device use

(Ambrose et al., 2020). Band et al. (2002) found that some parents expressed a fear of moving from traditional, direct therapy approaches to parent mediated approaches and located their fear in their belief that their “lack of training would do more harm than good,” (p. 219). When considered together, the literature appears to support self-efficacy as a plausible mediating factor on the role enacted by clients in therapy.

3.11.5 Critique of Major Theorists’ Model

Given the huge number of Health Behaviour theories available (Davis et al., 2015), the Major Theorists’ Model presents an attractive offer to a novice researcher by offering an accessible framework to understand the variables that are commonly implicated across theories. However, the theorists involved did not reach agreement on the detailed relationships between all constructs involved and the details of the causal relationship (Fishbein et al., 2001). This may inadvertently present a health behaviour as a static phenomenon, related to an isolated episode, when it appears plausible that many health behaviours occur in a dynamic context, embedded in a chain of events, with each event influencing the next. For example, it appears reasonable to assume that an individual’s self-efficacy and perceptions of expected benefits and costs may change following initial attempts at completing the health behaviour. These changes may thus strengthen or weaken subsequent intentions to complete the health behaviour.

The model has been criticized for its lack of empirical testing and the exclusion of certain factors (Conner & Norman, 2005). For example, the model does not include perceptions of severity and susceptibility, which are included in models such as the Health Belief Model (Rosenstock et al., 1988) and the Theory of Planned Behaviour (Ajzen, 1988) and conceivably may impact on the strength of an individual’s intent to perform the health behaviour. Additionally, the model does not address the complexity of the health behaviour involved. Research in relation to medical treatments suggests that the complexity of the

behaviour is related to completion of the behaviour (Martin et al., 2005). For example, a number of studies (e.g., Santer et al., 2014) have found that adherence to treatment lessens with increases in the complexity treatment (e.g., the number of different medications and frequency at which it must be taken). Another factor not included in the model, but potentially influential in the context of autism and [SLT](#), relates to workload. While the Major Theorists' model affords the opportunity to consider the burden of treatment involved in completing the intervention itself, it does not capture the other pulls that may be on an individual's time and energy. Shippee et al. (2012, p. 1042) emphasise the importance of considering the client's overall "workload" or all the everyday tasks and activities that a person is responsible for, stemming from the other roles in their life. They contend that the client's broader workload will impact on their capacity to perform the health behaviour.

Additionally, the model does not allow for the potential impact of clinicians on health behaviours. Preliminary evidence suggests that factors related to the clinician may impact on parents' involvement in therapy. For example, in relation to occupational therapy ([OT](#)) in an early intervention setting, Thompson (1998) found that parents reported increased participation in [OT](#) when the therapist involved was perceived to be friendly. In the field of medicine, studies suggest that patient involvement in decision-making in healthcare may be impacted by the racial concordance between doctors and patients (e.g., Saha & Beach, 2020). Danahy Ebert and Kohnert (2010) query if individual clinicians' differing skills and knowledge may explain some of the differences in outcomes in [SLT](#), perhaps with more skilled clinicians better able to motivate clients to participate in therapy. Indeed, a paediatric physiotherapy study by Lillo-Navarro et al. (2015) found that parents reported that individual clinician's teaching styles influenced their commitment to and time spent engaging their child in recommended exercise programmes.

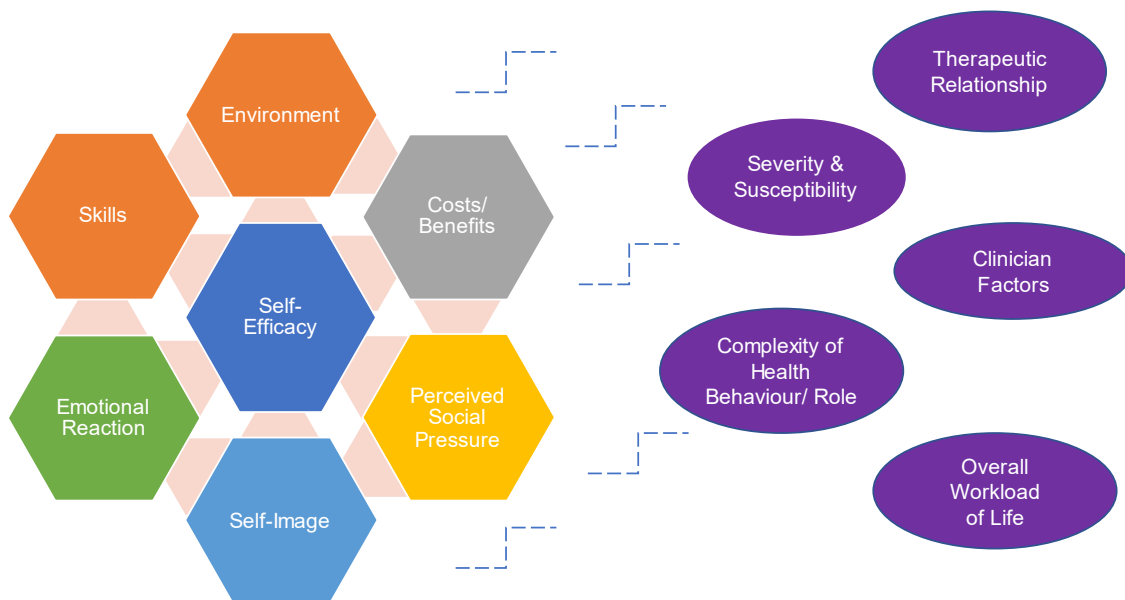


Figure 3.15 Graphic depicting some of the factors (shown in purple) not accounted for in the Major Theorists' Model (Fishbein et al., 2001).

Finally, there is a notable absence of any reference to the therapeutic relationship in the Major Theorists' model. Supportive therapeutic relationships are associated with client attendance (Winkworth et al., 2010), client engagement (Melvin et al., 2019), positive therapy outcomes (e.g. Sønsterud et al., 2019) and parental empowerment (Reeder & Morris, 2020). Researchers in psychotherapy (e.g., Wampold & Imel, 2015) contend that a supportive therapeutic relationship provides the foundation on which evidence-based treatments can take effect. Such authors assert that even treatments supported by high quality, randomised control trials may fail without a therapeutic relationship that encourages the client to engage with therapy. Family-centred care researchers (e.g., Dunst et al., 2002) conceptualise supportive therapeutic relationships as requiring relational and participatory practices. Relational practices involve the interpersonal domain of a relationship and include characteristics such as empathy and active listening, while participatory practices encompass the power dynamics of a relationship and include

behaviours such as shared decision-making (Espe-Sherwindt, 2008). Thus, in relation to health behaviours, a supportive therapeutic relationship may be influential in two core ways. Firstly, it may provide a safe and supportive context for the individual to attempt the behaviour. Secondly, by encouraging collaboration in goal setting and selecting treatment options, it may also harness greater motivation in the client at the initial stages of therapy.

In summary, both the appeal and disadvantages of the Major Theorists' Model lie in its simplicity. It provides a theoretical overview of the factors that likely impact on the performance of health behaviours, and thus arguably role enactment in healthcare. The birds-eye view adopted by the model lends itself to the omission of some potentially powerful variables. Nevertheless, taking such a view perhaps increases the applicability of the model to multiple contexts and client groups. Furthermore, the loose framework inherent in this model appears compatible with the exploratory, rather than explanatory nature of my research. Rather than imposing a detailed mould onto the data to determine goodness of fit, the model allows me to approach the data with a general sense of the factors that may be involved, perhaps facilitating a more open mind in approaching the question of how mothers make sense of and understand their roles in therapy.

3.12 Summary of Literature relating to Sense-Making of Roles

The available literature that illuminates understandings of how parents make sense of their role primarily stems from two theoretical fields – Role Theory and Health Behaviours. Role Theory offers different views on how roles are constructed or learned and arguably provides a useful framework to approach an exploration of how roles in general are made sense of. The field of Health Behaviours, while typically applied to a discrete behaviour or set of behaviours, offers an expansive theoretical and empirical base to study the specific role of patient or client and the factors that may influence how this role is enacted. When considered together, the literature relating to both Role Theory and Health Behaviours

indicate that the process of constructing and navigating the client role is likely delicate, complex and multi-factorial in nature. The lack of consensus across the different schools of Role Theory and Health Behaviours highlights the potential yields that further studies in this area may bring, particularly with regard to understanding the nuances of how sense-making may occur at an individual level.

PART THREE- WHY UNDERSTANDING ROLES MATTERS

The study of parent roles is of particular interest to me, given the challenges to role construction and enactment that I have observed in clinical practice. When a parent does not enact a role as expected, recommended or preferred by a clinician or practitioner, this may sometimes be construed as a sign of disengagement. Disengagement represents a significant and common difficulty in healthcare and is associated with substantial costs in terms of quality of life for the individuals involved and health economics for wider society (WHO, 2003). The final part of this chapter discusses disengagement and the diametric construct of engagement and points to the potential value that studies of roles in healthcare may make towards understanding these phenomena.

3.13 Engagement

Understandings of disengagement and engagement in healthcare have their origins in research relating to compliance and adherence. Both compliance and adherence refer to the congruence between a patient or client's behaviour and the behaviours recommended by the health professional (WHO, 2003). While compliance relates to behaviours determined by clinicians alone, adherence is typically used in contexts where the behaviours involved have been agreed by both the client and the clinician (WHO, 2003). Thus, it is perhaps unsurprising that the term "compliance" has been criticised for its associations with a paternalistic therapeutic relationship, and for carrying connotations of

blame and misbehaviour towards clients who do not 'comply' (Hanna & Rodger, 2002). The term "adherence" appears more prevalent in recent literature and is suggested to capture the effort involved for clients in 'sticking' to recommendations (Aronson, 2007). Nevertheless, both terms relate only to behaviours, for example, attendance at appointments or completion of exercises. The field of mental health has a long history of extending the focus beyond compliance or adherence to the broader concept of engagement. Contemporary conceptualisations of engagement (e.g., King et al., 2014) involve behavioural, affective and cognitive components. King et al. (2020, p. 18) summarise the domains involved as being synonymous with "being ready, willing and able." Figure 3.16 below shows an overview of my interpretation of such conceptualisations. This broad conceptualisation of engagement is supported by a number of recent studies. For example, King et al. (2020) explored how children, parents and professionals perceive engagement. They found that engagement was often viewed as different types of connections. Affective connections relate to investment and participation in the therapeutic relationship. Cognitive connections relate to commitment to therapy goals, while behavioural connections relate to partaking in therapy activities (King et al., 2020). More recently, the construct of engagement has gained popularity outside of mental health, with the term being applied across healthcare research fields, including allied health therapies (e.g., Melvin et al., 2020).

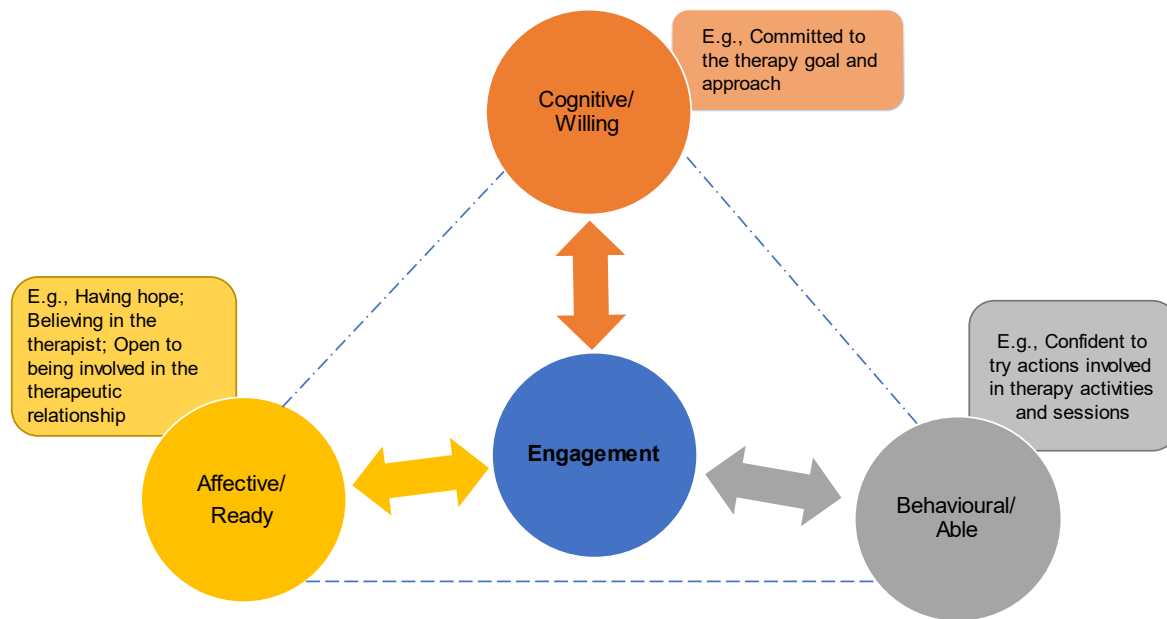


Figure 3.16 Graphic depicting my interpretation of engagement, as described by King, Currie and Peterson (2014) and King et al. (2020).

3.14 Disengagement

Despite this recent rise in interest in engagement in healthcare, disengagement appears less studied. It appears reasonable to assume that if engagement involves affective, cognitive and behavioural involvement, disengagement may occur across any or all three of these domains. For example, a person may be resistant to fully participating in a collaborative therapeutic relationship, but still complete therapy activities and exercises, albeit perhaps with less enthusiasm. Disengagement may be expressed overtly by the family, or may be inferred by clinicians from clients' behaviours (e.g., Lau et al., 2018). Overt disengagement involves the client challenging the relevance and feasibility of the intervention verbally, while inferred disengagement relates to therapists' perceptions that client participation in therapy is low in the absence of the client openly expressing dissatisfaction with therapy (Lau et al., 2018). It also appears likely that disengagement can occur without a clinician's awareness. For example, a client may continue to attend

appointments but unbeknownst to the therapist may not complete agreed therapy exercises at home. A recent study by D'Arrigo et al. (2020) suggests that engagement (and disengagement) may occur along a continuum. D'Arrigo et al. studied [OTs](#)' views of parental engagement and disengagement. The authors found that "low engagement" was described in terms of families missing appointments, adopting "negative" body language during sessions, being passive in interactions, and not completing therapy recommendations. "Middle ground engagement" was characterised as parents who were "engaged in the idea of therapy but not engaged in the doing of therapy," (D'Arrigo et al., 2020, p. 2887). High levels of engagement were characterized by routine, active participation within sessions, showing interest and enthusiasm and maintaining regular communications with the therapist.

3.14.1 Causes of Disengagement

It seems reasonable to assume that difficulties in any of the factors discussed in Part Two of this chapter (i.e., factors relating to theories of role construction or Health Behaviours) might result in a person disengaging from intervention. Indeed, the work of a number of authors aligns with this position. For example, May (2014, p. 3) argues that some treatment non-adherence should be conceptualised as "structurally induced," as it stems from restrictive policies, procedures and practices within health organisations. This appears compatible with Structural Role Theory's stance that organisations are highly influential to roles. Furthermore, Hunt and May (2017, p. 10) contend that treatment non-adherence can also be "relationally induced" by therapeutic relationships in which the clinician cannot or does not engage in shared decision-making and negotiation with clients, giving rise to treatment recommendations which clients perceive as impractical or too burdensome. This appears to align with Interactional Role Theory, with its focus on interaction. Additionally, aspects of Role Theory relating to role strain appear congruent

with the Major Theorists' Model's (Fishbein et al., 2001) position regarding the importance of self-efficacy and self-image to client's engagement with treatment (discussed below).

Role Strain

Role Theory approaches challenges to role enactment from the perspective of role strain. Role strain occurs when the enactment of a role results in significant stress, anxiety or frustration (Turner, 2001). Role Theory proposes three broad and sometimes connected categories of role strain.

1. Self-Efficacy and Role Strain

Role strain may occur when role incumbents perceive themselves to perform poorly in their role (Turner, 2001). This appears highly similar to self-efficacy. Role Theory proposes that this negative self-evaluation may stem from: a) role ambiguity, in which the person lacks clarity about the nature of their role (Brookes et al., 2007) and thus doubts their ability; b) an individual's general disposition as self-doubting; and c) the role incumbent's evaluations of how others treat and speak to them about their role enactment (Turner, 2001).

2. Self-Image and Role Strain

Role strain may also arise through role conflict, which occurs when a person holds two or more roles whose values and behaviours are not compatible with one another. Role conflict appears related to self-image. For example, an individual may conceptualise their role as a woman to involve being polite and agreeable. If this individual occupies a managerial role that requires them to challenge others' opinions and be directive, a role conflict may arise and the person may experience difficulties in enacting one or both of these roles.

3. Role Overload

Role overload occurs when a single person attempts to play multiple roles but lacks the time, energy or resources to play all roles sufficiently. It appears comparable to Shippee et al.'s (2012) discussion of a person's overall workload and how this impacts on their capacity to perform the role of the client or patient in healthcare. Rather than the person lacking the ability or resources to play the role, role overload occurs because of the number of roles that the person is attempting to play. For example, a university student who also works part-time, and has demanding roles in a number of university societies may feel overwhelmed in their attempts to play all roles to the best of their abilities.

While Role Strain by definition results in stress, anxiety or frustration, it also appears plausible that some disengagement in healthcare may occur without any negative emotional consequences for the client involved. For example, a client may knowingly choose not to engage in treatment as they do not perceive their disease or disorder as problematic or as a disease or disorder, (e.g., an adult espousing a neurodiversity perspective with regard to autism; a parent who does not share the concerns of others about their child's communication development). In such cases, a client may 'disengage' without any feelings of stress, anxiety or frustration.

3.14.2 Consequences of Disengagement in Healthcare

Much of the literature relating to rates of disengagement originates in medical studies of non-compliance and non-adherence. Thus, this literature primarily relates to behavioural disengagement and is typically comparable to the lowest level of engagement described by D'Arrigo et al. (2020). The research indicates that disengagement is not unusual in healthcare. For example, the World Health Organisation (2003) estimates that only half of all clients with chronic illness adhere to their recommended treatment regime completely.

A systematic review by Chacko et al. (2016) of interventions that involve parent training targeting behaviour, found that 25% of parents do not accept invitations to recommended interventions when offered, while a further 26% commence treatment but drop out prematurely. There is scant literature available in relation to estimated rates of engagement in [SLT](#). However, the limited research available suggests that low levels of engagements likely occur with relative frequency in [SLT](#) too. For example, a study of voice therapy found that 47% of clients did not return for scheduled therapy after their initial assessment (Portone et al., 2008). A small-scale study of parents' adherence to paediatric dysphagia recommendations found four of the ten strategies examined had an adherence rate of less than 60% (Charpentier et al., 2020). I am not aware of any studies that explored the prevalence of middle ground levels of engagement (D'Arrigo et al., 2020), however my clinical experience suggests that while such levels of engagement are not the norm, they are not uncommon in clinical practice either.

While it seems likely that disengagement may sometimes be preferred and volitional for some individuals, disengagement may impact on quality of life for others, and represents significant costs in terms of health economics for services and their funders (WHO, 2003). Medical literature estimates that non-adherence is associated with increased hospitalizations and additional secondary treatment costs related to the development or deterioration of preventable diseases or symptoms (Martin et al., 2005). Moreover, disengagement can be associated with poorer clinical outcomes for individual clients, including in some cases death (Martin et al., 2005). While there is little literature in relation to the consequences of disengagement in [SLT](#), it appears logical to assume that public healthcare systems absorb significant costs in terms of providing staff and resources for appointments that are missed due to disengagement. Additional costs may also be associated with "middle ground engagement," whereby rate of progress may be

impacted and further therapy may be required, with additional draw downs on public expenditure that were potentially avoidable (Moore & Symons, 2009).

A number of authors have suggested that disengagement can impact on the client-therapist relationship (e.g., May et al., 2009), however this is seldom explored in research. I found one early observational study by Patterson and Chamberlain (1994) of parents involved in interventions targeting behaviour management for children living in disadvantaged communities. This study found a correlation between parental disengagement behaviours and an increase in unhelpful therapist behaviours including confrontation and signalling of dislike of families. Preliminary evidence from the mental health literature (e.g., Alves de Oliveira & Vandenberghe, 2009) suggests that therapists who are routinely exposed to low levels of engagement may become less invested in their work, with some authors (e.g., Lau et al., 2018) querying if this may be a factor in therapist burnout.

Thus, the research suggests that disengagement may impact on all stakeholders: the client, the therapist, the service organization and the public who fund such services. Concerns regarding the consequences and impact of disengagement have led some authors (e.g., Haynes et al., 2002) to argue that research that yields improvements in engagement may lead to better healthcare outcomes across the population than any advances relating to specific treatments. Thus, it appears important to understand how clients make sense of their role, particularly if their enactment of their role may be interpreted as disengagement by the clinicians involved. A better understanding of how clients perceive their role and what may have contributed to these perceptions may help illuminate, to some degree, our understandings of disengagement and engagement, and thus potentially outcomes and satisfaction for all stakeholders involved.

3.15 Reflective and Reflexive Commentary

The literature discussed in this chapter triggered much reflection. In particular my reading of May et al.'s (2014) work on re-engineered patient-hood provided much food for thought. I considered my attitude to the parent role in parent-mediated interventions. I understood these interventions to be built on a solid evidence base and yet as a clinician, I often found implementing such interventions required me to “sell” the approach to parents. Often parents remained confused about these approaches or voiced their frustrations that their children weren't receiving direct intervention. I had always found such conversations difficult and had thoughts like, “They just want me to fix their child.” I had never delved deeper into where this assumed resistance was coming from. The role required in these types of interventions is dramatically different to the role involved in therapist-led direct, therapy approaches. Reflecting on re-engineered patient-hood, brought to the fore for me, a recognition that I was perceived as a power figure by some. I had never considered myself to hold any power prior to this. I and my professional community were leading a change that was in many ways instructing parents about the role they “had to” take. At what point were parents consulted about this?

May et al.'s (2014) work regarding the history of how patient-hood was reengineered highlighted for me the many different pushes and pulls on healthcare. My professional community's stance on the value of parent-mediated approaches perhaps wasn't just coming from the research; economics and politics were also likely influencing the growing popularity of these approaches to some degree. These readings challenged me to think about my assumed rationale for involving parents. How often did I use the word “empower” to rationalise the involvement of parents in therapy? Is it really empowerment if we demand someone takes a role they don't want or are uncomfortable

in? Is parent training really empowerment or is it me transferring jobs from my to-do list onto a parent's? These thoughts stayed with me throughout the PhD.

The writings on burden of treatment also brought home the work that parents take on in therapy. I reflected on how often I had qualified what I asked of parents with the word "just." "It's just five minutes a day; It's just pausing and waiting to follow his lead." It's never "just" any of those things. Taking on board any of my "just" home activities involved time and commitment, as well as the work involved for a parent to get themselves, their child and their household ready to try these strategies or activities out. I began to think more about costs and benefits in therapy. I started to recognise that up until this point, I had always assumed the costs of therapy to be minimal. I recognised the arrogance of this. I had assumed that my work would always offer greater rewards than costs. More so, I understood myself to be providing a reward through therapy. I was helping parents to help their children. Delving deeper, I realised that I had never considered parents to be helping me to help their children. This led me to interrogate how sincerely I had been relating to parents as "partners" in therapy.

3.16 Summary

This chapter provides an overview of literature regarding both perceptions of the parent role and the factors and processes that may be at play as parents attempt to make sense of their role in [SLT](#). The literature relating to perceptions of the parent role is relatively limited and largely involves attempts to define the parent role through behaviours alone. It suggests that many parents are relatively uncertain of their role but often hold role conceptions which broadly align with the Parent as Therapist-Aide Model. However, this role conception may be challenging to enact, given the literature suggesting that many services and therapists claim to espouse the Family-Centred Care Model. The literature relating to sense-making of roles suggests that a multitude of different factors and

processes may influence how parents make sense of their role. However, consensus has not yet been agreed among theorists and researchers regarding how these factors and processes relate to one another. The chapter also discusses the topic of engagement and disengagement, and the potential significance of these constructs to health economics, quality of life of clients and job satisfaction of health professionals. I argue that research regarding the client role may help to illuminate understandings of engagement and disengagement further and thus may benefit all stakeholders. The next chapter moves beyond the literature that forms the foundation for understanding parent roles, to explore the study's methodological approach.

Chapter 4: Methodology

4.1 Introduction

This chapter presents the methodology of the [IPA](#) study. It begins by stating the research questions, before discussing the research paradigm, methodology and methods involved in the study. It concludes with a discussion about reflexivity.

4.2 Research Questions

This thesis, and the core [IPA](#) study that drives it, are centred on the following research questions:

1. How do mothers of children on the autism spectrum perceive their role in [SLT](#) in Ireland? (i.e., what do they perceive their role to be)
2. How do mothers of children on the autism spectrum in Ireland make sense of their role in [SLT](#)?

These research questions are exploratory and focused on enhancing understandings of parent involvement in therapy. The nature of these questions both revealed and influenced my alignment with the constructionist research paradigm discussed below.

4.3 Research Paradigms

Research paradigms refer to the worldview or belief systems that guide researchers (Guba & Lincoln, 1994). A range of different paradigms exist, including post-positivism, constructionism and critical theory. A researcher's understanding and self-awareness of the paradigm from which they orient their research is important in terms of designing a robust study (Crotty, 1998). It should inform what types of knowledge are considered possible and legitimate (Crotty, 1998), thus having implications for methodological choices, the design of research questions and quality appraisal methods, as well as impacting on

how and what the researcher understands the findings to reflect. Brown and Dueñas (2020) suggest that a number of different interlinked components underpin a researcher's alignment towards a particular paradigm, including axiology, ontology and epistemology.

Axiology refers to the study of value, and is concerned with judgements of value and worth (Crowe, 2020). A core axiological concern in research relates to what science should be valued (Deane, 2018), for example causal, correlational or exploratory. Brown and Dueñas (2020) suggest that researchers should interrogate the motivation and values underpinning their interest in the research topic. In particular the authors discuss the importance of reflecting on what a researcher hopes to achieve (e.g., to explore, explain, measure or describe.) Ontology encapsulates how a researcher perceives the nature of reality (Petty et al., 2012). For example, is reality understood as singular and stable or subjective in nature. Epistemology refers to theories of knowledge (Crotty, 1998) and captures a researcher's philosophy of what knowledge is and how it can be studied (Petty et al., 2012). Epistemology may inform a researcher's stance on whether research garners objective or subjective knowledge, knowledge that is independent of influence from the researcher or co-constructed between the researcher and participants, as well as the researcher's position regarding the generalisability and transferability of findings. Different paradigms vary according to axiology, ontology, and epistemology. I reviewed a number of different paradigms at the beginning of my research journey, including positivism, post-positivism, constructionism and critical theory. The nature of my research interests, coupled with the aims of this study, and my general philosophical leanings, positions this research study in the constructionist paradigm. I discuss this paradigm and justify my alignment with it, below.

4.3.1 Constructionism

Axiology

Constructionism aims to increase our understanding of the lived experiences of people, rather than to establish universal laws of cause and effect or prediction (Chen et al., 2011).

Ontology

Constructionism is informed by a relativist ontology. The relativist ontology emphasises that we form meaningful 'realities' through our interactions and experiences with the world (Willis, 2007). In a world without people, there will still be a natural world with trees and oceans and mountains etc., but relativists argue that without people, things have no meaning and so this world has no meaningful reality (Crotty, 1998). Constructionists are concerned with understanding social realities. From a relativist perspective, social realities are not tangible 'things' that humans interpret, but instead are both composed of and informed by these interpretations (Blaikie, 1993). Interpretations are the dynamic product of context-bound individuals interacting with others to negotiate meaning (Blaikie, 1993) People give meaning to these 'things' and meanings develop through our experiences and interactions.

Epistemology

Constructionism's relativist ontology informs the subjectivist epistemology that it adopts. Constructionism views knowledge as subjective and inseparably intertwined with context (Chen et al., 2011). Constructionists stress that knowledge is continually constructed and reconstructed through our interactions and experiences (Schwandt, 2000) and is not something static that can be revealed. They posit that when we experience something we develop an internal concept or model of it. This internal concept adapts and changes as we gain further experiences and interact more (Schwandt, 2000). Constructionists argue that during research, knowledge is co-constructed between the inquirers and participants,

rather than revealed by the researcher (Costantino, 2008). Participants come to research with interpretations of their experiences informed by their context and interactions within society. In partaking in research, their interpretations may be reconstructed again through, for example reflections triggered by the researcher's discourse. The researcher also approaches the study with prior interpretations that will be reconstructed repeatedly through the research process. Thus, through the inquiry process new meanings are constructed by both the researcher and the participants. As knowledge is co-constructed rather than revealed, constructionists emphasise the importance of describing and analysing the knowledge construction process in order to make sense of the meanings constructed, and view researcher reflexivity as integral to the research process (Chen et al., 2011). The significance placed on context, as well as the co-construction of knowledge, contributes to cautious approaches towards the extension of research findings to other populations. Constructionists universally do not perceive their findings to be generalisable, but hold varying stances with regard to the transferability of findings (Chen et al., 2011).

Critique

The constructionist paradigm is often celebrated for its focus on 'life' rather than 'lab' experiences (Crotty, 1998). While other paradigms, for example, the post-positivist paradigm, may be helpful in examining isolated aspects of human functioning, their demands for objectivity and methodological controls can lead to results that feel far removed from the human experience. For example, the Lee Silverman Voice Treatment is a therapy programme that targets low speaking volume associated with the speech disorder dysarthria. A post-positivist, randomised control trial by Ramig et al., (2001) showed statistically significant improvements in objective measures of voice loudness on tasks including sustained vowel phonation, reading a passage and producing a

monologue. These objective results are extremely encouraging but tell us little about the subjective meaning of the results. For example, how, if at all, did the treatment impact on participants' participation and enjoyment of life? Constructionism with its recognition and respect for multiple sources of knowledge allows us to explore the 'lived experience' (Willis, 2007) and reduces the disconnect between research and life that is often apparent in positivist and post-positivist studies. The constructionist paradigm recognises the significance and influence of human agency. While positivism and post-positivism are useful, and easily and appropriately applied in physical sciences, the world as experienced by humans can be a very different world to the physical one. Thoughts and feelings are not objective and cannot be controlled for and therefore from a positivist perspective are not credible sources of knowledge (Crotty, 1998). In positivist and post-positivist research paradigms, studies of humans are reduced to what can be observed – behaviours. By contrast, constructionists acknowledge and celebrate human agency and the role it plays in creating subjective realities, arguably leading to knowledge that is richer and closer to our lived experiences than positivist and post-positivist studies (Willis, 2007).

A major criticism of constructionism relates to its relativist ontology. Critics question how can it be claimed that there is no reality. For example, with regard to the health sciences, Broom and Willis question (2007, p. 27) "What can be more 'real' than cancer, pain or diabetes? How can it be argued that these phenomena are socially and culturally determined rather than purely physiological conditions?" In practice, constructionists studying such conditions tend to take a 'middle ground' approach (Broom & Willis, 2007), differentiating between natural reality and social reality (Dilthey & Rickman, 1976, as cited by Crotty, 1998). Natural reality relates to the physical world in which we reside and can be extended to the physical aspects of human existence – our body as a physical vessel. Social reality refers to the world of subjective human experiences, thoughts, feelings and

judgements (Crotty, 1998). Thus, cancer or pain or diabetes manifests in both the natural and social reality – it is something physical but how the person interprets it gives it meaning. For example, is it a source of fear or a challenge to fight back against? Is it the person's or the whole family's? This 'middle-ground' approach to relativism informs my research philosophies.

Epistemology in constructionism also attracts criticism. Subjectivism has been accused of creating an 'all views are equal' pseudoscience (Matthews, 1998). Matthews argues that subjectivism fails to distinguish between the perspective of the objective scientist and "flat-earthers," astrologists and creationists. Here Matthews seems to have confused the focus of constructionist research – its focus is on increasing understanding. Constructionism does not attempt to answer questions regarding causality, prediction or truth. From a constructionist perspective, any questions, relating to "flat-earthers," astrologists or creationists would relate to their perceptions, experiences and interactions and how these contribute to interpretations. Constructionists do not seek to address questions relating to whether the views of "flat-earthers" are right or wrong, but to understand how those views are formed and experienced.

Subjectivism also lends itself to accusations of bias and of questionable validity and reliability. Constructionists take the position that their findings are context-bound and co-constructed. If findings vary according to context and cannot be replicated, then some positivists and post-positivists argue that they are no more than anecdotal accounts rather than the conclusions of scientific study (Schuermans, 2013). This criticism is difficult to resolve, given that constructionists agree that the researcher influences any knowledge constructed, but contend that researchers influence all knowledge constructed, regardless of the paradigm espoused (Giorgi, 2000). For example, in choosing what measures to use, or what populations to target in an experiment, a researcher may influence which effects

are observed and which go unevaluated and undiscussed. While questions of validity and reliability may not be perceived as appropriate under constructionism, the paradigm allows for other approaches to manage the quality of the research and findings. Such approaches are discussed later in this chapter.

A final critique of constructionism originates in those researchers who espouse critical theory. Critical theorists argue that rather than simply seeking to understand and describe phenomena, research should also seek to transform society by revealing and critiquing hidden power relationships (Chilisa, 2012). However, demanding that research should always seek to transform suggests an assumption that subjective realities of participants involve 'problems' that requires transformation (Willis, 2007). While it is admirable to aspire to transform, such an approach may not be well suited to exploratory studies.

Justification for My Constructionist Position:

Different paradigms reflect different philosophies and different researcher curiosities. I am interested in understanding and describing the parent experience of [SLT](#). Such an interest is not compatible with positivist and post-positivist approaches which seek to answer questions of causation and prediction (Willis, 2007). While I was motivated to do this PhD because of frustrations stemming from my clinical experiences, I was also keen to approach the phenomenon from an exploratory position and to attempt to limit my presuppositions within reason. Thus, I did not aim to produce research that would be transformative. This limited the compatibility of the study with critical theory. Additionally, my reflections regarding ontology and epistemology helped me to identify more readily with relativism and subjectivism, albeit while still understanding the merits of realism and objectivism to the advancement of scientific study. This position is most compatible with

constructionism. An awareness of this helped to guide and ground my choice of methodology, discussed in the next section.

4.4 Methodology

A research methodology refers to the general philosophical and theoretical system that researchers use to guide decision-making and interpretation in research (Willig, 2013). A researcher's choice of methodology should match the paradigm a researcher aligns with and be compatible with the research questions (Crotty, 1998). This study's primary methodology is Interpretative Phenomenological Analysis ([IPA](#)). [IPA](#) is a qualitative research methodology that was founded by Jonathan Smith (Biggerstaff & Thompson, 2008). [IPA](#) aims to increase understanding of how particular people experience particular phenomena of meaning to them (Smith et al., 2009). [IPA](#) seeks to describe an experience, and interpret it in relation to the person involved – how does the person who had this experience make sense of the experience and what meaning does the experience hold for them (Smith & Osborne, 2003).

4.4.1 Justification for the Choice of IPA

Exploratory Nature and Inductive Approach

As discussed in Chapter 3, research in the area of parent involvement in [SLT](#) is limited. As such, I considered an exploratory rather than explanatory approach appropriate. [IPA](#) approaches research topics and questions from an exploratory stance (Smith et al., 2009). Alternative methodologies, such as Grounded Theory, were considered for this study, however these approaches seek to explain phenomena (Willig, 2013) and so were not compatible with the research questions. [IPA](#) research is primarily inductive (Smith, 2004). Inductive research is driven by the data collected. It looks for patterns and concepts in the data in order to form hypotheses (Fox, 2008), rather than starting with a pre-existing theory or hypothesis and gathering data to test out these hypotheses as is the case in deductive

research. [IPA](#)'s emphasis on induction is compatible with the exploratory nature of this study. The [IPA](#) researcher forms a broad research question that allows a breadth of rich data to be collected. In doing so the participants' understandings can emerge freely (Smith et al., 2009). Smith et al. (2009) note that in practice, [IPA](#) also involves some degree of deduction as researchers always come to studies with prior knowledge and understandings that may influence data collection and analysis. This recognition of both induction and deduction in the research attracted me to [IPA](#). Other methodologies claim to adopt an exclusively inductive approach to analysis, for example, classical Grounded Theory (Willig, 2013). My relativist ontology and subjectivist epistemology lend towards a view that purely inductive research can only ever be aspirational.

Idiographic

My clinical experience suggests that clients and families' experiences of the same phenomena are never the same and yet are often similar. I recognise and embrace the importance of exploring commonalities in experiences, in order to maximise the potential impact on clinical practice. However, I also contend that to produce research that reflects only what is shared, provides an overly simplistic account and does not echo the clinical realities facing practitioners and parents. While some methodologies, for example, Giorgi's Descriptive Phenomenological Method (Giorgi, 2009), are interested in only the commonalities of an experience, [IPA](#) seeks to discover both the shared and the unique experiences of phenomena (Wagstaff & Williams, 2014). It strives to take an idiographic focus – To provide a rich and detailed analysis of how a particular phenomenon is understood from the perspective of a particular person/ group of people who experience that phenomenon within a particular context (Smith et al., 2009). [IPA](#) advocates that the researcher analyses each single case in detail to develop an understanding of that particular person's view of an experience, before conducting a cross-case analysis (Smith,

2004). This cross-case analysis explores how participants' accounts of the same phenomena converge and diverge – what is unique and what is shared (Smith, 2011). In doing so, [IPA](#) aims to retain the individual voices of the participants involved, even the voices which may be dismissed as statistical outliers from other methodological perspectives.

The idiographic focus of [IPA](#), has also been viewed as limiting. For example, Pringle et al., (2011) report that it may be viewed as a barrier to theory generation as the findings are not generalizable. However, [IPA](#) findings are considered transferable. Transferability relates to research findings that act as local guidelines which foster understanding of people or events in a particular context and time, rather than acting as hard rules that apply across all contexts to all people (Willis, 2007). Additionally with regard to theory generation, Caldwell (2008) argues that while the primary purpose of [IPA](#) is not theory generation, it can play a role in helping to explain phenomena, when accumulative techniques across studies are applied. This involves the [IPA](#) study being reviewed in relation to other studies on the same topic. Willig (2013, p. 94) surmises the benefit of using accumulative techniques as follows: "Rather than relying on one isolated qualitative study, we aim to integrate the findings from a number of comparable studies to draw wider conclusions."

Shared Philosophy of Methodology and Researcher

As discussed above, I subscribe to constructionism. This paradigm is compatible with [IPA](#) but not many other methodologies. For example, Giorgi's Descriptive Phenomenological Method (Giorgi, 2009) promotes an interpretivist philosophy and Action Research is heavily influenced by Critical Theory. Constructionism's stance that knowledge is co-constructed between the researcher and participants aligns well with the principle of double hermeneutics which guides [IPA](#). The [IPA](#) researcher endeavours to access (as

closely as possible) humans' interpretations of their experiences. Thus, my research aims to describe parents' *interpretations* of therapy roles. In attempting to get close to the parent experience, I interpret parents' accounts, thus interpreting their interpretations. This is referred to as double hermeneutics – the researcher is interpreting the participants' interpretations of the experience (Smith et al., 2009). Unlike some phenomenological methodologies, for example, Giorgi's Descriptive Phenomenological Method (Giorgi, 2009), [IPA](#) proposes that the researcher can only ever *attempt* to 'bracket' off their own beliefs, values, assumptions, in order to view the data without bias (Smith et al., 2009). The [IPA](#) researcher engages in researcher reflexivity in order to bring these beliefs, values and assumptions to the fore of their awareness and then engages with this awareness when attempting to understand/ interpret the participants' experiences (Willig, 2013).

IPA as a Novel but Compatible Methodology

Relatively little research has been conducted in the area of parents' perceptions of therapy roles in [SLT](#). The majority of studies reviewed used thematic analysis to analyse all or some of the data collected (e.g., Lyons et al., 2010). Some studies opted for different methodologies, for example a mixed methodologies approach was used by Carroll (2010) and Davies (2014), and grounded theory was applied by Marshall et al., (2007). One study (Hoogsteen & Woodgate, 2013) used a phenomenological approach. However, this study broadly focused on the experience of parenting a child with autism. No study reviewed used an [IPA](#) approach, and therefore adopting [IPA](#) offered the opportunity to add to the knowledge on this topic from a different perspective.

4.5 Overview of Research Design

The research project involved a core [IPA](#) study, two survey studies and a deductive analysis of additional interview data. This design was born out of my constructionist leanings, status as a novice researcher and reflective learning style. This research began

as a traditional [IPA](#) study involving data gathered from six mothers of children on the autism spectrum. This stage involved in-depth individual case analyses and my first attempt at a cross-case analysis, which gave rise to three superordinate themes. Following this preliminary cross case analysis, I doubted my understandings of the participants' experiences, particularly in relation to two of the themes. To explore these themes further and broaden my understanding of these two themes, I then completed two survey studies. The surveys were supplemental to the core, [IPA](#) study and were most significant in opening further iterative cycles of analysis regarding the core [IPA](#) data. As such, the design and results of the survey studies are discussed separately in chapters 5 and 6. Following completion of these survey studies, I returned to the [IPA](#) study to interrogate my original findings further and conducted a repeat but in-depth cross-case analysis. This further layer of scrutiny moved my analysis from one that was primarily descriptive to an analysis that was also interpretative. Four final super-ordinate themes were constructed at this point. Owing to my uncertainty about my competency as an [IPA](#) researcher, and my early doubts about if [IPA](#) study was sufficient to meet the criteria for a PhD, I decided to conduct an auxiliary, deductive analysis. I was also curious to know whether the themes were unique to the IPA participants or had a more general value. These factors prompted me to conduct an auxiliary, deductive analysis. This deductive analysis was based on interview data from six additional mothers of children on the autism spectrum. It was designed to investigate if the superordinate themes from the [IPA](#) analysis were evident across other cases. The final layer of analysis and theme construction occurred as I wrote up the study and attempted to bring all my findings together.

Figure 4.1 depicts an overview of the overall research project. The survey studies and deductive analysis are depicted as peripheral to the research process, as their most significant contribution was to activate further reflections and different interpretations of the

[IPA](#) data. Although on first inspection, this study might be considered a mixed-methods study, in fact it is an [IPA](#) study focused on idiographic perceptions and sense-making, but complemented by data from survey analysis and a deductive analysis of additional data sets. The current chapter discusses the design and methods of the [IPA](#) study and auxiliary deductive analysis.

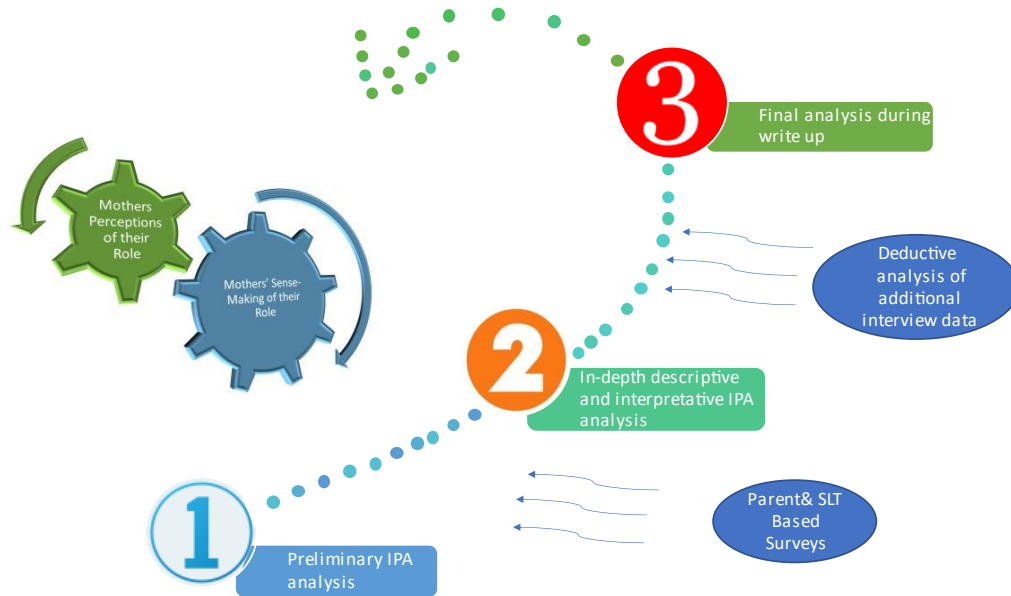


Figure 4.1 Graphic depicting the overall research project process.

4.6 Ethics

Ethical approval for the study was granted by the School of Linguistic, Speech and Communication Sciences in Trinity College Dublin (see [Appendix A](#)). Christians (2005) and Willig (2013) recommend that researchers observe the ethical principles related to participants' right to withdraw, informed consent, no deception and privacy and confidentiality. I attempted to address these principles through my recruitment, data collection and analysis process, and data storage procedures.

Participants were recruited through advertisements about the study posted online. Those who responded were sent a participant information leaflet (see [Appendix B](#)), highlighting that participation was voluntary and outlining information to facilitate informed consent. During a phone call to schedule interviews, the research process was verbally summarised. On the day of the interview the participants were again given verbal information on the study and reminded that participation was voluntary. Written consent was obtained and the participant completed a consent form (see [Appendix C](#)). Following transcription, the participants were provided with written transcripts of their interviews, and offered the opportunity to request changes, ask for clarification or to withdraw consent for the use of the data. No changes were requested. This study involved full disclosure of the purpose of the research, the procedures involved in data collection, and who I was. As such this study involved no deception.

In all transcripts, pseudonyms are used to refer to the participants, and family members and professionals discussed by them. A password protected document with a key linking pseudonyms to the participant's identity was created and kept on an encrypted USB key. The participants are referred to by their pseudonym in all other documentation. To further protect confidentiality, names of non-[HSE](#) agencies, and geographic areas were described rather than named.

4.7 Sampling

4.7.1 Criterion Sampling

This interview-based study used criterion sampling. This sampling method involves the selection of participants who fulfil specified inclusionary criteria (Palys, 2008). Smith et al. (2009) advocate for the use of criterion sampling in [IPA](#) research in order to access a

homogenous population who all share a lived experience of the phenomenon being explored. The criteria required for participation in interviews were:

1. Person above 18 years.
2. Parent of a child or children on the autism spectrum.
3. The child on the autism spectrum must be primary school-aged, (i.e., between the ages of 4:0 years and 13:0 years.)
4. The participant had no previous personal or professional relationship with me.

Rationale for Inclusionary Criteria

The decision to target parents of primary school aged children was guided by a number of factors. I hypothesised that parents in this group may offer rich data stemming from their potential to have a greater range of experiences to draw from, in terms of models of service delivery and types of therapy approaches, than parents of toddlers. Additionally, parenting children in this middle-childhood age range, is typically focused on beginning to prepare a child for greater independence and autonomy (Collins & Madsen, 2019). Middle childhood is typically associated with significant leaps in a child's cognitive, social and emotional development (Collins & Madsen, 2019). My clinical experience suggests that many parents of children with disabilities perceive the gap between their child and his/her peers to widen during middle childhood. I theorised that this may contribute to parents reflecting on therapy and their role in it to a greater degree, thus potentially offering greater insight into the phenomena of interest. Additionally, this age range was chosen, as I anticipated that children of this age were less likely to have received their diagnosis in the recent past, and as such their parents may be psychologically more prepared when reflecting on potentially upsetting experiences. I also specified that participants should have no prior professional or personal relationship with me, to facilitate participants speaking freely about their experiences.

4.7.2 Recruitment

Eide (2008) proposes that a key principle of recruitment in qualitative research is that the researcher must identify and invite the participants who are best placed to inform the research topic. In striving to adhere to this principle, I advertised the study through internet forums, parent groups, and advocacy groups for children with special needs (or specifically children on the autism spectrum). Data collection in response to this strategy was initially slow, so I later changed my recruitment approach. I advertised the study directly through schools via school newsletters and also by providing presentations on the study to parents on school sites. All interviews took place a minimum of seven days after the initial date of contact. Figure 4.2 below shows a timeline of the data collection process

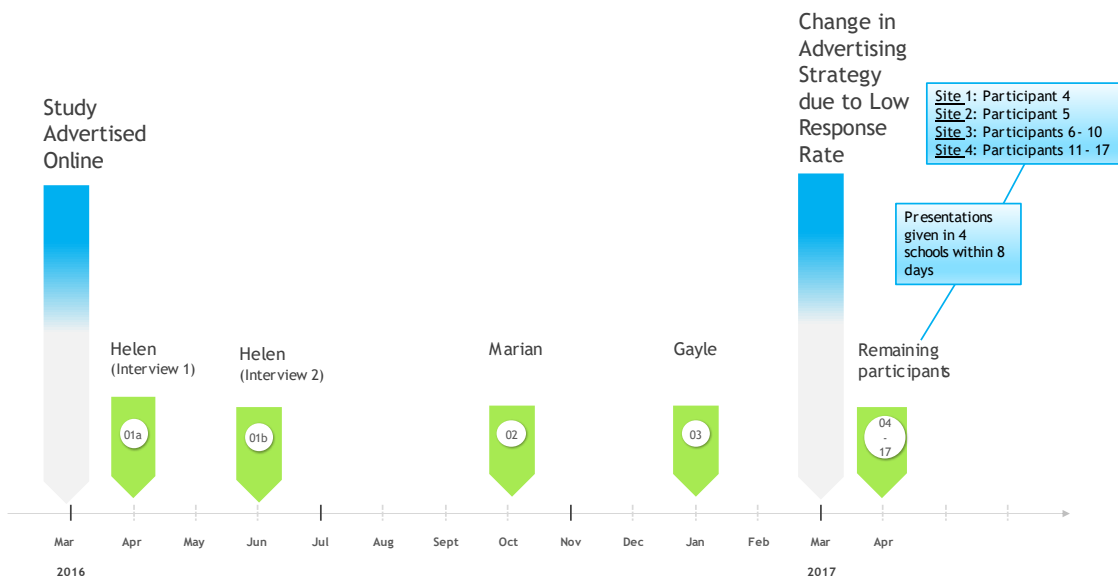


Figure 4.2 Timeline of Data Collection

Sample Size

Small sample sizes are recommended in [IPA](#), in order to fulfil its commitment to rich, detailed analyses and an idiographic focus (Smith et al., 2009). Sizes typically range from single case studies to approximately 10 participants (Smith et al., 2009).

Pietkiewicz and Smith (2012, p. 364) recommend that decisions about sample sizes in [IPA](#) studies, should be guided by four considerations, “1. the depth of analysis of a single case study, 2. the richness of the individual cases, 3. how the researcher wants to compare or contrast single cases, and 4. the pragmatic restrictions one is working under.”

Over the course of data collection, I conducted 18 interviews with 17 participants (the first participant was interviewed twice.) Three participants were interviewed over a ten-month period. Following the change in recruitment strategy, 14 participants self-selected to partake over an 8-day period. This was unexpected as prior to this data collection had been slow. I was aware that a sample size of 17 was not compatible with a high-quality IPA study, particularly given my novice researcher status. However, I felt compelled to accept all of the final 12 participants as they had all approached me in person, as two cohesive groups, who had all attended the same two presentations together (held on consecutive days). I understood the ethical dilemma inherent in interviewing 14 further participants when I knew in advance that not all participants could be included in my study, owing to both IPA’s commitment to idiography and the time involved in completing each case analysis (Smith et al., 2009). However, knowing that the potential participants were known to each other, I was also concerned about the potential implied message in inviting only some of the 14 parents to an interview that they were ‘more interesting’ than others. Furthermore, I was aware that high-quality IPA requires rich, reflective data (Spiers & Riley, 2019), and without any prior knowledge of any of the final 14 participants, it was difficult to determine who, if any, would provide such data. I decided to interview all of the 14 participants and to then cease data collection.

Following data collection, I began the difficult process of selecting which interviews to use for analysis. One of the 17 participants demonstrated limited fluency in English during the interview and difficulty understanding the interview questions and so I excluded

this case from the dataset. I was dedicated to producing a thesis in which the voices of individuals were not lost into a collective experience. I was concerned that sample sizes closer to 10 would dampen individual participants' voices. I was also aware of maintaining quality in the study, and that [IPA](#) is dependent on accessing rich data from participants. I reviewed the interviews completed. I noted that I felt more drawn to use some interviews over others, because I had experienced them as both a thought-provoking and emotional experience. I also noted the interviews in which I had been most struck by the participants' openness and the level of intimate details shared with me. Finally, I utilised Spiers and Reilly's (2019) definition of rich data to further guide my selection. They characterise rich data in [IPA](#) as data involving deep insight and reflection, interesting language or novel accounts. Table 4.1 below provides an overview of my review of each case. This led to the selection of six cases for [IPA](#) analysis.

IPA Participants

As discussed above, the core [IPA](#) study involved six participants. All six participants were married mothers with more than one child. Half the sample reported being in paid employment. The demographic details of the participants are presented in Table 4.2 below. Each participant had one child on the autism spectrum, ranging in age from 4 to 12 years. The majority of children were reported to have other co-occurring diagnoses, including two with Oppositional Defiance Disorder ([ODD](#)), two with Attention Deficit Hyperactivity Disorder ([ADHD](#)) and two with Global Developmental Delay ([GDD](#)). Further details about their children's diagnoses and educational placements are presented in Table 4.3. An overview of the children's experience with [SLT](#) is provided in Table 4.4. The participants reported working with [SLTs](#) episodically over a range of 2 to 10 years, (median = 2.75 years). All but one participant reported engaging with both publicly- and privately-funded [SLTs](#), in both uni-disciplinary and multidisciplinary teams. All participants

reported interacting with a number of different health professionals, including [OTs](#), physiotherapists and psychologists. With regard to [SLT](#), half of the sample reported receiving a mixture of direct and indirect therapy; two participants only had experience of direct therapy and one participant had experience of indirect therapy only.

Participant Number	Deep Insight & Reflection	Interesting Language	Novel Account	Open, detailed account	Instinctually drawn to account	Comment	Decision
01	√	√	√	√	√		IPA Analysis (Helen)
02	√	√		√	√		IPA Analysis (Marian)
03	√	√		√	√		IPA Analysis (Gayle)
04				√		Experience of assessment only. No experience of therapy.	Not selected for analysis
05	√		√				Deductive Analysis (Susan)
06	√			√			Deductive Analysis (Sinead)
07		√	√	√	√		IPA Analysis (Mel)
08		√				Short interview. Participant did not appear comfortable sharing details with me.	Not selected for analysis
09	√		√				Deductive Analysis (Sarah)
10						Participant did not appear to understand many of the questions.	Excluded due to concerns regarding

							English comprehension
11	√	√		√	√		IPA Analysis (Gloria)
12	√		√				Deductive Analysis (Robyn)
13	√			√			Deductive Analysis (Trish)
14		√		√			Deductive Analysis (Mary)
15	√	√		√	√		IPA Analysis (Mila)
16						Participant focused on concrete behaviours and events and did not appear comfortable reflecting on why and how questions.	Not selected for analysis
17						Participant focused on concrete behaviours and events and did not appear comfortable reflecting on why and how questions.	Not selected for analysis

Table 4.1 Details of my review of all interviews which guided data selection

	Helen	Gayle	Marian	Mila	Mel	Gloria
Province	Munster	Leinster	Leinster	Leinster	Leinster	Leinster
Ethnicity	White, Irish	White, Irish	White, Irish	White, European	White, Irish	White, Irish
Age Bracket	40 – 50 years	30 – 40 years	30 – 40 years	30 – 40 years	30 – 40 years	30 – 40 years
Educational Background	Completed university	Completed university	Completed university	Completed secondary school	Completed secondary school	Completed university
Occupational Status	Full time carer at home	In paid employment full time	Full time carer at home.	In paid employment part-time	Full time carer at home	In paid employment part-time
Marital Status	Married	Married	Married	Married	Married	Married
Family Profile	Living with husband and three children.	Living with husband and two children.	Living with husband and two children.	Living with husband and two children.	Living with husband and two children.	Living with husband and two children.

Table 4.2 Demographic details of the core IPA study’s participants

	Helen	Gayle	Marian	Mila	Mel	Gloria
Child's Pseudonym	John	Liam	Cormac	Nina	Stephen	Jake
Diagnoses	Autism, ODD	Autism	Autism, ODD , ADHD , intermittent hearing loss.	Autism, GDD	Autism, ADHD ,	Autism, GDD
Age of child when diagnosis of autism given	11 years	2 years	4 years	4.5 years	3 years	2 years
Age of Child at time of interview	12 years	5 years	8 years	7 years	4 years	5 years
Type of School Placement	Mainstream class in mainstream primary school	Mainstream class in mainstream primary school	Mainstream class in mainstream primary school	Mainstream class in mainstream primary school	Autism outreach class in mainstream school	ABA Preschool, awaiting placement in autism outreach class

Table 4.3 Details of core IPA participants' children's diagnoses and educational placements.

	Helen	Gayle	Marian	Mila	Mel	Gloria
Age when child first seen by SLT	18 months	3 years	2.5 years	4.5 years	2 years	2 years
Funding	Mix of private and public	Mix of private and public	Mix of private and public	Mix of private and public	Public only; pending commencement of private SLT	Mix of private and public
Team Set Up	Uni-disciplinary & Multidisciplinary	Uni-disciplinary & Multidisciplinary	Uni-disciplinary & Multidisciplinary	Uni-disciplinary & Multidisciplinary	Uni-disciplinary & Multidisciplinary	Uni-disciplinary & Multidisciplinary
Direct/ Indirect Therapy	Direct and indirect therapy	Direct and indirect therapy	Direct therapy	Direct therapy	Direct and indirect	Indirect
Individual sessions/ Group sessions	Mix of blocks of individual and group therapy	Mix of blocks of individual and group therapy	Mix of blocks of individual and group therapy	Mix of blocks of individual and group therapy	Individual therapy only	Mix of blocks of individual and group therapy
Location of sessions	Clinic based	Clinic based	Clinic based	Mix of home and clinic-based therapy	Clinic based with school visits	Clinic based
Areas of communication targeted as reported by participants	Engagement, receptive and expressive language, articulation, pragmatics, verbal reasoning	Pragmatics, food aversions	Phonology, Articulation and pragmatics	Receptive and expressive language; pragmatics	Attention, engagement, turn-taking, AAC , vocabulary	Attention, engagement, receptive and expressive language

Table 4.4 Details of core IPA participants' experiences with SLT as reported by participants

4.8 Data Capture

I used semi-structured interviews to collect data from participants. Smith et al. (2009) note that in-depth semi-structured interviews are frequently used and highly compatible with [IPA](#) research. In semi-structured interviews, researchers rely on a set of predetermined questions to guide the interview (Ayres, 2008). Flexibility and responsiveness are facilitated through the use of unplanned questions and not all planned questions must be asked (Ayres, 2008). While interviews are commonly used in qualitative research (Willig, 2013), they are not without criticism. Common critiques of interviews are presented below. This is followed by a discussion of my rationale for choosing semi-structured interviews and an overview of how interviews were conducted in this study.

4.8.1 Critique of Interviews as a Method

Veracity and Authenticity

Critics of interviews as a method argue that interviews are reliant on 'honest' participants who tell the 'truth' (Ten Have, 2004). Proponents of interviews contend that fostering an open and non-judgemental atmosphere and building a rapport with participants mitigates the risk of conscious mistruths (Ten Have, 2004). However, researchers who espouse constructionism view interviews as "situated, constructed reports, not actual representations of facts or 'true' experiences," (Koro-Ljungberg, 2008, p. 431). As such, I view concerns regarding the veracity and authenticity of interviews as having limited relevance to this study.

Influence of Context & Interaction

Willig (2013) notes that interview data, when engaged with naively, lends itself to an over-simplified analysis that can fail to account for the influence of context and interaction on

the data yielded. Potter and Hepburn (2005) note that the content and manner of questions asked by researchers impact on the responses provided, and yet published studies frequently only include quotations from participants, and omit the surrounding data, including the question asked. They also highlight the potential influence of footing in interview data (2012). Footing relates to the different roles speakers can play. For example, the participants in this study were aware that I was also a working clinician. It is plausible that the same participant may provide different responses to the same questions, depending on their perceptions of the salient identity of the interviewer. For example, participants who viewed me primarily as a clinician may have felt compelled to answer more positively and politely, than those who viewed me more as a researcher. Potter and Hepburn (2005) argue that such issues are difficult to manage in interviews and advocate for using naturalistic records, such as everyday conversations, instead. However, achieving a rich, detailed account of the phenomenon of interest through naturalistic methods would likely require a great deal of time and resources and even more luck. With this in mind, I chose to use interviews but to commit to diligently engaging in researcher reflexivity (discussed below) to bring heightened sensitivity of the impact I had on data collection, analysis and outcomes.

Interviews' Dependence on Language

Interviews are reliant on participants using language to respond. Much theoretical debate exists among qualitative researchers regarding the role of language in describing versus constructing experiences (Willig, 2013). Viewing language solely as a descriptive tool suggests a belief that language is representational. Such a standpoint opens interview-based research to the criticism that the data collected will always be impacted by participants' linguistic competencies (Willig, 2013). The counter argument proposes that language is constitutive, actively involved in the construction of realities and experiences

(Willig, 2013). Proponents of language as constitutive exist along a spectrum. Some (e.g. Berger & Luckmann, 1991) contend that language predates cognition and acts as an inherited cultural symbol that shapes thoughts (Andrews, 2012). Rather than viewing language as the driver of thought, Willig (2013) notes that language may be perceived as a tool used to make sense of our thoughts and to construct a subjective reality. This position suggests that interview-based research yields data about how an individual “talks about” their experience, rather than “the experience itself”, (Willig, 2013, p. 282). My interpretation of [IPA](#) suggests that it is most compatible with this latter constitutive position. [IPA](#), with its reverence for double hermeneutics, openly acknowledges that analysis of interview data yields a researcher’s interpretation of the participants’ interpretation. However, I also consider the criticisms of language as representational as relevant to [IPA](#) interviews. [IPA](#) interviews are reliant on participant data that is linguistically, psychologically and emotionally rich. Accessing such data is dependent on both the participants and interviewers involved. The richness of the data will ultimately determine the level to which a researcher can engage with the topic, to develop a deeper insight into the participant’s lived experience.

4.8.2 Rationale for Using Interviews

As discussed above, semi-structured interviews are not without their limitations. [IPA’s](#) idiographic focus demands rich data that provides an insight into participants’ thoughts, feelings and sense-making related to their specific experiences (Smith et al., 2009).

Additionally, [IPA](#) promotes a primarily inductive approach to research. These commitments preclude certain methods of data collection from [IPA](#) research. For example, structured interviews and questionnaires do not facilitate induction. Data collection methods such as semi-structured interviews and unstructured interviews are highly compatible with the principles of [IPA](#) (Smith et al., 2009). Focus groups (e.g., Love et al., 2020) and

observational methods (e.g. Larkin & Griffiths, 2002) have also been used to conduct [IPA](#) research successfully. However, Smith et al. (2009) caution that certain methods, while compatible are complex to do well in [IPA](#) research and as such may not be suitable for novice researchers. For example, extrapolating idiographic experiences from focus group data, which may be more prone to constructing a collective account, can be more challenging (Love et al., 2020; Tomkins & Eatough, 2010). Smith et al. (2009) also suggest that unstructured interviews can be unpredictable and require great skill to maintain interview flow. Owing to its compatibility with [IPA](#) as a methodology and my inexperience in research, I decided to use semi-structured interviews in this study.

4.8.3 Overview of Use of Interviews for this Study

Smith et al. (2009) recommend beginning the interview with an open, descriptive question that invites the participant to adopt the role of the main speaker. They caution against the use of leading questions, closed questions and over-empathic questions, which may unduly influence the participants' responses or damage the interviewer-respondent relationship. I used these guidelines to support the development of the interview schedule shown in [Appendix D](#). All participants had one interview, with the exception of the first participant Helen, who was interviewed twice (an initial interview and a second clarifying interview). This reflected my status as a novice researcher. On beginning analysis of Helen's case, I became aware of occasions in which I had not prompted her to expand or probed certain aspects of her experience for more detail. Following Helen's interviews, I was careful (and more comfortable) in encouraging participants to give more detail and engage with topics more. Interviews ranged from 55 to 112 minutes, with a median duration of 99 minutes. Further details regarding the length and composition of each interview are found in Table 4.5 below. Each interview took place in a location selected by participants – five in the participant's home and in the case of Gayle, at her place of work.

4.9 IPA Analysis

While Smith et al., (2009) offer a recommended approach to [IPA](#) analysis, they stress that in [IPA](#), analysis is defined by the observance of characteristic features, rather than adherence to a sequence of steps in the analytical process. Analysis should involve:

- Deep engagement with the data, typically through line-by-line analysis (Smith et al., 2009) of each individual case separately.
- Cross-case analysis in studies involving multiple participants, to reflect what is both shared and unique in participants' experiences (Smith et al., 2009).
- Iterative and inductive cycles of analysis (Eatough & Smith, 2008) both at an individual case level and cross-case level.
- The construction of themes, organized into a relational framework (Smith et al., 2009), which sustain a direct relationship with participants' original accounts (Eatough & Smith, 2008).
- Engagement with the data to such an extent and depth that analysis moves beyond description to also include interpretation (Smith et al., 2009).
- Engagement in reflexivity (Smith et al., 2009)

In [IPA](#) studies with multiple participants, each case is analysed separately before conducting a cross-case analysis to explore what is shared and unique to participants' experiences and sense-making (Smith et al., 2009). Figure 4.2 below shows the chronology of my analysis of each individual case. This approach is largely consistent with Smith et al.'s recommendations. While Smith et al. describe the analytical process as beginning with multiple readings of the interview transcripts, I perceived my analysis to begin during data collection and to continue during transcription of the interview data

	<i>Participant</i>	<i>Helen Interview 1</i>	<i>Helen Interview 2</i>	<i>Gayle</i>	<i>Marian</i>	<i>Mila</i>	<i>Mel</i>	<i>Gloria</i>	
<i>Length of interview in minutes</i>		1 hour 52 minutes	1 hour 33 minutes	1 hour 39 minutes	1 hour 40 minutes	55 minutes	1 hour 26 minutes	1 hour 52 minutes	
<i>MAXQDA Speaker Contribution Measures</i>	<i>Number of Contributions</i>	<i>Interviewer</i>	824	455	569	458	379	475	441
		<i>Respondent</i>	821	454	572	455	376	474	467
		<i>Other*</i>	0	0	0	0	0	0	49
	<i>% of Contributions</i>	<i>Interviewer</i>	50.09%	50.06%	50%	50.27%	50.07%	50.05%	46.08%
		<i>Respondent</i>	49.91%	49.94%	50%	49.73%	49.93%	49.95%	53.5%
		<i>Other*</i>	0	0	0	0	0	0	0.42%
	<i>Number of Characters</i>	<i>Interviewer</i>	16626	12573	9271	7634	6424	7007	5676
		<i>Respondent</i>	105095	67749	91451	104674	33547	76268	99137
		<i>Other*</i>	0	0	0	0	0	0	4173
	<i>% of Characters</i>	<i>Interviewer</i>	13.66%	15.65%	10%	6.8%	16.07%	8.41%	5.21%
		<i>Respondent</i>	86.34%	84.35%	90%	93.2%	83.93%	91.59%	90.96%
		<i>Other*</i>	0	0	0	0	0	0	3.83%

Table 4.5 Details of interview duration and speaker contributions for each IPA interview. (Other* = spouse who briefly entered the room during the interview).

and beyond. I also added some additional layers of analysis, as discussed below.

Throughout data collection, analysis and write up, I engaged in researcher reflexivity which facilitated my interpretative analysis of the data at all points. Elements 1 to 5 of Figure 4.3 are discussed immediately below, while researcher reflexivity is discussed at the end of this chapter.



Figure 4.3 Overview of chronology of analytical process for each individual case

4.9.1 Interview Notes

During data collection I made brief notes, which took the form of noting single words or phrases on the interview agenda page. These words recorded topics discussed by participants or occasionally the specific language participants used during interviews. I initially used them to keep track of the interview and topics I wanted to return to. However, after completing each interview, I used these notes, combined with my memory of events, to engage in reflexive journaling. The notes were helpful in initiating reflection on the participant's experience at a broad, descriptive level.

4.9.2 Transcription

All interviews were audio-recorded and transcribed verbatim. Smith et al. (2009) recommend that transcription should reflect a semantic record of the content of the interview, rather than detailed transcriptions of paralinguistic features of speech. The transcription key used in this study is shown in [Appendix E](#). Each interview was transcribed into a Microsoft Excel file. Smith et al. recommend that initial phases of analysis should involve three different types of noting or "comments." Descriptive comments relate to the semantic content of the participant's account (e.g., what topics participants discuss and what meaning they give to different topics). Linguistic comments relate to the participant's use of verbal and non-verbal language (e.g., notes about the participant's use of metaphors, pronouns, repetitive language, as well as their use of pause or dysfluencies). Conceptual comments typically relate to the researcher's earliest emerging and developing interpretations (rather than descriptions) of the participant's accounts. Smith et al. note that conceptual comments often initially take the form of questions, as researchers begin to search for understandings of the meaning and relevance of the data to the lived experience. In the Excel document containing the transcription, I created three additional columns to the right of the interview transcription

for each category of comment. As I transcribed the interview data, I began my initial noting. My noting at this point was often almost exclusively descriptive or linguistic in nature.

4.9.3 Multiple Readings

After the transcription of the interview was completed, I moved to working primarily with the text rather than audio of the interview. I analysed the interview transcript line by line, making further comments. At this point of analysis, I perceived myself to have immersed myself in the data sufficiently to commence including conceptual comments in my noting. Conceptual noting represented the beginning of my overt engagement with hermeneutic circles of analysis. The hermeneutic circle involves meaning-making derived from a process of moving back and forth between “the part” and “the whole,” (Smith et al., 2009).

[IPA](#) researchers engage with many different “part-whole” relationships during data analysis. At this point of analysis, I mostly moved between individual words or phrases and the sentences they were contained in, as well as individual extracts and the entire transcript in my efforts to decipher the meanings and sense-making of the participant. Each transcript was read and analysed line by line a minimum of three times. On some occasions, in which I was grappling with the meaning of certain data extracts, I returned to the audio recordings of these interview segments and engaged in further analysis and noting. An example of my initial noting is shown below in Figure 4.4. Further examples of my initial noting are shown in [Appendix F](#) and [G](#).

Gayle Interview Transcription - Excel

Interview questions adopted an open questioning style and prompted Gayle to discuss her expectations and experiences of SLP but responses provided related to all therapies.

Line No.	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
190	R	So the thing is I would have felt- and what I always felt was, they were packaging	Mistrust	packaging up - trying to mis-sell her something?		Lip service	trust
191		up what they were suggesting for Liam, as the <i>best</i> thing for him, where all		Best thing - tone infers Gayle feels it's the opposite to this		Lip service	trust
192		along, I knew and I still know it was all they were resourced to provide him. Had	Resources			Lip service	trust
193		they just acknowledged that -	Professionals not being honest	acknowledged- does this hint at a perception of pretence?	If they had acknowledged this, would Gayle have had more trust?	Lip service	trust
194	I	Mmm					
195	R	That would have helped my mental health a lot.	Parent mental health		Does this suggest that these actions DIDN'T help her mental health?	parent well being	
196	I	Mmm					
197	R	Had they stopped suggesting that this was the <i>best</i> for him. That this was <i>the</i>		Best for him	Very absolute terms	Lip service	trust
198		gold standard.		Gold Standard		Lip service	trust
199	I	Mmm		justify - connotations of defend as if it is			

Figure 4.4 Example of initial noting in Gayle's case.

4.9.4 Constructing Themes

The next focus of my analysis was to attempt to both enrich and distil my interpretations down into what I perceived to be the core elements of the participant's experience and meaning-making. Practically, this took the form of constructing a hierarchy of themes.

Theme construction in [IPA](#) involves many iterative cycles of analysis, involving different hermeneutic circles (see Figure 4.5 below for the different part-whole relationships involved at this point of analysis).

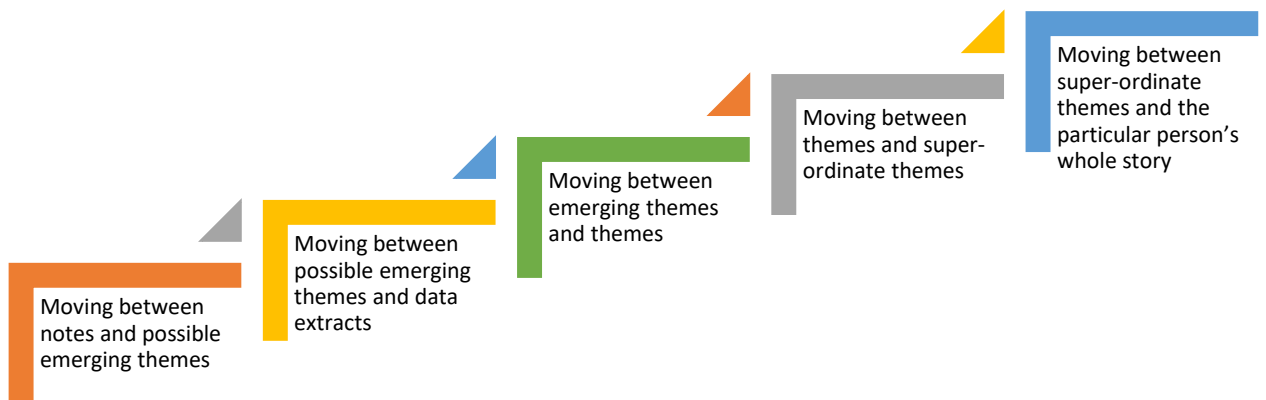


Figure 4.5 The different part-whole relationships involved at each stage of the construction of themes during individual case analysis

Stage One: Developing Possible Emerging Themes

Smith et al. (2009) recommend beginning the process of theme construction by focusing on the descriptive, linguistic and conceptual notes and searching for patterns or connections between these notes. I approached this by printing all of my notes. I read this

print out at least three times before asking myself, “What bigger ‘thing’ is this note about?” as I scrutinised each individual note. I made loose notes in the margins of the page, beginning a process of brainstorming potential emerging themes. I then returned to the Excel document containing the transcript and added two additional columns beside the columns for notes (see Figure 4.3 above). I entitled each of these columns “Possible Emerging Theme” as I was aware that at this point there were many notes that I felt might belong to multiple themes. I created a drop-down list of possible emerging themes and began to systematically assign “possible emerging themes” to the notes made. Following this, I was typically left with a large number of possible emerging themes (often 100 to 150 items.) I next printed out each possible emerging theme. I placed all of the possible emerging theme names on the floor and assembled and reassembled them around into various clusters until I was satisfied that each cluster represented a distinct group.

Stage Two: Crystalizing Emerging Themes

The next point of analysis involved adding an additional step to the process of theme construction recommended by Smith et al. (2009). This step was designed to refine the groups of emerging themes further and to ensure that the themes constructed were grounded in the data. It involved the creation of new Excel files for each of the clusters described in Stage one above. I then returned to the interview transcript and collected together all of the data extracts that corresponded to the possible emerging themes that made up these clusters. I analysed each cluster of data extracts to determine if they appeared to relate to one another cohesively and coherently. I also interrogated them further by questioning what, if anything, they might collectively mean about the phenomena being studied. This process often led to emerging themes being renamed to reflect both further developments in my interpretations of their meaning, and also to reflect some themes collapsing together into a single emerging theme or dividing into multiple

themes. I treated the themes that remained at the end of this process as “emerging themes.” I retained a copy of the raw data extracts that supported each of these emerging themes in an Excel document to both facilitate the write up of the study and contribute to the audit trail for the study. An overview of this process, illustrated using the example of the construction of the theme of “Lingering Mistrust” evident in Gayle’s case is shown in Figure 4.6 below.

Stage Three: Searching for Relationships between Emergent Themes and between Major Themes

Smith et al. (2009) recommend that researchers should next search for connections and relationships between emerging themes. This involves grouping emerging themes together “according to conceptual similarities and providing each cluster with a descriptive label,” (Pietkiewicz (Pietkiewicz & Smith, 2012, p. 368). To do this I printed out the name of each emergent theme and arranged and rearranged the emerging themes into a variety of different groups until I was satisfied that the group constituents represented a single group united in meaning. I then named each group of themes. To construct a group name, I reviewed the supporting raw data to determine if I could use direct quotations from the participant in the title, to help maintain the idiographic focus of the study. I printed out each group name (Major Theme name) and through a process of trial and error assembled these Major Themes into different groups. Each group eventually constituted a superordinate theme.

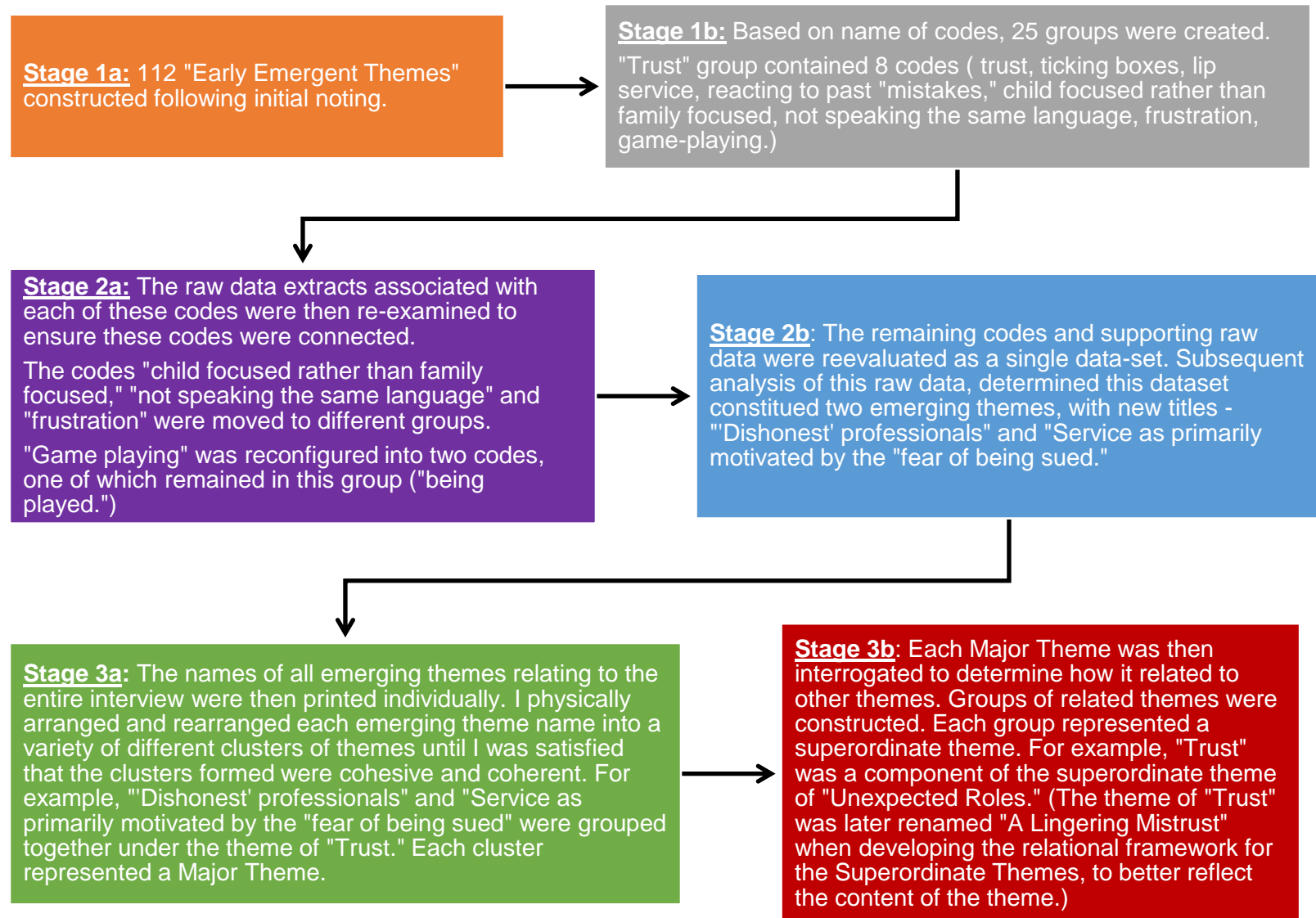


Figure 4.6 Overview of Process of Constructing Individual Component Themes in Gayle's single case analysis

Stage Four: Developing a Relational Framework for Superordinate Themes

Smith et al. (2009) suggest that researchers should develop a graphical representation of how themes are related to one another and to the particular lived experience being explored. I interrogated the superordinate themes to construct a framework for how each superordinate theme related to one another and to the case as a whole. I used PowerPoint to illustrate this framework. An example of the relational framework constructed for Gayle's case is shown in Figure 4.7 below. I also developed basic radial cycle charts to show each Major Theme and the related constituent emerging themes.

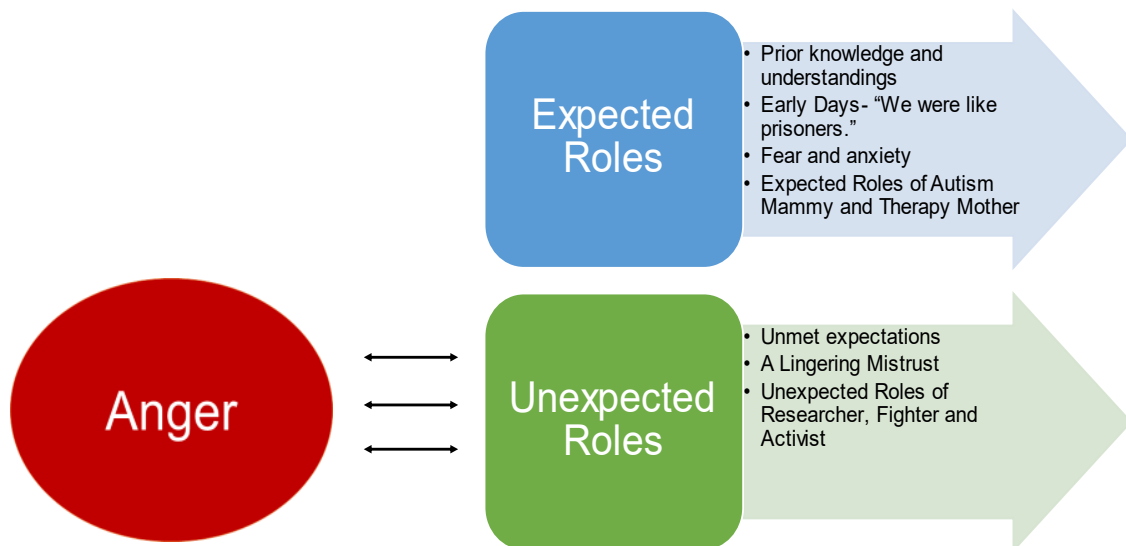


Figure 4.7 Relational framework of superordinate themes in Gayle's individual case analysis

4.9.5 Write up of Individual Case

Following the construction of themes, I chose to add a further layer of analysis beyond that recommended by Smith et al. (2009). This took the form of writing up each case as a single [IPA](#) case study. I then presented this case orally and in writing to my supervisor. The process of writing up involved using data extracts to evidence my findings. Returning to the raw data through the lens of the framework of themes constructed, contributed to me interrogating the raw data in more detail and through a more interpretative lens. In particular at this point my linguistic analysis of the data became deeper and more detailed. In writing up the case, certain superordinate themes dominated more than others; occasionally this led to the reorganisation of my relational framework. Additionally, when writing up the case, I began to see some overlap between themes that had previously appeared distinct. This sometimes led to me collapsing some themes together, giving rise to individual themes that were sometimes multifaceted. Presenting the case to my supervisor involved defending my findings. Sometimes the questions raised in these supervision meetings highlighted aspects of my analysis that required deeper interrogation. On other occasions these meetings helped me to consider different interpretations of the data.

4.9.6 Moving to the Next Case

After each case analysis was complete, I engaged in reflective and reflexive writing in my journal to heighten my awareness of the preconceptions and understandings that were at the fore of my thinking from the prior case analysis, with a view to increasing my sensitivity to recognising bias in my analysis. I then began a new single case analysis as described above, beginning with the interview notes and concluding with the write up and presentation of the case.

4.9.7 Preliminary Cross Case Analysis Conducted Prior to Survey Studies

When all individual case analyses were completed, I conducted a preliminary cross case analysis. Smith et al. (2009) recommend that cross case analysis should begin by comparing and contrasting cases, to explore how cases converge and diverge. Cases may have shared or unique themes. The same themes may manifest in different ways or have conflicting meanings for different participants. Cross case analysis can also illuminate the themes that are most prevalent across cases and the ones that are the most powerful. I approached this preliminary cross case analysis by first conducting multiple readings of each case write up. I then printed out all of the major theme names from all studies and arranged and rearranged them into different families, and grouped different families together under provisional superordinate themes. At this point the provisional superordinate themes were:

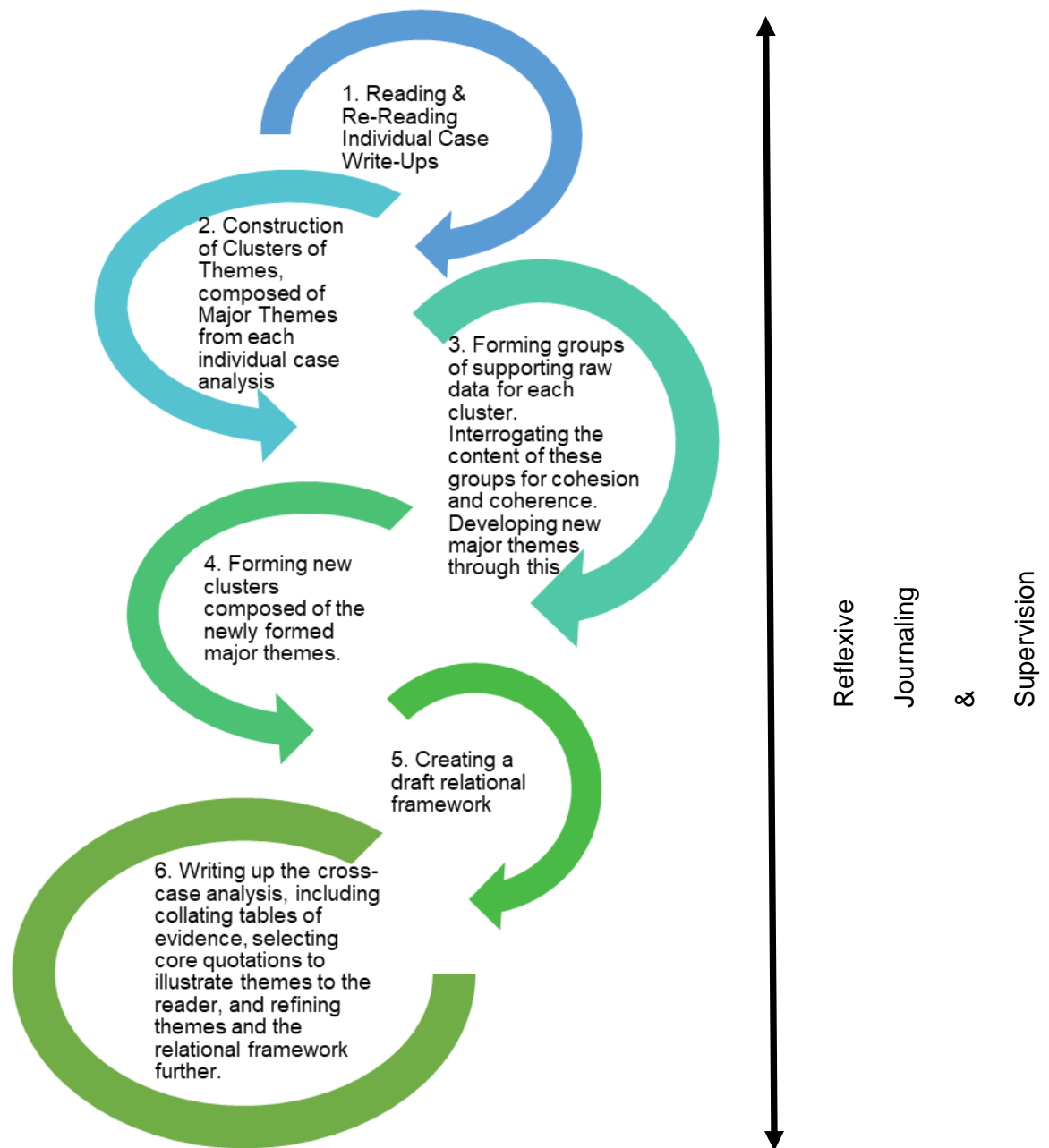
1. Understandings and Expectations
2. *"Therapy Mother"*
3. Conflict

I perceived my analysis at this point to be relatively interpretative, however questions remained for me about how these superordinate themes related to one another. I also felt particularly uncertain about the theme of conflict. I was not sure if using the lens of conflict captured participants' collective experience adequately. I was guided through supervision to consider conducting supplemental survey studies before writing up my findings. While strategically these surveys offered an avenue to contextualise, and perhaps add to the trustworthiness of my findings, they also provided further space for reflection and fuel to consider the [IPA](#) data from different perspectives. The results of the survey studies are discussed in Chapter 6.

4.9.8 Detailed Cross Case Analysis

The completion of the survey studies contributed to shifts in my thinking, and raised further questions about the [IPA](#) data. These are detailed in Chapter 6. I returned my focus to the [IPA](#) study and chose to challenge my preliminary findings by repeating the cross-case analysis. While Smith et al. (2009) recommend an approach to cross case analysis that is heavily based on searching for connections between names of themes and clusters of themes, I added additional cycles of analysis that involved repeated evaluations of groups of supporting data extracts. An overview of this analytical process is shown in Figure 4.8. I found repeatedly returning to the raw data helpful both in developing my interpretations, and in gaining confidence about the trustworthiness of my findings. Initially I engaged in repeat readings of the individual case write-ups. I then printed out all the major themes involved in each case and grouped these by theme name only. I then approached each group one at a time. I collected together all the raw data from the various participants involved that related to each group. I questioned whether the raw data supported grouping these themes together as a single unit. This process resulted in some themes and/or supporting data being reassigned to a category which I called, "To be reconsidered." I interrogated the remaining raw data in this set asking the following questions:

- What is the shared experience of this theme?
- What (if any) is the divergent experience of this theme?"
- How does this help me understand role construction in therapy?
- What discrete part of the universal story does this collective group of data tell?



How do these mothers' perceptions of their role in SLT converge and diverge?

How do these mothers' sense-making of their roles converge and diverge?

Figure 4.8 Overview of chronology of analytical process for detailed cross case analysis

Following this interrogation, I chose a name for the theme that aimed to capture the experience of the group, not just a single participant. I also created a list of the characteristics of the theme. I repeated this process for each group of themes. Finally, I returned to the category called, “To be reconsidered” and its associated supporting raw data. I approached this data with the following questions:

- Is this data compatible with any of the newly formed themes?
- Is this data essential for understanding how the mothers collectively or individually make sense of roles?
- Is this data essential for understanding how the mothers collectively or individually perceive their roles?

This resulted in me disregarding some data as superfluous to the analysis and moving the rest to existing themes. I then created a list of theme names and cut out each theme name before beginning the process of assembling and reassembling these themes into different clusters, with each cluster representing a superordinate theme. Finally, at this point I developed a draft relational framework of how I understood the themes and superordinate themes to connect with one another. There were some significant differences between my understandings and interpretations at the preliminary cross analysis and the detailed analysis. For example, prior to the survey I understood “Conflict” to represent a superordinate theme largely focused on the role of fighting that some participants undertook. Following the detailed cross case analysis, I understood conflict to capture aspects of some major themes, but not the collective experience of all involved. I reframed my understanding of this superordinate theme using the lens of “a game of survival” which appeared relevant to all involved and provided a different insight into the experience of conflict that related to some participants. I now credit this detailed cross

case analysis as pivotal in moving my thinking beyond description and more towards interpretation.

4.9.9 Writing Up the Thesis

The final stage of [IPA](#) analysis involved the subtle refinement of my understanding of the themes and how they related to one another. This occurred during the write up of the thesis, as I committed my interpretations into writings which I understood I would be interrogated as part of the academic process. The write-up involved developing tables of evidence to support each theme and selecting key data extracts to illustrate the themes.

4.9.10 Deductive Analysis of Additional Cases

When this write-up was complete, I began to reconsider the limitations of the study to date. I evaluated the quality of the study, using Yardley's (2000) principles of quality in qualitative research. One of Yardley's key principles relates to the impact and importance of the study. I anticipated that my small size of 6 participants might challenge the dissemination of the study's findings through publications, and thus restrict the impact of the study. Larkin, Shaw and Flowers (2018, p. 195) note that using adapted [IPA](#) approaches can sometimes increase the persuasiveness of the findings and "may have the potential to bring a moderated version of 'generalisability' or 'abstraction' back online for phenomenology, albeit a complex, cautious, and contextually sensitive one," (2018, p. 195). In an attempt to augment the impact of this study, an additional stage of analysis was completed following the traditional [IPA](#) analysis. This involved a deductive analysis of interview transcripts from some of the remaining participants whose data was not previously analysed. Due to time constraints, I chose to match the number of participants in the original [IPA](#) study, rather than attempt to analyse all remaining cases. Of the ten remaining participants, I selected the six with the richest data.

The traditional [IPA](#) analysis led to the construction of four super-ordinate themes- “Understandings and Expectations of Autism,” “Understandings and Expectations of [SLT](#),” “*Therapy Mother*,” and “A Game of Survival.” I analysed the interviews of the remaining 6 participants for evidence of these superordinate themes. Details about these participants and their children are found in Table 4.6 and 4.7 below. I listened to each remaining interview once for evidence of theme one; a second time for evidence of theme two, a third time for evidence of theme three, and a fourth time for evidence of theme four. Any evidence found was transcribed verbatim and recorded to facilitate an audit trail. The findings of the deductive analysis are presented at the conclusion of each relevant chapter on the individual superordinate themes.

	Mary	Sarah	Sinead	Susan	Robyn	Trish
County of Residence	Leinster	Leinster	Leinster	Leinster	Leinster	Leinster
Ethnicity	White, Irish	White, Irish	White, Irish	White, Irish	White, Irish	White, Irish
Age Bracket	30 – 40 years	30 – 40 years	30 – 40 years	50-60 years	40 – 50 years	40 – 50 years
Educational Background	Leaving Certificate	Leaving Certificate	University	Leaving Certificate	Higher Diploma	University
Occupational Status	Part-time paid employment	Full-time carer in the home	Part-time paid employment	Full-time carer in the home	Full-time carer in the home	Full-time carer in the home
Marital Status	Married	Married	Married	Married	Married	Married
Family Profile	Living with husband and three children.	Living with husband and two children.	Living with husband and two children	Living with husband and three children	Living with husband and four children.	Living with husband and three children.

Table 4.6 Demographic details of participants involved in deductive analysis

	Mary	Sarah		Sinead	Susan	Robyn	Trish
Child's Pseudonym	Jake	Daniel	Sarah	Leo	Peter	Matthew	Paul
Diagnoses	Autism	Autism	Autism, ODD	Autism, ODD , ADHD	Autism, Moderate ID	Autism, Moderate ID	Autism
Age of child when diagnosis of autism given	4 years	2 years	6 years	4 years	3 years	2 years	4 years
Age of Child at time of interview	5 years	4 years	7 years	5 years	13 years	5 years	5 years
Type of School Placement	Autism outreach class in mainstream school	Autism outreach class in mainstream school	Mainstream class in mainstream primary school	Mainstream class in mainstream school	Special school for children with ID	Mainstream class in mainstream primary school	Autism outreach class in mainstream school

Table 4.7 Details of children of participants involved in deductive analysis

4.10 Research Reflexivity

Concurrent to the stages of analysis described above, I also enriched my analysis by engaging in reflexivity from the point of data collection to the completion of my final draft of the thesis. Reflexivity in research involves disciplined self-aware reflection and critique (Finlay, 2012; Glass, 2015). Reflexivity is guided by the position that the qualitative researcher is an active participant in the generation of knowledge (McGarry, 2019), with the potential to influence the research process, context and findings (Finlay, 2012). Engaging in reflexivity facilitates the development of richer understandings (Finlay, 2012) and can act as a means to demonstrate rigour (e.g., Tong et al., 2007). While researchers often use common tools such as field notes, journaling, supervision and debriefing to aid reflexivity, how, why and when researchers use these tools differs according to factors such as the researcher's epistemological stance, chosen methodology, and personal preferences (Finlay, 2012).

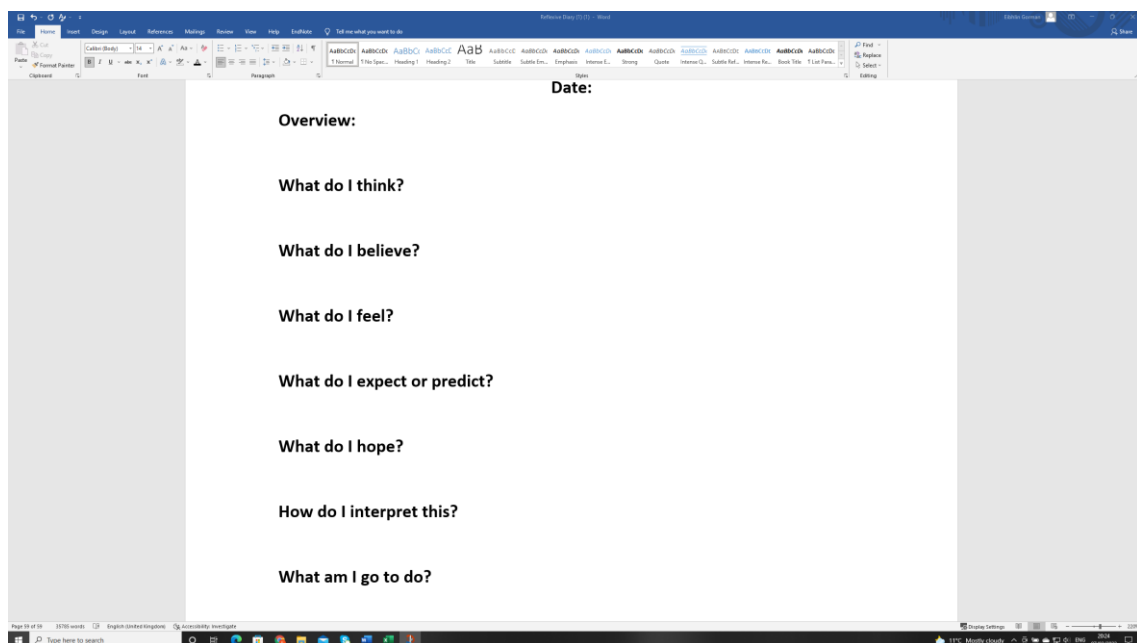
As I position this research within the constructionist paradigm and value the principle of double hermeneutics, I used reflexivity for four reasons:

- 1) To attempt to somewhat mitigate my impact on the study by bringing my underlying thoughts, beliefs, attitudes, biases, prejudices and motivations into my self-awareness. In doing so, I hoped to interrogate the research study's process and outcomes with a heightened sensitivity of my potential influence, while accepting that I could never 'bracket' myself completely.
- 2) To attempt to track my interaction and influence on the research, with a view to better understanding my role in the construction of knowledge.
- 3) To create opportunities and space to understand phenomena in different ways, by raising my awareness of what thoughts, feelings, beliefs etc., were already being utilized, and then engaging in imaginative exercises about what opposing and alternative perspectives might exist (Gemignani, 2017).

4) To draw on my fore-understandings as possible “source[s] of insight,” (Finlay, 2009, p. 82) that when investigated could lead to new ways of approaching and understanding the question and data.

I chose to use a combination of journaling and supervision during data collection, analysis and the write up of the thesis. As I am a novice researcher, and initially felt both unsure and unconfident about journaling, I used a template in Microsoft Word that contained prompt questions to guide my journaling. A copy of this template is shown in Figure 4.9.

Figure 4.9 Template used for reflexive journaling.



Finlay (2012) proposes five different, but overlapping, lenses that researchers may use when engaging in reflexivity. These five lenses and their relationship to my research are discussed below.

4.10.1 Strategic reflexivity

Finlay (2012) suggests that researchers may employ strategic reflexivity to critically appraise their decision-making and thought processes regarding their research design

and analysis. For example, my journal contains entries questioning the value and relevance of my survey studies given my philosophical leanings towards constructionism. This strategic reflexivity contributed to me returning to the literature on research paradigms to determine if my philosophical leanings had shifted towards a different paradigm. It also prompted me to interrogate the depth of my affiliation to constructionism. I asked myself questions like, “Do you claim to espouse this philosophy because it’s convenient given your choice of methodology or because you actually believe this?” This reflexivity also led me to question what this alignment meant for how I judged and appraised other research and what this meant for my perceptions about evidence-based practice. Engaging in this line of self-critique facilitated me in developing a deeper understanding of my perspective and where the thesis was situated.

4.10.2 Contextual-discursive reflexivity

Finlay (2012) notes that researchers also use reflexivity to engage in critical self-reflection about the micro and macro contexts of data collection and analysis. She refers to this as contextual-discursive reflexivity. Self-reflection about the macro context involves an awareness and critique of one’s own socio-political context, as well as that of the research and participants, and the potential impact that factors such as gender, class, race, age, ethnicity, nationality, sexuality, and religion may have on the research process and outcomes (Macleod & Bhatia, 2008). In my research, having a heightened sensitivity to my own macro-context and those of the [IPA](#) participants, was most significant to me during data analysis. I shared the same gender, class, race, nationality, and in some cases age bracket, as many of the participants. I noted feeling at times, “This could have been me,” or having thoughts like, “I would have done the same thing.” Reflexivity helped me to note these thoughts and feelings and recognise the potential for prematurely assuming a deeper level of understanding, stemming from beliefs about shared backgrounds. In cases, where I perceived there to be disparities

between my own macro-context and those of participants, self-reflection about my positionality helped to me to critically analyse my interpretations. For example, Mel disclosed to me that she had borrowed money and sometimes missed mortgage payments to fund private interventions. I felt anxious and concerned when Mel told me this. I initially interpreted this a misguided act of desperation. Reflexivity allowed me to recognise that my middle-class beliefs about living within your means, were interrupting my analysis. When other participants had informed me of their involvement with private interventions, I had interpreted this as communicating their identity as strong, protective mothers who were committed to helping their children. I asked myself why I interpreted Mel's case differently and what Mel was trying to convey to me by telling me this part of her experience. This reflection added to the depth of interpretation as I understood it as signalling a mother willing to take risks to protect her child.

The micro-context that Finlay discusses relates to the discursive aspect of research – both in term of data collection and the discourse used by researchers to communicate their research. Finlay emphasises the relevance of Goffman's (1975) concept of dramaturgy, which asserts that when engaging in discourse and interactions, we are all "performing;" displaying ourselves as we wish to be seen by the listener and the world. In data collection this may influence both the content and structure of participant's narratives, as they choose what to reveal and retain as private (Finlay, 2012), and what to emphasise and play down. All participants were aware of my role as an [SLT](#), as well as a researcher. Self-reflection about this led me to consider how this impacted on the data collected. It contributed to me approaching the data set with questions like, "How did politeness impact on the participants' responses?" "Does Helen's emphasis that she was not a "*pushy parent*" come from her grappling with identity or is it influenced, even to some degree, by a desire not to offend me?"

Furthermore, this contextual-discursive lens refocused my analysis of later occurring interviews in the data collection process. Due to the initially slow nature of data collection, I had analysed some single cases prior to collecting the final interview data. Sensitivity to this situational context, gained through reflexive journaling and supervision, helped me to become aware that I entered later interviews with expectations and presuppositions of likely themes that would arise. I was aware of this only superficially during the data collection, but my understanding of the potential impact of this grew during data analysis. I appreciated that these expectations and presuppositions facilitated me to probe more on these topics and possibly gain richer data. However, I also began to recognise the need to more closely analyse my questions and responses during these later interviews, in order to investigate if I had unconsciously signalled to participants. “This is what’s important. Tell me about this,” and in doing so biased data collection. This resulted in a deeper and longer analysis of interview data collected later in the process.

4.10.3 Embodied Reflexivity

The third lens for reflexivity that Finlay (2012) describes is embodied reflexivity. This reflexivity lens relates to a self-awareness and self-critique of the physical domain, for example physical sensations, body language and gesture primarily during data collection and analysis. Finlay discusses her recognition during an interview that both she and the participant had adopted a similar body position and how this awareness led to questions about who was mirroring who and what, if anything this communicated about the phenomenon being explored. My reflexivity during the research process seldom adopted an embodied reflexivity lens. Indeed, Finlay (2012) notes that different researchers will be drawn to different types of lenses. While I can theoretically appreciate the potential insights such a lens might yield, my status as a novice researcher, relying on audio rather than video recording, contributed to me infrequently taking note of my body and “felt senses” (Finlay, 2012). My limited use of this lens may

also stem from my uncertainty about my position and abilities regarding using the physical domain as an avenue to access what is psychological or cognitive.

The occasions when I did draw on physical sensations in my reflexivity related to data extracts that during analysis caused me to tear up and on some occasions cry. I reflected on these moments when journaling, wondering why I had reacted that way and what if anything it told me about the data. For example, I found Mel's data analysis triggered a lot of eye-tearing and sometimes crying. Self-reflection revealed that parts of her experience triggered personal memories. However, deeper self-critique about this reaction helped to reveal a personal sense of shame related to feeling part of "the system" which had partly caused or exacerbated some of Mel's pain. This helped me to review my analyses more critically, scrutinising my analysis for signs of, for example, defensiveness or being overly empathetic in my interpretations of the data.

4.10.4 Relational Reflexivity

Finlay's (2012) relational reflexivity lens involves a self-critique of how the researcher and participant relate to one another and how this may impact on the research process and outcomes. Potter and Hepburn (2012) note that researchers enter into research interviews with research philosophies and agendas that may influence their interview style and how they relate to the participant. It also seems plausible that participants may enter into an interview with an agenda and intentions about what they want to communicate and how they want to be perceived, which may in turn impact on how the researcher relates to them. Gubrium and Holstein (2012) note that we all occupy multiple identities, each associated with different patterns of communication and interaction, which may influence how the other party in the interaction relates to us and which identity they are responding with. Relational reflexivity thus raised questions for me, such as "Does my interview style reflect the identity of researcher or therapist or perhaps both? How does the participant see me? Do their responses correspond with

their identity as a mother or perhaps more collectively as a representative of parents of children with autism?”

I found the relational lens particularly useful with Gayle’s case. During data collection and analysis, Gayle triggered memories of parents I had experienced professional conflict with. During the interview I felt anxious, and identified with the therapists that Gayle described feeling anger towards. It felt effortful to remain in my researcher identity and to encourage Gayle to speak openly and without judgement. Acknowledging this through reflexive journaling and supervision helped me to review the interview transcript more closely to determine if I had related to Gayle as I had related to other participants. When Gayle’s interview concluded, I had had thoughts such as “I’m glad I’m not her therapist,” and “I bet she’s scary to work with.” My instinctive interpretation was that Gayle was an angry person and this anger translated into aggression at times. Indeed, Gayle appeared to agree with me, as she described having trouble controlling her anger. However, when I had finished transcribing Gayle’s interview and immersed myself in the transcript, I began to notice that my case analysis shifted to be more empathetic. I interpreted her anger to stem, in part, from anxiety about her son. In supervision I noted this and through further reflexive journaling I became aware that my early interpretations of Gayle were being driven largely by my therapist identity and my memories of conflict with parents. I became aware that in Gayle’s case distancing myself from the audio-recording helped to diminish memories that interrupted my analysis and I took note that this might be helpful should I have similar experiences in the future.

4.10.5 Ethical Reflexivity

The final reflexive lens described by Finlay (2012) relates to self-critique that exposes ethical issues in the research process. Finlay notes that this lens is often used when reflecting on the locus of power in research. Finlay gives the example of researchers becoming aware of the power they hold, in determining which aspects of a person’s

experience are important enough to report, and thus which aspects to add to knowledge pool that other stakeholders may draw from. She describes the discomfort that researchers, such as myself have felt in distilling a person's whole experience down into a few pages. In my case, this prompted questions like, "Am I doing this person's experience justice or am I presenting an overly simplified account because of the constraints of word limits?"

I engaged in ethical reflexivity intermittently throughout this research. For example, ethical reflexivity was important to me, when considering my decision-making regarding which participant cases to use in the core [IPA](#) study. I had met and collected data from a number of women who shared their experiences with me for the purposes of research, but I only included some of these case in the [IPA](#) study. Journaling and supervision facilitated reflexivity about the ethics of this. Pragmatically I understood that certain cases could not be included (due to concerns about the participant's language comprehension) and I understood that [IPA](#) is not compatible with large sample sizes. However, reflexivity also helped me to acknowledge that my personal motivations and aspirations to produce good quality research had also influenced my decision-making regarding sample size. I felt guilt that I had perhaps needlessly collected data and thus potentially exposed participants to harm as they described experiences that were sometimes upsetting. I also felt guilt in determining why one person's account warranted in depth [IPA](#) analysis while another received deductive analysis. I wondered if I had truly gained informed consent when I had not informed participants that their data might not be used. I decided that practically I could not analyse all the data set using [IPA](#) and that while not all data collected was analysed, any data collected was reflected on and so played some role in informing my understandings. Nonetheless I never felt that I reached a comfortable conclusion to this internal ethical debate.

4.11 Quality

A number of approaches to evaluating quality in qualitative research have been proposed (e.g., Elliott et al., 1999). I have chosen to use Yardley's (2000) quality principles, which are promoted as compatible with [IPA](#) in Smith et al.'s (2009) core text.

4.11.1 Sensitivity to Context

Yardley (2000) asserts that researchers should demonstrate strong awareness and knowledge of the different contexts of the study.

- **Project Context:** I have drawn from multiple and varied substantive and theoretical perspectives in the literature review and discussion chapters of this thesis, in an effort to illustrate the wider context in which this research project is located.
- **Research Process Context:** I endeavoured to demonstrate my understanding of the theoretical and philosophical contexts that underpin my chosen methodology through my writing on research paradigms and [IPA](#) and by overtly discussing my decision-making throughout the thesis (e.g., my choice of using interviews for data collection.) My use of researcher reflexivity, as discussed above, demonstrates my awareness of my impact on the research process, from data collection and analysis to the construction of findings.
- **Participant Context:** My choice of [IPA](#) requires a committed sensitivity to the context of individual participants. Chapter 7 provides a detailed overview of each participant's experience. Quotes from each of the participants are provided to evidence the themes constructed in an attempt to illustrate the meaning of the themes for the individuals involved.

4.11.2 Commitment and Rigour

Yardley's principle (2000) of commitment relates to the researcher's engagement and dedication to the research project and process across the duration of the study. Rigour, according to Yardley (2000, p. 221) refers to "the completeness of data collection and analysis." I endeavoured to address my commitment and rigour through:

- Prolonged engagement with the topic: I have been engaging with the topic of therapy roles on a formal and informal basis since I began working 14 years ago. My interest in this topic arose over the years preceding my commencement of the PhD and its importance and relevance to me continues through my clinical work and academic interests.
- Developing my competency in [IPA](#): In order to commit to my methodology of choice, [IPA](#), I recognised my need to upskill and attended additional training on this methodology. I joined the IPA Ireland research group, and also attended the [IPA](#) conference in Glasgow in May 2017. Additionally, I participate in [IPA's](#) email forum and use this forum to seek confirmation and clarification on methodological questions.
- Adequacy of sample: To show my commitment to [IPA](#), I discuss in the thesis how and why I selected my sample size in order to access rich, reflective data suitable for IPA analysis.
- Prolonged engagement with the data: I detailed above the duration of each [IPA](#) interview in minutes and the percentage of characters in the interview transcripts attributed to each participant. This reflects the volume of data that supported the study. As outlined above, transcription and analysis involved a long, detailed process spanning several weeks or months per case. This facilitated deep immersion in each individual data set.
- Thick description: To capture the idiographic nature of my study, I incorporated detailed overviews of the individual participants' experiences in the introductory

findings chapter. I was keen to preserve individual, as well as collective participants' voices and used quotations from all participants throughout the Findings chapters.

- Completeness of analysis: [IPA](#) requires both description and interpretation. In the findings and discussions chapters, I have attempted to illustrate how the themes constructed represent both a descriptive and conceptual account of the participants' experiences and the phenomena being studied.

4.11.3 Transparency and Coherence

Yardley's (2000) principle of transparency and coherence relates to the persuasiveness of the research. Transparency is demonstrated by providing enough information to the reader so that data collection and analysis can be replicated (Yardley, 2000), albeit with different results expected, given the role of the researcher in interpreting the data. Coherence involves producing and communicating research that is logical, well written and well-argued (Flowers, 2008). I attempted to address the study's transparency and coherence by:

- Providing an audit trail detailing how I collected and analysed the data and illustrating how themes were constructed.
- Including interview extracts throughout the thesis to evidence my findings and also providing tables of evidence relating to each theme (see chapters 8, 9 and 10).
- Providing an overview discussion of my use of researcher reflexivity, as well as reflexive commentary throughout the thesis, to illustrate my influence on the research process and outcomes.
- Attempting to write a thesis that is both coherent and cohesive, while also engaging and representative of my experience grappling with this topic.

4.11.4 Impact and Importance

Yardley (2000) contends that potentially the most significant marker of quality is that a study is useful. This study has changed my personal, professional and academic thinking, as discussed in Chapters 12. I believe the study's findings offer the potential to understand existing theory differently and if I am successful in disseminating my findings it may contribute to practice and policy change.

4.12 Summary

This chapter provided an overview of the philosophical underpinnings of the study and a description and justification for the methodology and method used in the core [IPA](#) study. The chapter also discusses how I modified the recommended analytical process by refocusing on the raw data repeatedly at different intervals and supplemented the [IPA](#) study with a deductive analysis of additional datasets. The chapter concludes with a description of how I engaged with researcher reflexivity throughout the study, and the efforts taken to address the quality of the study. In the next chapter I present the methods used to design and analyse the survey studies.

Chapter 5: Survey Methods

5.1 Introduction

The [IPA](#) study, described in the previous chapter, forms the core component of my research. I also completed two survey-based studies, given my uncertainty about some of findings of the preliminary [IPA](#) analysis. The survey studies had two purposes:

- To contextualize the findings of the [IPA](#) study.
- To open further iterative cycles of analysis of the [IPA](#) data, with a view to developing deeper understandings of the participants' sense-making (see Figure 5.1)

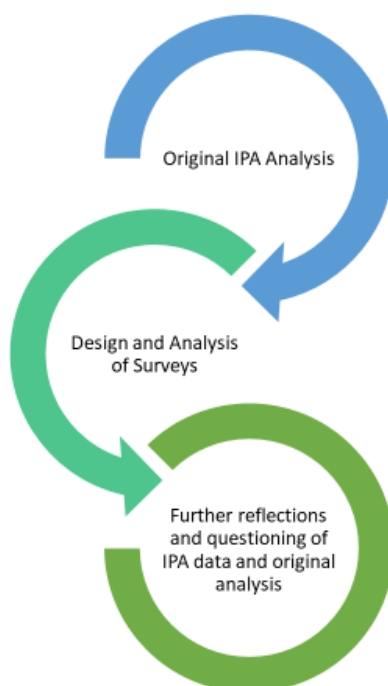


Figure 5.1 Graphic depicting overall iterative process of analysis

This chapter provides a discussion of the methodology of both surveys, beginning with a focus on the research questions involved.

5.2 Research Questions

The research questions central to the parent and [SLT](#) survey studies were driven by different preliminary findings of the [IPA](#) study and influenced by different literature reviews and are thus discussed separately below.

5.2.1 Parent-Survey Research Questions

The parent-based survey study arose out of my uncertainty about the specific components and relationships involved in the preliminary [IPA](#) themes of “Understandings and Expectations,” (discussed in Chapter 8). This preliminary theme encompassed understandings and expectations related to the role of the therapist and parent, as well understandings of autism, communication disorders and the therapy process. While I felt I had a broad understanding of this theme, I doubted my analysis of the specific components involved in this theme. The parent-based survey study aimed to address three questions:

- What behaviours and attitudes do parents living in Ireland believe are expected of a parent whose child attends [SLT](#)?
- What behaviours and attitudes do parents living in Ireland expect from [SLTs](#) working with children?
- What understandings do parents living in Ireland hold about communication disorders and the nature of [SLT](#) for children?

5.2.2 SLT-Survey Research Questions

The therapist-based survey study was inspired by the preliminary [IPA](#) finding that the mothers involved attempted to navigate their role construction in a context sometimes embodied by conflict, powerlessness and isolation (discussed in Chapter 10). Many of the participants interpreted this lack of power as stemming from how service organisations and professionals related to them. The therapist- survey was designed to contextualise this [IPA](#) finding by developing a provisional map of the practices and

operations of [SLT](#) services in Ireland that I hypothesized might impact on client engagement. The survey explored the following questions:

- What involvement are parents of children on the autism spectrum invited to have in decision-making in [SLT](#)?
- What care pathways are recommended for children deemed to require a diagnostic assessment for autism?
- What intervention care pathways are in use for children in Ireland with and without a diagnosis of autism?

5.3 Ethics

Ethical approval for the study was granted by the School of Linguistic, Speech and Communication Sciences in Trinity College Dublin (please see [Appendix H](#)).

Participation in these studies was voluntary. Neither study targeted vulnerable participant groups; participants were required to verify that they were over the age of 18 years. I advertised the parent study online using parenting forums, Facebook groups and by contacting parent organisations by email and inviting them to advertise my study. I advertised the therapist study online using Facebook groups and by contacting special interest groups, the Irish Association of Speech and Language Therapists and the [HSE SLT](#) managers group by email and requesting that they share information about my study with their members and teams. Participants from both studies self-selected to visit the webpage that displayed the surveys. The first page of each survey contained information about the study and the survey questions (see [Appendix I](#) and [J](#)). This information included the purpose of the study, risks and benefits of taking part, information about confidentiality and voluntary participation and a [GDPR](#) statement. The survey did not request participant names or identifying information.

5.4 Data Capture

Both studies were based on online questionnaires, designed specifically for the research reported here. A copy of the questionnaires is found in Appendices K and L. The surveys were anonymous and delivered through Google Forms. Non-probability, convenience sampling was used in both studies. I recognise that collecting data via online means only lends itself to coverage error as it automatically excludes, for example those parents who do not have access to or do not use the internet or social networks. I also recognise that my use of non-probability, convenience sampling limits the study's generalisability. However, an online survey offered a time and cost-effective option that was compatible with the peripheral nature of the studies involved.

	Parent Based Study	SLT Based Study
Inclusion Criteria	<ul style="list-style-type: none"> • Over 18 years • Parent of a child under 18 years • Resides in Republic of Ireland 	<ul style="list-style-type: none"> • Over 18 years • Qualified SLT • Works with children on the autism spectrum or with children suspected to be on the autism spectrum who have been referred for diagnostic assessments for same. • Works in the Republic of Ireland
Exclusion Criteria	<ul style="list-style-type: none"> • Has previously completed the questionnaire 	<ul style="list-style-type: none"> • Has previously completed the questionnaire

Table 5.1 Inclusion and Exclusion Criteria for the survey studies.

Participants self-selected to partake. Duplicate entries were avoided by asking participants to confirm that they had never completed the survey before. A list of the inclusion and exclusion criteria for each study is shown in Table 5.1. Both surveys collected data from April 2019 to July 2019. Each survey study's participant details are presented separately below. This is followed by a discussion of the design of each survey.

5.5 Participants- Parent Survey

Of the 165 responses received in the parent survey, 155 were eligible (see Table 5.2 for information on ineligible responses).

Reason for Exclusion from Data Set	Number of Participants Excluded
Not above 18 years	1
Reported previously completing survey	3
Parent of a child over 18 years	4
Residing outside of the Republic of Ireland	2

Table 5.2 Details of participants excluded from the parent study

The 155 eligible participants reported a range of different types and levels of experience and familiarity with [SLT](#). Almost half of the sample (45%, $n= 70$) reported no experience of [SLT](#). The remaining participants reported a variety of different types of experience ranging from direct experience associated with their child attending [SLT](#), indirect experience associated with liaising with [SLTs](#) through their occupation and limited levels of experience related to the participant having a child on the waiting list for an initial [SLT](#) assessment. Further details of the range of types of experience are shown in Table 5.3.

	Type of Experience	Subgroup Total	n=
No Experience Group	No experience	70	70
Some Experience	Parents of children who attended or attends SLT	60	85
	Parents of children waiting for an SLT initial assessment	11	
	Parents who attended SLT as a child.	6	
	Parent who has had contact with SLT through their work as a teacher etc.,	6	
	Other	2	

Table 5.3 Details of parents' reported levels of experience with SLT in the parent survey study

5.6 Participants- SLT Survey

Of the 151 responses received in the therapist survey, 147 were eligible. Four participants responses were excluded as they reported that they did not work with children on the autism spectrum or suspected of having a diagnosis of autism in their current post. This sample of 147 participants represents 7.5% of all registered SLPs in Ireland (CORU, 2019a). Participants reported working in 24 of the 26 counties in the Republic of Ireland, however the majority of participants (69%) worked in Leinster. Table 5.4 shows the geographic breakdown of the sample by province in Ireland. Participants were also asked if their caseload was primarily urban, rural or mixed. More than half (58.22%) of the sample reported having a mixed caseload. Approximately a third (31.51%) of the sample reported having an urban caseload and 10.27% reported having a rural caseload.

Province	n=	%
Leinster	102	69.38%
Munster	33	22.45%
Connaught	17	11.56%
Ulster	5	3.4%

Table 5.4 Geographic details of participants in SLT survey

Service Type	Description	n=	% of Overall Sample
Disability Team	Multidisciplinary teams working with children with significant and multiple therapy needs in defined age brackets.	56	38.1%

HSE Primary Care	Uni-disciplinary teams designed to work with children whose needs are deemed non-complex.	46	31.29%
Disability Service	Multidisciplinary teams working with individuals with specified diagnoses, e.g., autism or intellectual disability in a service setting that provides care across the lifespan.	21	14.29%
Private Practice	Privately funded and operated services, typically uni-disciplinary in nature.	14	9.52%
<u>CAMHS</u>	Multidisciplinary teams working with children and adolescents whose primary diagnosis relates to their mental health.	5	3.4%
Other	Mixture of services including paediatric hospital settings and AoN services, and services employed on a pilot basis to work in areas of economic and social disadvantage	5	3.4%

Table 5.5 Type of services that SLT survey respondents reported working in.

The largest service type represented in the sample was disability team (38.1%). These teams provide publicly funded multidisciplinary care to children with significant and multiple therapy needs in defined age brackets. Primary care teams (accounting for 31.29% of the sample) provide uni-disciplinary, publicly funded care to children who do not meet the criteria for more specialist services. The remaining participants worked in a range of other settings including disability services that provide care across the lifespan and paediatric hospitals (see Table 5.5).

5.7 Survey Design

The preliminary [IPA](#) findings informed the survey research questions. Reviews of the literature and clinical experience contributed to the development of the first prototype surveys. Discussions with my supervisor, [SLT](#) colleagues and other PhD candidates led to changes to the content, language and layout of the questionnaires. The specific details relating to the design of the content of each survey are presented separately below. This is followed by a discussion of how the format of both surveys was designed.

5.7.1 Content Design

Parent Survey Content Design

The [IPA](#) study found that understandings and expectations relating to [SLT](#) and autism were central to how mothers involved made sense of their role. Questions in the parent survey were designed to explore understandings and expectations of the therapist's role and the parent's role in [SLT](#). I also included questions exploring participants' understandings of communication disorders as my preliminary [IPA](#) analysis suggested this was important to mothers' role constructions. The literature relating to Role Theory, with its focus on behaviours and attitudes involved in roles, further influenced the survey content. Furthermore, a review of the literature relating to therapy roles in [SLT](#),

in addition to clinical experience also influenced the survey content. For example, the question regarding the impact of treatment intensity and age was inspired by my clinical experience working with parents, some of whom have expressed the belief that the persistence of their child's communication difficulties related to their history of access to treatment.

SLT Survey Content Design

The [SLT](#)-survey was influenced by the [IPA](#) study's finding that many of the mothers involved perceived professionals' practices and services' operations as contributing to experiences of powerlessness, isolation and conflict. The specific practices and operations discussed by the mothers directly inspired some of the survey content. These included questions relating to family involvement in decision-making and the use of direct versus indirect intervention. A review of the literature relating to family-centred care further emphasised the importance of including questions relating to decision making and flexibility of service provision. A review of the literature relating to families' experiences of interacting with services for children with developmental disabilities contributed to the inclusion of questions regarding access to autism diagnostic assessments and questions about service provision in different age ranges. My clinical experience influenced the inclusion of the question relating to discharge and the question probing what clinical areas different services targeted when working with children on the autism spectrum.

5.7.2 Survey Format Design

The design of the survey was influenced by the peripheral nature of the surveys, as well as my attempts to encourage item and unit-response and minimize question order effects (Dillman et al., 2014). As this survey did not function as my primary research, the survey was designed pragmatically to facilitate quicker data analysis by primarily including closed questions. Partially closed questions and Likert scales were also used; however, no open-ended questions were included. The exclusion of open-ended

questions increases the risk of bias in the study, as participants' responses may be influenced by the choice of answers provided. Additionally, a participant's desired response may not be provided as an option, in which case some participants may feel obliged to choose an alternative answer (Dillman et al., 2014). In an attempt to somewhat mitigate the risk of participants misrepresenting themselves, no questions were mandatory, with the exception of questions relating to eligibility criteria.

While the exclusion of open-ended questions limited the scope of the study, it may have helped to encourage item and unit-response. There is preliminary evidence (e.g., Peytchev & Hill, 2010) that open-ended questions are associated with high-item non-response in self-administered surveys, particularly those completed on mobile phones, which can introduce a non-response bias. Item and unit-response was also targeted in the format of the survey by ensuring the survey was quick to complete and providing information on each page of the survey as to what percentage of the survey had been completed. Additionally, in an attempt to engage with participants, the parent survey included two questions in which the choice of answers was depicted using photographs. The use of images in surveys may increase participant interest and enjoyment (Couper et al., 2004), and thus potentially encourage survey completion by participants. Nonetheless, the inclusion of images also introduces challenges to the analysis of these questions, as unintended inferences may be made by participants that researchers cannot be aware of (Couper et al., 2004). In a further attempt to facilitate unit-response and survey completion, related questions were grouped when possible. Dillman et al. (2014, p. 230) propose that grouping relating questions facilitates participants' responses and encourages them to provide more considered answers as the participant engages with one topic at a time.

A review of the literature on survey design heightened my awareness of the potential impact of the order of questions on responses provided. These order effects can be cognitive-based or normatively based (Dillman et al., 2014). Cognitive-based

order effects include priming and carryover stemming from earlier questions, and anchoring, in which early questions create a benchmark that the participant uses to compare and decipher subsequent questions. Normative-based order effects include participants providing similar responses to earlier questions in an attempt to be consistent or fair. To address these order effects, I followed Dillman et al.'s recommendation of isolating questions into separate sections and more frequently onto separate pages of the survey. Dillman et al. propose that this signals to participants that questions should be appraised individually and thus may reduce the probability of the individual relying on context and their memory of previous questions.

Further to question order effects, norms can also impact on responses in other ways. For example, the norm of "presentation of self in good light" may contribute to participants' responding in an effort to be perceived more desirably. The self-administered, anonymous nature of the survey may have helped to manage some of the impact of the social desirability bias (Dillman et al., 2014). In an effort to address social desirability, questions in the parent-study referred collectively to "parents" and avoided using pronouns such as "you" or "your." Personal pronouns were included in the [SLT](#) survey as it related to individual therapists' reported practices. However, in an effort to somewhat limit the impact of social desirability, the term "your service" was more frequently used than "you."

5.8 Survey Analysis Design

Both surveys were analysed using descriptive statistics. I recognise that studies designed to use inferential statistics offer opportunities to explore generalisability. However, due to the preliminary and peripheral nature of this strand of my research, I chose to use descriptive statistics that were compatible with both the sampling method used and the survey design employed.

5.9 Summary

This chapter discussed the methods employed in both the parent-based and [SLT](#)-based survey studies. It discussed the research questions and ethical considerations involved in both studies, as well as the design of each survey and analysis used. An overview of the participants involved in each study was also provided. The next chapter will present the results of both surveys.

Chapter 6: Survey Findings

6.1 Introduction

The survey studies are supplemental to the IPA study. Their main benefit was to inspire further iterative cycles of analysis in the IPA study. Nonetheless they also serve to contextualise the [IPA](#) study's findings and as such, I have chosen to retain these studies in the thesis but to present the findings prior to the findings of the main [IPA](#) study. The current chapter first reports the findings of the parent-survey. A discussion of the [SLT](#)-survey findings follows this. The chapter concludes with a brief reflection on how both survey studies influenced my final analysis of the [IPA](#) data.

6.2 Parent- Survey Findings

The parent-survey aimed to explore parental expectations of both the parent and therapist role in [SLT](#), as well as parental understandings of communication disorders and therapy. The participant sample involve two sub-groups of parent respondents – those with experience of [SLT](#) and those with none. However, visual analysis of the data made it clear that any differences in responses between groups were minimal, so no further analysis of differences between sub-groups was undertaken. The results reported below relate to the overall group, i.e., both parents with and without experience of [SLT](#).

6.2.1 Parental Expectations of Therapy Roles

Participants in the parent-survey reported relative certainty about their understanding of therapy roles. More than 85% of all respondents reported feeling '*fairly confident*' to '*very certain*', while 74% of the overall group reported feeling '*fairly confident*' to '*certain*' that they understood therapists' roles. These confidence ratings appear justified in relation to participants' understanding of speech and language therapy assessment. The majority of participants understood that assessment could involve the therapist, the child and the

parent using both direct assessment (using pictures - 97.42%, and toys – 92.26%) and indirect assessment (parent interview – 83%, observation of parent-child interaction - 72.26%). However, the data relating to how respondents understood therapy points to an understanding of the therapist role reflective of traditional models of care as described in Chapter 3. In the questions regarding responsibilities and attitudes, participants' responses indicate that they expected the therapist to play an expert-authority role in therapy. Most identified the therapist as responsible for making a diagnosis (81.21% of overall group) and providing expert knowledge (86.09% of overall group). Responses indicated expectations that the therapist either had sole responsibility or the greater share of responsibility for several other therapy duties related to leading and directing therapy (see table 6.1).

	SLT Alone	Mostly the SLT, but also the parent
Setting goals	40.14%	57.04%
Leading therapy	65.56%	30.46%
Training others	50.35%	34.04%
Willingness to give advice	50%	47.4%

Table 6.1 Results from “overall group” regarding division of responsibilities for duties related to leading and directing therapy.

The results regarding the parent role align best with “Parent as Therapist Aide” models of care. The majority of participants expected to be present during therapy sessions (90% of overall group) and to have a role in observing the therapist during sessions (88%). Most (80.8%) of the overall group responded that parents and therapists share the responsibility for being committed to “working hard”. During therapy sessions participant responses indicate that they expected to be involved in praising and motivating

their child (83.12% of respondents), in engaging in discussions with the [SLT](#) (78.57%) and in sharing responsibility with the [SLT](#) for completing therapy tasks (81.56%). After sessions, participants expected to complete exercises at home (96.73%). In between sessions, participants expected to share responsibility with the therapist for problem solving (82.04%), for helping their child’s communication development (93.69%), and for keeping other professionals up to date (76.71%). At all times, participants expected an active role in learning, with 88.41% of all responses indicating that the parent had sole or shared responsibility for learning in therapy. This aligns with the data showing that the large majority of participants perceive parents’ role in [SLT](#) to include the adoption of attitudes that support learning and development (see Table 6.2).

	Parent Alone	Mostly the parent, but also SLT
Openness to learn	40.14%	57.04%
Willing to try new things	65.56%	30.46%
Willing to do as instructed	50.35%	34.04%

Table 6.2 Results from “overall group” regarding division of responsibilities for adopting attitudes related to learning in therapy

6.2.2 Loose but Complex Understandings of Communication Disorders and SLT

Analysis suggests that the participants in the parent-survey had a relatively narrow understanding of the range of different types of communication disorders. Overall, there was good awareness of disorders related to “pronunciation” (95.48% of participants) and “stuttering/ stammering” (90.32%), but awareness of language disorders was less evident. With the exception of “vocabulary”, areas of language were identified by less than half of all participants as possible areas of disorder (see Table 6.3).

	Overall Group
Vocabulary	75.48%
Understanding	46.45%
Grammar	47.74%
Storytelling	48.23%

Table 6.3 Group responses relating to the areas of language that “an SLT helps children with.”

Responses suggest that the parents sampled understood potential causes of communication disorders primarily through a medical, body structure/function lens. More than 90% of participants selected hearing difficulties as a primary cause. The second most frequently chosen cause was a diagnosis such as “Autism Spectrum Disorders” (88.39% of responses). “Weak muscles” were identified by approximately half of all participants in each group. Environmental factors were selected less frequently. For example, approximately 40% of the overall group chose “too much time spent with TV or screens” as a cause of a communication difficulty. However, responses indicate that the medical metaphor was less influential in participants’ understanding of the therapy process, with less emphasis on body structure and function. The majority of participants (72.55%) indicated that therapy is not expected to cure all communication difficulties for all children, even if provided from a young age and at a high intensity. Furthermore, in the questions in which participants were asked to select the professionals who worked most similarly to SLTs, medical-type professionals were chosen infrequently overall (see Table 6.4).

	Overall Group
Physiotherapist	17.53%
Doctor	13.63%
Nurse	11%

Table 6.4 Participants' perceptions of which medical-type professionals work similarly to an SLT.

The data provides tentative evidence that rather than primarily drawing from medical encounters, participants drew, to some degree, from their experience with teachers, in forming expectations of therapy. "Teacher" was one of the most frequently chosen professions (61.69% of responses) in the question asking which professionals worked most similarly to [SLTs](#). Separately, in the question asking participants to choose the photographs that showed how a therapist works, 63.87% chose the picture showing a teacher-like figure standing in front of a blackboard. Additionally, almost all (96.73%) participants indicated an expectation that they would be given and required to complete "homework" in therapy.

On balance, the responses point to lingering expectations of traditional, therapist-led direct intervention approaches in the perceptions of most parents sampled. Less than 10% in all groups agreed with the statement "Therapy can involve working mostly with the parent and very little with the child." In the photograph questions relating to how the therapist works, the three most frequently selected options from the overall group all showed direct intervention (one-on-one interactions involving use of flashcards - 89.03%; mirror work - 76.77%; and pretend play - 67.74%). The four least commonly selected choices in the overall group included the only three photographs showing potential examples of indirect intervention (parent coaching using video feedback - 28.37%; parent group training - 20%; parent counselling – 11.61%). In the question asking participants to

choose the photographs that show how they understood the parent to be involved in therapy, less than one third (31.82%) of respondents chose the picture showing parents sitting in a group looking at a PowerPoint presentation (i.e., illustrating a form of indirect intervention). In sum, the data suggests a complex understanding of therapy, in which participants may draw from their experience in both medical and educational contexts to varying levels. While participants seemed to understand the causes of communication disorders as primarily biomedical, their understanding of therapy suggested a more holistic view, that was nonetheless underpinned by an expectation of therapist-directed interactions.

6.3 SLT-Survey Findings

The [SLT](#)-survey was focused on mapping the [SLT](#) care pathways in operation for children on the autism spectrum and the ways that parents of children on the autism spectrum are invited to be involved in decision making in [SLT](#) in Ireland.

6.3.1 SLT Care Pathways and Access to Services

Analysis of the [SLT](#)-survey indicates that many families who have a child with a confirmed or suspected diagnosis of autism in Ireland experience challenging contexts of [SLT](#) service provision. Many parents likely experience limited access, no access or loss of access to [SLT](#) services for their children at some time. For example, one question asked participants about the care pathways recommended by a service when a diagnosis of autism is suspected (see Table 6.5). More than 20% of respondents reported that once a child was referred for a diagnostic assessment, the child was then discharged from the referring service. This largely reflects the portion of the sample who work in uni-disciplinary settings (e.g., Primary Care settings) which are not resourced for children with complex needs. However, the lengthy nature of waiting lists for publicly funded services in Ireland indicates that these children who are discharged likely go without either a diagnosis or any therapies

for a considerable time following that discharge. Their parents may be left with no professional support during a period characterised by distress and anxiety (Connolly & Gersch, 2013). The survey also involved two questions about the areas of intervention that [SLTs](#) target directly or indirectly. Only 68.71% of the sample reported providing [AAC](#) interventions and less than half of participants reported offering feeding interventions (48.98%). Perhaps these findings reflect the caseloads of participants, as children in unidisciplinary services should have less complex needs. However, the high incidence of feeding difficulties in children on the autism spectrum (Ledford & Gast, 2006), for example, suggests that it is highly likely that some families who have a child with feeding difficulties have no access to any feeding interventions. It seems plausible that unmet needs and gaps in service provision may be interpreted by some parents to reflect how committed and reliable a service, and by extension the professionals employed within that service, are. This may conceivably impact on the therapeutic relationships within which roles are constructed.

The survey also explored reasons why children are discharged from services. The results signal the competing responsibilities that services juggle as they attempt to implement family-centred models of care, while simultaneously managing resources and throughput. For example, 30% of the sample report that children are discharged when they have exhausted all pathways available. In cases where pathways available are constrained by resources and/or training for staff, it is possible that children with ongoing, treatable needs may be inappropriately discharged. Furthermore, 57.69% of participants indicated that children on the autism spectrum are discharged following non-attendance. Given the lifelong nature of autism and the known risk of poorer parental mental health in families with children on the autism spectrum (e.g., Hayes & Watson, 2013), this result raises questions regarding the supports provided to help families engage in therapy.

Finally, 20% of the sample reported that children are discharged when professionals alone are confident that the family can self-manage, suggesting that some families may be discharged against their wishes. These results indicate the potential for conflict that may occur between families and therapists when decisions regarding discharge are being made.

	Pathway	%	Total
Continue to offer intervention - no break in service	Immediately refer for a diagnostic assessment, continue to offer therapy until the child commences assessment.	27.62%	60.96%
	Offer therapy first and if signs of autism persist, refer onwards but the child remains active on your caseload pending the outcome of their diagnostic assessment.	19.05%	
	Refer but continue to offer intervention regardless.	11.43%	
	Immediately refer. Discharge once child is receiving input from another service either as an assessment or therapy.	2.86%	
Discharge with possible break in service	Immediately refer for a diagnostic assessment, offer a single block of intervention and then discharge.	9.52%	21.9%
	Immediately refer for a diagnostic assessment and discharge the child from your service.	7.62%	
	Offer therapy first. If signs of autism persist, refer onwards and discharge.	4.76%	
Other	Case by case decision	10.48%	17.15%
	Other	3.81%	
	Immediately refer. Continue to manage child's mental health	2.86%	

Table 6.5 Recommended care pathways in the service if a therapist suspects a child may meet the criteria for an autism diagnosis.

6.3.2 SLT Decision-Making Practices

The results of the [SLT](#)-survey suggest that services operate variable practices in relation to the flexibility of service delivery and parent involvement in decision-making. One question asked participants if they could modify how intervention is provided when the service's care pathway did not appear appropriate. The majority (63.01%) of participants agreed they could, while approximately one third reported this was possible but only in specific situations as dictated by their service, for example when working with a family with challenging social circumstances. These results suggest that the majority of [SLTs](#) sampled have some autonomy in decisions regarding the flexibility of care provided, but approximately a third are constrained to some degree by service factors. However, less flexibility seems possible when the need is identified by the parent alone. For example, one question enquired if services offered flexibility in how interventions are provided if families do not agree with the recommended care pathway. Only 16.44% of participants reported that their service allowed such flexibility at all times, while 58.9% reported that such flexibility was provided only if resources were available. Additional comments indicated that flexibility was sometimes only provided if professionals deemed parents' reasons for disagreeing as "*valid*."

Data analysis suggests that opportunities for parent involvement in decision-making are largely limited to goal-setting. Nearly all (97.6%) of the sample agreed that they involved the family in setting goals for direct therapy. However, only 39.2% of participants reported that they involved the family or child in choosing the type of therapy used when direct intervention approaches were being considered. Similarly, less than half of the sample reported explaining the advantages and disadvantages about different therapy approaches to families both in relation to parent mediated interventions (46.9%) and direct therapy approaches (46.4%). Only 45.13% reported that they allowed families to choose which parent-mediated interventions they wanted to do, and less than 16% of participants reported that their service allowed families to

choose the order in which they completed these interventions. This suggests that the majority of participants neither offer a choice of interventions nor inform families about the potential disadvantages of the therapy approach selected. These results raise queries regarding the nature of the consent being granted by families and signal the potential presence of a power imbalance in the therapeutic relationships of many participants, which may arguably impact on role construction and negotiation.

6.4 Influence of Survey Findings on final IPA Analysis

6.4.1 Contextualising the IPA study

Both surveys aimed to help contextualise the core [IPA](#) study. Analysis of the survey data suggests that the experiences of many parents may involve some loss of access or limited access to services, as well as unmet service needs. The findings indicate that many parents' interactions with services and professionals may be characterised by a power imbalance, with parents afforded limited opportunity to partake in decision-making about their child's therapy. This is the challenging context in which many parents attempt to construct and negotiate roles often based on complex but loose expectations and understandings of therapy and therapy roles. The significance of the survey findings to the [IPA](#) analysis is discussed below.

6.4.2 Triggering Further Iterative Cycles of Analysis

The survey data is located in the general parent experience, and the [IPA](#) in specific, individual mother's experiences. Nonetheless, the survey analysis helped to extend my [IPA](#) analysis by bringing different perspectives and new questions to my interrogation of the data. For example, the survey data suggests that perhaps before becoming a parent or being aware of their children's autism, the participants may have held traditional understandings of therapy. This led me to approach the [IPA](#) data with questions about the relevance of autism to the construction of roles. I began to ask questions like, "Are the [IPA](#) participants' expectations of direct therapy influenced by the experience of autism?" It led me to reflect on anecdotal discourse I have

experienced with therapist colleagues that can sometimes explain a parent's desire for direct intervention as related to a parent's assumed desire to "fix" or "cure" autism. I began to consider how probable such a position is, when the survey data suggests that most parents, regardless of whether their child has a disorder or not, expect therapy to involve direct intervention? Counter to this, I also queried if the experience of autism might heighten the meaning attached to the belief that therapy is performed in a traditional, direct manner. I wondered if for some families the stakes become higher in the context of autism and beliefs about the value of direct intervention might become strengthened and perhaps entrenched to some degree. I used these reflections to further analyse the [IPA](#) data relating to the theme of "Understandings and Expectations of Autism."

The parent-survey data suggests that parents hold expectations that therapy will take a relatively traditional, expert led format. This indicates to me that parents may enter therapy with an expectation, and perhaps a desire that the "expert" will lead decision-making. I considered this in the context of the conflict and feelings of powerlessness that some of the [IPA](#) participants described. I wondered how an initial expectation and perhaps desire for decisions to be led by experts can translate into a "fight" and a desire to be more involved in decision-making. I reflected on the findings of the [SLT](#)-survey and the many unmet needs that many families may experience. I considered what (if any) impact these service-related issues might have on the parent-therapist relationship and the role that parents wished to have in therapy. I then returned to my earlier reflections about the significance of previous experiences and again asked myself, "How, if at all, does each therapeutic relationship impact on the next, and what might this mean for role construction?" Additionally, the [SLT](#)-survey also prompted reflections about the role of service organisations in role construction. I postulated that if services sometimes determined the pathway, and type of therapy that families were offered does this suggest that parents are negotiating roles with a service

rather than a therapist? When finalizing the [IPA](#) data analysis during the write-up of this thesis, I used the reflections described above, as well as others inspired by my reading, reflexive journaling, supervision and informal discussions with therapist colleagues and other parents to re-interrogate the [IPA](#) data.

6.5 Summary

This chapter discussed the findings of both the [SLT](#) and parent surveys. These survey results, while preliminary, suggest that many parents enter therapy with loose but complex understandings of therapy and communication disorders. Analysis indicates that many parents likely expect traditional therapy roles similar to those involved in the Parent as Therapist Aide models of care. The [SLT](#)-survey analysis points to a likely parent experience of therapy characterised by periods of restricted or loss of access to services and limited parent involvement in decision-making beyond goal-setting. The chapter discusses how the surveys, while peripheral to the IPA study, functioned to open further cycles of [IPA](#) analysis, contributing to deeper, more interpretative reflections and analysis. The next chapter will introduce the [IPA](#) participants and outline how the major IPA findings will be presented in the thesis.

Chapter 7: Introduction to IPA Findings

7.1 Introduction

[IPA](#) research is committed to providing a rich and detailed analysis of how individual participants make sense of their experiences (Smith et al., 2009). To honour this, this chapter first presents an overview of each participant before briefly introducing the main findings of the study.

7.2 Understanding the Participants' Individual Contexts

Each participant's meaning making of their role in [SLT](#) was located in their journey through the healthcare system with their child. A descriptive account of these journeys, as well as some reflexive commentary on my interactions with each participant and engagement with their data is provided below.

7.2.1 Helen

Helen was the first participant I interviewed, and the only participant I interviewed twice. Helen struck me as a calm, open person who had reflected in detail on certain parts of her experience, including the function of therapy, public versus privately funded services and the impact of autism on family relationships. Helen shared her story, spanning over ten years regarding her son, John, (12 years) who is on the autism spectrum. Helen became concerned about John's communication when he was a young toddler. John was seen at approximately 18 months by the Primary Care [SLT](#) and onward referral for a diagnostic assessment was recommended. Helen and her husband agreed for John to be assessed by a paediatrician who recommended that John access the local Early Intervention Team ([EIT](#)) for a diagnostic autism assessment.

When John's case was opened by the [EIT](#), an autism assessment was offered. Helen and her husband declined this assessment as they wanted to give John more time to "mature." John accessed [SLT](#), [OT](#) and physiotherapy from the [EIT](#). His parents

also supplemented this with private interventions, one of which included DIR® Floortime. Helen described Floortime as a “*textured therapy*” approach that contributed to a shift in her understanding of both the nature of John’s difficulties and how she and therapy could most meaningfully help him. Up to this point, Helen had favoured direct intervention with more concrete therapy targets, such as vocabulary development or speech production. She credited Floortime as facilitating her to adopt a broader view of therapy and its purpose.

After a number of years engaging with the [EIT](#), Helen became frustrated with the care John was receiving. The family chose to discontinue John’s involvement with public health services at this point and instead to continue with only private therapists. A number of years passed where John accessed only private therapies. When John was in fifth class, he had a class teacher who Helen believed was committed to helping John. This teacher advised that a diagnostic assessment for autism would be helpful in preparing John to transition to secondary school. Helen attempted to access this assessment through the public health system, but was advised that the waiting time for assessment was lengthy. She opted to see a psychiatrist privately. This psychiatrist diagnosed John with autism and Oppositional Defiance Disorder. John then began to access resource hours in school and continued to attend private [SLT](#). At the time of the interview, Helen’s main concerns were how best to prepare John for his transition to secondary school and his subsequent transition to adulthood.

7.2.2 Gayle

Gayle was an articulate, passionate participant who had reflected at length on her experience as a mother of a child on the autism spectrum and her relationship with health professionals. The definition of therapy, the roles expected of parents in therapy, and gaps in service provision were particularly salient in Gayle’s account. Her interview had political undertones throughout, as well as overt descriptions about her

experiences and thoughts in relation to disability activism, and the role of money and power in accessing services.

Gayle's experience involved her eldest son, Liam. At the time of the interview, Liam was 5 years old. When Liam was 2 years of age, Gayle approached her Public Health Nurse ([PHN](#)) about her concerns about Liam's feeding, poor sleep, excessive fears, low threshold for frustration and unusually "*adult-like*" manners of communication. The [PHN](#) recommended applying for an Assessment of Need ([AoN](#)). Liam received a diagnosis of autism (aged 2 years and 9 months) through [AoN](#). Gayle then arranged an Applied Behavioural Analysis ([ABA](#)) home tutor and private play therapy and [OT](#). Fourteen months after he was first referred, Liam's case was opened by [EIT](#) (aged approximately 3 years). At the initial intake meeting, Gayle met some [EIT](#) team members. She felt reassured by professionals that Liam would receive "*intervention*" now. A week later, different [EIT](#) team members visited Gayle and outlined how services were delivered, informing her about unfilled staff vacancies on the team and that much of the therapy provided would take the form of parent-mediated intervention. Gayle reported feeling considerable anger at professionals and services at this point. Liam went on to access [OT](#), [SLT](#) and physiotherapy from the [EIT](#). This was largely delivered as parent-mediated group interventions. Gayle was dissatisfied with the amount, type and frequency of therapy on offer, and voiced this to the [EIT](#). She was informed that parent-mediated interventions represented the "*gold-standard*" of intervention. Gayle also reported considerable frustration that the health service did not have a feeding service that Liam was eligible for, as his difficulties related to food aversion rather than dysphagia. Gayle and her husband funded private [SLT](#) and [OT](#) at the same time as Liam was attending the [EIT](#).

When Liam turned 5 years, he was discharged from the [EIT](#). The [EIT](#) recommended referral to the School Aged Disability Team ([SADT](#)). The [SADT](#) declined Liam's referral as they did not view Liam's needs to be complex enough to require an

interdisciplinary approach. Liam was then referred to Primary Care [OT](#), psychology and [SLT](#). At the time of the interview Gayle discussed her feelings of anger about the state's provision of healthcare for her son. She was involved in community and political advocacy and activism for children with additional needs.

7.2.3 Marian

Marian was an engaging, open participant whose account was characterised by a sense of disbelief and sadness about the challenges she had faced in feeling both heard and believed by many health professionals. I was struck by how much Marian appeared to seek reassurance from me during the interview that I believed her story.

Marian first became concerned about her son Cormac when he was a baby. She contacted her [PHN](#) several times to request [SLT](#) referral, but each time was refused. At 18 months of age, Cormac was reviewed by the Area Medical Officer ([AMO](#)), who recommended [SLT](#), audiology and an assessment with an Ear, Nose and Throat ([ENT](#)) Consultant. Cormac's family paid for a private [ENT](#) assessment and Cormac underwent a number of surgeries to address hearing difficulties. Before she could access an [SLT](#) assessment, Marian noted she was "*obligated*" to engage in a pilot play therapy scheme which confused and frustrated her. Following this, the Primary Care [SLT](#) attempted to assess Cormac (age 2.5 years) but advised that she could not complete the assessment due to Cormac's attention and behaviour. She referred Marian to a parenting course targeting behaviour. Marian sought a second opinion from a private [SLT](#), who concluded that Cormac had a speech disorder and referred Cormac to the Cleft Palate Team in a hospital for a second opinion. No palatal or velopharyngeal dysfunction were found and intervention targeting speech was recommended. Cormac received one block of [SLT](#) from Primary Care and was then discharged and referred to [EIT](#) due to concerns about his overall development.

While waiting for Cormac's case to be opened by the [EIT](#), Cormac's family funded private [SLT](#) and other therapies. At 3.5 years Cormac was seen by the EIT.

He received blocks of [SLT](#), [OT](#) and physiotherapy intervention. Marian was advised that due to vacancies on the team, diagnostic team assessments were not available. Frustrated by this, Marian wrote to the [AMO](#), who referred Cormac to a public hospital as an outpatient. Cormac received a diagnosis of autism from this hospital team. Marian reported that the [EIT](#) did not accept the hospital's diagnosis, and recommended reassessment. Cormac was later reassessed by the [EIT](#) and diagnosed with autism again. Cormac was discharged from the [EIT](#) at 6 years, due to his age and referred to a Child and Adolescent Mental Health Service ([CAMHS](#)) to determine if he also met the criteria for [ADHD](#) in addition to autism. At the time of the interview, Cormac was accessing input from psychiatry ([ADHD](#) medication) and [SLT](#) and [OT](#) in [CAMHS](#). Marian reported feeling content with his current service provision, but noted that her prior experiences had impressed upon her the importance of advocacy. Marian described how she had adopted an active role in a community group for families with children with autism, and was involved in lobbying for improved services.

7.2.4 Mila

Mila was a quiet, considered respondent whose interview sometimes felt overshadowed by a pervasive sense of guilt and self-doubt. Mila's interview was temporarily suspended when Mila became upset. Despite the interview triggering upset, Mila was keen to continue and did so with remarkable openness. Mila impressed upon me a sense of quiet determination to do the best for her daughter even when she was uncertain about what that was and about her abilities to do so.

When Mila's daughter, Nina, was between two and three years of age, Mila noted concerns about her development. She applied for an [AoN](#), and Nina was assessed by a psychologist who recommended [SLT](#) and [OT](#) intervention and further diagnostic assessment if appropriate. Nina accessed blocks of [OT](#) and [SLT](#) intervention in Primary Care. The therapists involved recommended a review diagnostic assessment through [AoN](#). Nina (aged approximately 4.5 years) then

received a diagnosis of autism and [GDD](#) and was referred to the [EIT](#). The [EIT's](#) policies stated that they did not see children older than 5; 0 years of age. Given Nina's late age at referral, the [EIT](#) agreed not to discharge Nina until she had accessed some input from all the necessary professionals. While in [EIT](#), Nina accessed blocks of direct therapy from [SLT](#), physiotherapy and [OT](#) and her parents attended parent education courses about autism. The [EIT](#) then discharged Nina and referred her to the [SADT](#).

Approximately 9 months later, Nina began to access [OT](#) and [SLT](#) from the [SADT](#). Mila attended and observed all therapy sessions. She conducted daily "sessions" at home with Nina to replicate the work being completed by the therapists. She also continued to do the physiotherapy programme that was designed by Nina's [EIT](#) physiotherapist. Mila's home "sessions" were an important discussion point for her, as she reported feeling like the "bad cop" who forced her daughter to do this extra work. At the time of the interview, Mila had learned that Nina's [SLT](#) was leaving. Mila was unsure of if or when the [SLT](#) would be replaced. Mila's overall interview conveyed a strong desire to help her daughter, but feelings of uncertainty and powerlessness about how to do so.

7.2.5 Mel

I interviewed Mel while she was experiencing depression, the onset of which Mel attributed to her son's (Stephen) diagnosis of autism. Mel participated in the interview with a brave level of honesty about her depression and the impact it had on her interactions with service providers and therapists working with Stephen.

At 2 years of age, Mel's son, Stephen, attended a routine developmental check with the [PHN](#). The [PHN](#) raised concerns about Stephen's development and recommended a referral for a hearing test and also to the [EIT](#). Mel reported feeling in shock about the [PHN's](#) concerns. After approximately a year, Stephen's case was opened by the [EIT](#). The [SLT](#) worked with Mel to introduce the Picture Exchange Communication System ([PECS](#)) to Stephen. He also received a block of six, once-

monthly sessions of joint [SLT-OT](#). Mel was unhappy with the pace of events and arranged a private assessment with a psychiatrist who diagnosed Stephen with autism and [ADHD](#).

Following Stephen's diagnosis of autism, Mel began to experience a persistent low mood. After a number of months of feeling this way, Mel visited her General Practitioner ([GP](#)), who diagnosed her with depression, prescribed antidepressants and referred Mel to a publicly funded counselling service. Shortly after this visit to the [GP](#), Stephen received a diagnosis of autism from the [EIT](#). Mel depicted how her depression gradually worsened. After being on the waiting list for counselling for eleven months without an appointment, Mel described reaching a crisis point with her mood. She visited her [GP](#) for an emergency appointment. The [GP](#) advocated on Mel's behalf and Mel received a counselling appointment the next week. At the time of the interview Mel was continuing to attend counselling.

Following the diagnosis of autism from the [EIT](#), Mel and her husband were invited to attend a Hanen™ *More Than Words* course. Mel declined this invitation, noting that she did not feel capable of attending due to her mood. The [EIT](#) offered Stephen further individual therapy. Initially Mel and her husband both attended these appointments together. Eventually Mel's husband stopped attending as neither he nor Mel felt the therapy was "working," perceiving the therapists to "*be only playing.*" While, still attending the [EIT](#), Mel organised private [OT](#) for Stephen but chose not to disclose this to the [EIT](#) professionals. At the time of the interview Stephen's [SLT](#) had left her post and the service was unable to advise how long this post would be vacant. Mel reported she was trying to find funding to access private [SLT](#) too. Mel's interview impressed upon me the wider context of fear, hope and hopelessness in which she was attempting to navigate services and protect her son.

7.2.6 Gloria

Gloria's was one of the last interviews I completed. I was struck by the tension between Gloria's optimism and hopefulness and her openly negative perception of autism. Her communications with me radiated a warmth and love for her son, but also conveyed acute sadness about his autism and the services he had received.

Gloria first became concerned about her son, Jake's, development when he was approximately 2 years of age. She noticed signs of regression, toe-walking and no signs of recognition of familiar songs. Gloria brought Jake to see two different private [SLTs](#). Neither therapist reported concerns about autism nor recommended onward referral. Nonetheless Gloria remained concerned and requested onward referral from her [PHN](#). Jake was then seen by the [AMO](#) who shared Gloria's concerns and referred Jake to Primary Care [SLT](#). The Primary Care [SLT](#) saw Jake at age 2 years 3 months. and referred Jake to [EIT](#) for a diagnostic assessment. Three months after Jake's Primary Care [SLT](#) assessment, Jake's case was opened by the [EIT](#). Jake underwent a diagnostic assessment and received a diagnosis of autism and [GDD](#) at 2 years 10 months. Following Jake's diagnosis, he began to receive [ABA](#) home tuition. The [EIT](#) began to invite Jake's parents to a number of "courses" about autism and adjusting to the diagnosis. Gloria and her husband were frustrated that no "therapy" appointments were offered and made a complaint to the [EIT](#). They were then invited to attend Hanen™ *More Than Words* which they both attended. While Gloria considered this group helpful, she reported that she was led to believe by therapists that this group would be a precursor to direct therapy. All of the therapy offered by all disciplines within the [EIT](#), with the exception of physiotherapy took the form of parent-mediated interventions, often based on manualised group programmes. Jake then received one further block of [SLT](#). This also focused on implementation of the Hanen strategies.

As per the [EIT](#)'s policy, Jake was discharged 12 months after his case was opened. While Jake's needs were complex and required an interdisciplinary approach,

he was too young to be referred to the [SADI](#). Instead, he was referred back to Primary Care as no other services were available. Gloria was aware that Jake would only be offered one block of therapy from each Primary Care discipline, before being discharged and referred to the [SADI](#) which had a three-year waiting list. Gloria's account illustrated a loving and dedicated mother, committed to helping her son in whatever way possible, who felt "left" by services and many professionals to help him alone.

7.3 Introduction to the IPA Findings

The above accounts illustrate the many different journeys to diagnosis and intervention that each participant took. While each experience was unique, participants shared a meandering journey in and out of services. This resonates with the findings of the survey studies which suggest that many families with children on the autism spectrum may experience periods of no service, limited service or loss of service. Unifying all of the above descriptive accounts was the mothers' strong sense of protectiveness towards their children, and heightened emotion regarding service provision. This is the context from which participants constructed and navigated their roles. The [IPA](#) analysis (discussed in Chapter 4), found that four superordinate themes were significant to addressing the questions of how these participants perceived and made sense of their roles (see Figure 7.1 below).

1. "Understandings and Expectations of Autism" – This theme encompasses the differing and dynamic perceptions of autism held by participants and how this influenced their involvement in therapy.
2. "Understandings and Expectations of [SLT](#)" – This theme captures how participants held loosely defined understandings of [SLT](#), grounded in traditional expert-led models which informed their expectations of therapy roles.
3. "*Therapy Mother*"- Participants' accounts pointed to two different categories of roles in [SLT](#). Initially participants interpreted their role to be an "Apprentice

Builder.” This involved learning from “*expert*” therapists and applying this learning with continued support from therapists, in an effort to “*build*” their child’s communication. However, most participants understood themselves to be compelled by services or gaps in services to adopt the role of “Manager-Therapist-Mother.” This role involved striving to act in a professional capacity as their child’s therapist and case manager, sometimes manifesting in conflict with their identities as mothers.

4. A Game of Survival- Participants perceived their interactions with services and professionals as akin to being propelled into a game of survival. Interpretations of being “*let down*” by services and sometimes professionals contributed to participants adopting defensive and offensive “game-playing” advocacy roles. These game-playing roles were perceived to interact with participants’ identities in different ways, sometimes affirming their identities as “good” protective mothers, and sometimes conflicting with how participants viewed themselves as individuals.

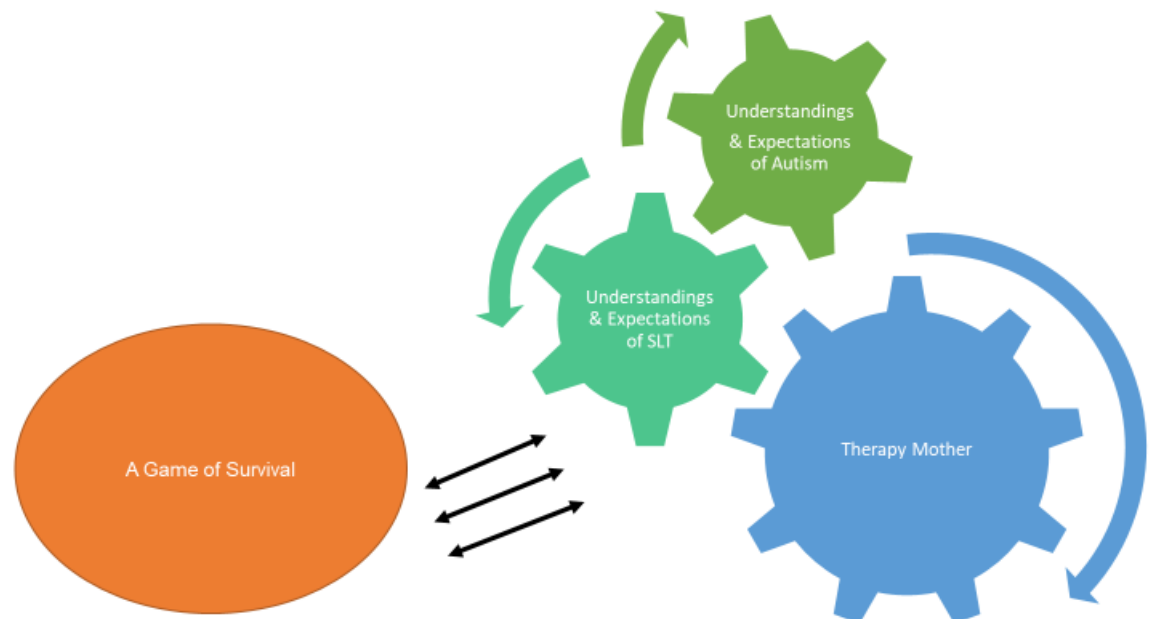


Figure 7.1 Relational Framework of Superordinate Themes

7.4 Summary

This chapter presented an overview of each participant and the core findings of the [IPA](#) study. A detailed description of each superordinate theme is presented in the coming chapters. Chapter 8 discusses “Understandings and Expectations of Autism and [SLT](#).” “*Therapy Mother*”, and “A Game of Survival,” are presented in Chapters 9 and 10 respectively.

Chapter 8: IPA Findings – Spotlight on “Understandings and Expectations”

8.1 Introduction

Following the completion of the [IPA](#) analysis and deductive analysis described in Chapter 4, four superordinate themes were constructed. Two of these themes related to understandings and expectations and are discussed in this chapter. The theme of “Understandings and Expectations of Autism” is first presented. This is followed by a discussion of the theme “Understandings and Expectations of [SLT](#).” The chapter concludes with reflective and reflexive commentary.

8.2 Understandings and Expectations of Autism

Data analysis suggests understandings and expectations of autism influenced how participants made sense of and negotiated their role in therapy (see Figure 8.1 below). An overview of the evidence supporting this theme is shown in Table 8.1 below (format adapted from Larkin & Thompson, 2012). When asked about their experiences of [SLT](#), all participants responded with a largely chronological account of their experiences with services in general, with significant time spent describing the period surrounding their children’s diagnosis and their reaction to this diagnosis. For some participants their understandings of autism appeared so frightening and overwhelming at times, that they became all-consuming, acting as a barrier to involvement in therapy (see theme “*Autism is kind of consuming me*”). Many participants eventually experienced a shift in their understanding of how autism related to their particular child and formed a working relationship with autism in their lives (see “Not ‘*Working against the Autism*’.”) However, understandings of autism remained complex, paradoxical and unique (see theme

“Complex Relationship between Understanding of Autism and Hopes for Therapies.”)

Regardless of how autism was perceived, a feeling of time pressure was frequently experienced in the years immediately following diagnosis, with some participants rushing to act and feeling compelled to do as much as possible before their child’s “*window of learning*” (Gloria) closed (see theme “In a Race against the Clock.”)



Figure 8.1 Superordinate Theme of "Understandings and Expectations of Autism"

Superordinate Theme	Understandings & Expectations of Autism		
Participants Involved	All participants		
Subthemes	Participants involved	Supporting Evidence	Indicative Quotes
Negative understandings of autism	Gayle, Gloria, Helen, Mel, Mila	Gayle (L386 – 387; 405 – 407; 1363 – 1386); Gloria (L1716 – 1725), Helen (AL100- 104; 478 – 481); Mel (L516 – 519); Mila (L349- 345; 616-635)	<i>“I mean your sort of vision of that is, emm ... probably an uncommunicative or poor communicative, emm, sort of emotionally stunted, if that’s the right expression ... child.” (Helen)</i>
“Autism is kind of consuming me.”	Gayle, Gloria, Helen, Mel	Gayle (L739-743; 1101); Gloria (L1711 – 1715); Helen (AL510-519), Mel (L130 – 131; 476 – 497).	<i>“Autism ... is kind of consuming me ... And I really don't want to go on courses about autism. I know people say like, "Oh you should. It's this, that and the other." But the husband said now he'll go when it comes up. ... Because ... it's good one of us goes but I, I really wouldn't be able for it now.” (Mel)</i>
In a race against the clock	Gayle, Gloria, Mila	Gayle (L316 – 322); Gloria (L425 – 430); Mila (L329 – 333)	<i>“I knew that for your child to have the best outcome, you needed to hit the ground running and invest a lot of time and energy into therapies, but that in the long run it would be worth it.” (Gayle)</i>

Not “working against the autism”	Gayle, Helen, Marian, Mila	Gayle (L752 – 778, L1108-1118); Helen (AL 523-540); Marian (L567- 574; 580 – 588; 2035 – 2043); Mila (L72-74; 269 – 285)	<i>“I couldn't get past emm, emm, emm through that autism and emm ... But living the you know and doing the therapies and doing the research and you know, doing all the, the, the emm the programmes for parents and looking and <u>knowing more</u> about it emm ... We are incredibly lucky” (Mila)</i>
Complex relationship between understandings of autism and hopes for therapies	Gayle, Gloria, Mila	Gayle (L1267 – 1286; 1449 – 1456.); Gloria (L772 – 773, 892, 1697-1698), Mila (L817 – 826)	<i>“And hopefully we will get there. [Cries] And hopefully they will say that she's fine.” (Mila)</i>

Table 8.1 Overview of Evidence Supporting “Understandings and Expectations of Autism”

8.2.1 Negative Understandings of Autism

Evidence of negative understandings of autism were found in five of the six participants' data. For Gloria and Mel, these negative understandings were depicted in the present tense. For Helen, Mila and Gayle, the theme largely dominated discussions about the time surrounding their children's experience of getting a diagnosis of autism. Participants' understandings of autism during this diagnostic period often appeared extreme, frightening and grounded in stereotypes. For example, Helen described an early encounter with a paediatrician who told her that she felt Helen's son was likely on the autism spectrum.

"She ... You know, she did the neuro testing and she said that she didn't think he needed a, a scan and that she thought he was probably on the spectrum and, emm, used the au- the word autism, which was hard, because I mean your sort of vision of that is, emm ... probably an uncommunicative or poor communicative, emm, sort of emotionally stunted, if that's the right expression ... child." **Extract A1- Helen (AL 478-481)**

Helen became dysfluent recounting this event and initially struggled to use the word "*autism*", hinting at the emotion underpinning the memory and the heightened emotion attached to this diagnostic label. Her use of the term "*emotionally stunted*" suggests an early perception that people with autism were less developed than those without autism. Mel's data also intimates an understanding of people with autism as "less human" and almost foreign.

"... But some of them now- They are a lot older but they're a lot violent, like. A lot of them are violent when they're older and some of them are trying to take their own lives. Like they don't even want to live. Like they're self-harming and all this and ... It's just horrendous." **Extract A2 – Mel (L515 – 518)**

Mel uses the pronoun “*they*” repeatedly to describe people with autism, indicating an understanding of people with autism as a relatively homogenous and separate group to the rest of society, and also perhaps hinting that she struggles to recognise her son as belonging to this group. She perceives “these” people as frightening and dangerous to others and themselves. Her utterance, “*they don’t even want to live,*” hints at both her incomprehension and perhaps a belief that “these” people lack this basic human desire. The data supporting Mel’s understanding of autism as almost wholly negative extends from the diagnostic period to the present tense of the interview. Similarly, Gloria’s data relating to this theme is also located in the present. When asked, at the conclusion of her interview if she had anything to add, Gloria told me “*I hate autism,*” and added ““*Don’t tell me there’s a God up there who ... you know gives kids things like this.*” Analysis of this extract highlights that Gloria perceives autism so strongly and negatively that it provides proof for her that God cannot exist. Other participants’ data signalled that while they experienced some reduction in their fear of autism over time (see theme: ‘Not “*working against the autism*” below), some level of fear persisted to some degree, particularly in relation to what autism may mean for their families’ futures.

8.2.2 “*Autism is kind of consuming me*”

Analysis shows that autism was experienced as an all-consuming force by four of the participants. For Gayle and Helen this perception was grounded in the diagnostic period. Helen, when describing her reaction to a paediatrician’s suggestion that her son might be on the autism spectrum, likened autism to a bullet that “*hit[s] you between the eyes*” and to cancer. Part of Helen’s reaction to this encounter is depicted in the extract below (I= interviewer and R= respondent).

I: What were you thinking?

R: Emm, I suppose it was more a label thing. You know, you kind of get stuck in your mind. It's like somebody says 'Oh you've cancer' and then when things are ... ironed out, you realise that well it's cancer, but it's treatable, and there's a good chance of getting -

I: Mmm

R: You know, getting to a very ... high functional state. That's kind of what I thought with John, when I thought it out. But when you get the label between the eyes, it's quite ... the worst-case scenarios probably come into your head so –

Extract A3- Helen (AL514 – 519)

The imagery of both bullets and cancer in the above extract highlight Helen's perception that autism can be life threatening. Linguistic analysis indicates that this threat related to Helen rather than her son's life. The bullet is directed at her, suggesting a perception that her life as she knows it is over and her imagined future life is also under threat. Gayle describes this period as being in a "fog," and says, "*I thought I'd never smile again.*" This fog metaphor is suggestive of not being able to see clearly and feeling lost as the life hoped and dreamed for is no longer visible. While Gayle and Helen eventually emerged from this "fog," Mel continued to experience it at the time of the interview. Mel described developing depression following her son's diagnosis. Mel stated, "*Autism ... is kind of consuming me.*" In contrast to the suddenness and abruptness of the pain conjured by Helen's language, Mel's language intimates an ongoing pain that continues to grow. Mel's account suggests that her thoughts are dominated and overwhelmed by autism.

R: *I just- Autism ... is kind of consuming me.*

I: *Yeah*

R: *And I really don't want to go on courses about autism. I know people say like, "Oh you should. It's this, that and the other." But the husband said now he'll go when it comes up.*

I: *Mmm*

R: *Because ... it's good one of us goes but I, I really wouldn't be able for it now.*

Extract A4- Mel (L479 – 486)

Mel resisted therapy related to autism education and attending support groups, as she perceived herself to be so weakened that she, *"really wouldn't be able for it now."* Perhaps by avoiding further exposure to autism, Mel believes she can limit the pain and impact of autism on her life. Gloria's account also hinted at a perception of autism as something that she reluctantly endures. She stated, *"I hate that we have to live with it."* Autism appeared to act as an unwelcome, permanent intruder in Gloria's life. Her use of the pronoun "we" suggested a perception that it has impacted her family as a whole, while her use of the modal verb *"have to"* suggests that she perceives autism as a powerful force that has deprived her of a life she would have chosen.

8.2.3 In a Race against the Clock

For some participants, feeling *"consumed"* by autism eventually came to an end. The next part of some participants' experiences, was characterised by a compulsion to act and move quickly, as time was running out. This is evidenced in Gayle, Gloria and Mila's accounts of feeling a pressure to *"hit the ground running and invest a lot of time and energy into therapies,"* (Gayle) so that their children's *"window for learning"* (Gloria) wasn't

missed. For Mila this time was characterised by “*rushed decisions*” and consequently sometimes regret and doubt. In the case of Gloria and Gayle, this perceived time pressure fostered a need to work rapidly and intensely to try and help their children make the most gains, which impacted on their expectations and preferences for therapy.

8.2.4 Not “*Working Against the Autism*”

While some participants desired and felt compelled to move rapidly in the time after their children’s diagnosis, their understanding of autism developed at a more gradual pace. Four of the participants’ accounts suggested a shift in their relationship with autism, moving from one of resistance to co-existence. Initially participants resisted autism, attempting to “*get past*” or “*through*,” (Mila). Participants gradually entered into a more ‘civil’ relationship, that involved working alongside rather than “*against the autism*,” (Marian). The building of this relationship was effortful and required participants to regain some control over their thoughts again. This is described as getting, “*myself straight in my head*,” (Gayle) and getting things “*ironed out*” (Helen), intimating both the interpretation that their thoughts previously were ‘messy’ and that they perceived the adjustment process to require active and effortful work. Mila stated:

“I couldn’t get past emm, emm, emm through that autism and emm ... But living the you know and doing the therapies and doing the research and you know, doing all the, the, the emm the programmes for parents and looking and knowing more about it emm ... We are incredibly lucky” **Extract A5- Mila (L280 – 283)**

Extract A5 highlights that gaining a broader understanding of autism as a spectrum was helpful for Mila in moving forward with a more positive outlook. Gaining this understanding and knowledge required effort and occurred gradually. Marian describes:

*“You know what I learned- The little bit that I knew years ago, I know a vast amount now. There's stuff- I mean I go to conferences. I go - I, I- You know I go to- I hear, you know, the best speakers in the world, about autism and Asperger's or whatever.” **Extract A6- Marian (L2035 – 2038)***

Marian's extract hinted at her pride in becoming more knowledgeable about autism. She emphasised the word “vast” and spoke about attending conferences alongside professionals. This perhaps suggests that Marian interpreted her understanding of autism to now be on par with that of professionals. This broader understanding of autism helped participants develop a more individualised understanding of what autism meant for their particular child. Their data indicated that they formed perceptions of their children's autism as being “*top level*” (Gayle) and distant from their early stereotyped understandings of autism. Analysis suggests that most participants experienced a shift in how they perceived their particular child's autism, rather than developing a more positive view of autism in general. Mila, Helen and Marian compared their children's autism to others, leading them to feel “*incredibly lucky*” (Mila) that their children are not “*more severe*” (Mila). They depicted how their children attend organised groups with other children with autism, but these children are on a similar “*level*” (Mila) to their own. Indeed, Mila described her decision to stop sending her daughter to a social skills group for children with autism, as there was a child there who made a “*very strange noise*,” and Mila was afraid that her daughter “*would get on their level*.”

Gayle's shift in understanding extended to a point where she viewed autism as bringing positivity to her life. Gayle embraced the community of families in her area who had children with autism. She also identified autism as responsible for the close nature of her relationship with her son. Gayle was aware of this shift in her perspective. Her data was suggestive of the process of change feeling challenging, but worthwhile. She stated:

“Two years down the track. And I wouldn't- I wouldn't genuinely change it for the world because autism, autism has brought us as many good things as brought us as many challenges. I know he's little, but we have a circle of friends we would never have had but for it. My son and I have a relationship that I don't think we ever would have had, had autism not been on the table.” **Extract A7- Gayle (L756 – 760).**

8.2.5 Complex Relationship between Understanding of Autism and Hopes for Therapies

Participants' complex relationships with autism are apparent in the data relating to their hopes for therapy. Analysis suggests that having a more positive understanding of autism did not automatically translate to a shift away from the desire to 'normalise' their children. Evidence suggests that some participants, such as Mila understood the lifelong nature of autism and adopted a working relationship with it. Yet, this working relationship didn't appear to signal acceptance of autism. Mila noted, in relation to her daughter, that *“in an ideal world, she wouldn't have autism.”* When asked if she envisioned reaching a point where her daughter would no longer require therapy, Mila responded, *“that would be my goal”* and became tearful and elaborated:

“And hopefully we will get there. [Cries] And hopefully they will say that she's fine.” **Extract A8- Mila (L825- 826)**

This extract suggests that Mila's understood that intervention would be required until her daughter presented with no more differences or difficulties. It is unclear who *“they”* refers to. Perhaps it refers to professionals who Mila may have perceived to have the expertise to make judgements about her daughter's abilities. However, it may also represent society, with this interpretation suggesting that her goal is to get to a point where society accepts Mila's daughter and determines her to be good enough. When discussing

the areas that her daughter had difficulties with, Mila qualified this discussion with the statement, “*don’t get me wrong. She is fabulous.*” This statement appears to act as an attempt by Mila to convey that she loves her daughter regardless of this list of challenges. Mila appeared to struggle to reconcile loving her daughter for who she is, with her desire to protect her and make life “*easier*” for her by perhaps “changing” her.

Gayle’s data was also suggestive of paradoxical understandings of autism and therapy hopes. Gayle was the only participant who reported that autism brought some positivity to her life. She noted:

“Emm so yeah it’s one of those things that if, if they said to me I could have prevented it, I probably would have. If they said to me, “Here’s a tablet and you can cure it,” I wouldn’t.”

Extract A9- Gayle (L765 – 767)

Gayle’s relationship with autism appeared complex. While she stated that she wouldn’t want to “cure” her son’s autism, analysis pointed to a desire for her son to appear more neurotypical. She advocated strongly for more therapy for her son, and this desire appears to relate, to some degree, to the goal of attaining more ‘normal’ behaviours. For example, when asked to describe her best experience of [SLT](#), Gayle described working with a therapist who helped Liam to tolerate eating a greater variety of cream crackers. As part of her explanation for why this was her best experience, Gayle stated, “*Cream crackers are not an unusual food for other kids to eat,*” hinting that part of the benefit of this therapy related to how it normalised some of her son’s behaviours. This tension between embracing autism while still valuing what is “normal” was also illustrated in Gayle’s account of her son’s forming his first independent friendship. Gayle recounts that initially she got “*a bit of a land*” when she realised that this new friend was “*quirky as bedamned.*” She explained:

"I just presumed that Liam would make friends with someone, because he was in a mainstream school, I presumed that he would make friends with someone ... typical."

Extract A10- Gayle (L1277 – 1280)

Gayle later qualified this experience by stating, "*But they just love each other so I don't care anymore [laughs].*" This account intimates that while Gayle held positive understanding of autism and neurodiversity, her hopes and expectations for her son continued to be influenced to some degree by neurotypical values. When describing this experience, she stated "*I don't care anymore,*" suggesting an initial, negative reaction to her son's friend not appearing neurotypical. Gayle appeared apologetic at this point, leaving sentences unfinished and pausing to carefully choose the word "*typical*" in lieu of another choice such as "normal." Analysis indicates that Gayle may have experienced both surprise and shame at her initial reaction. Gayle appeared to identify a neurodiversity perspective as preferable, but her data suggests that she sometimes found adopting this perspective effortful. While her attitude to autism appeared more positive than other participants, she also appeared to value and hold some hopes of a more "normal" life and future for her son.

In contrast to Mila and Gayle, Gloria retained a strong, negative opinion of autism as something to "*hate,*" yet data analysis did not indicate that this translated to therapy hopes related to normalisation. Gloria described her goals using phrases such as "*enhance his life,*" "*better quality of life,*" and "*give him as much as a start as you possibly can.*" Her reference to "*start*" is suggestive of a view of therapy as short lived rather than ongoing until a child no longer presents with differences or difficulties. Her focus appeared broader and more long-term than Mila and Gayle's. This may have related to Gloria's son's profile. At the time of the interview, he used [PECS](#) to communicate and while affectionate, Gloria's description of him suggested that he seldom engaged with others for social

reasons. Perhaps Gloria perceived his difficulties to be more severe and had adjusted her hopes for therapy in response to this. Nonetheless, these cases highlight that for participants in this study, understandings of autism are unique, complex, sometimes paradoxical, and dynamic. In the context of therapy, it is plausible this may contribute to changeable expectations and preferences and may also impact on a parent's capacity and desire to engage with therapy.

8.3 Understandings and Expectations of SLT

Figure 8.2 below provides an overview of the subthemes of "Understandings and Expectations of [SLT](#)." An overview of the evidence supporting this theme is shown in Table 8.2 below (format adapted from Larkin & Thompson, 2012). All participants were asked some direct questions about their expectations of [SLT](#). However, data relating to participants' understandings and expectations of [SLT](#) was also found in response to many other questions in the data-sets, particularly questions regarding general experiences of [SLT](#) and participants' best and worst experiences of [SLT](#). Data analysis indicates that participants' understandings and expectations of [SLT](#) informed their role constructions and role negotiations. Initially participants held loose expectations of [SLT](#) (see "Not really knowing what to expect but expecting to be involved.") Expectations and understandings of [SLT](#) and roles inherent in it, were largely influenced by conceptualisations of therapy as expert-led, direct intervention. Participants' data suggests that they defined therapy as something novel and specialised and a form of "*external help*" that fostered hope for the future. Therapy was sometimes described in a polarised way, as either "*right*" or "*wrong*," with some participants identifying "*wrong*" therapy as potentially harmful. Analysis also suggests that understandings of communication and communication disorders influenced how participants made sense of therapy. There is evidence that conceptualisations of communication and communication disorders varied across participants, and in some

cases these conceptualisations changed with experience and time. The sub-themes and data supporting them are presented below.



Figure 8.2 Superordinate Theme of "Understandings and Expectations of SLT."

Superordinate Theme	Understandings & Expectations of SLT		
Participants Involved	All participants		
Subthemes	Participants involved	Supporting Evidence	Indicative Quotes
Not really knowing what to expect, but expecting to be involved	All	Gayle (L325- 328); Gloria (L568- 570; 869-873); Helen (AL: 1605- 1606; BL 512); Marian (L1373- 1376); Mel (L 657); Mila (L837- 841; 851- 856)	<p><i>“Well emm initially I didn’t know what was going to happen. I really didn’t have a clue. I had no clue ...” (Marian)</i></p> <p><i>“It’s a big investment of yourself ... You’re not passing it on. It’s very much, you’re involved ... constantly ...” (Helen)</i></p>
Expectations and understandings grounded in direct, expert-led therapy	All	Gayle (L199-201; 435 – 444); Gloria (L292 – 298; 501- 504); Helen (AL316 – 317); Marian (L1671 – 1677); Mel (L57 – 58, 334- 336, 679 -688); Mila (L841- 848)	<p><i>“Silly me! Emm probably. Emm, I thought that we will be getting emm therapies on one on one and that we will probably will be needing somebody, emm you know on a weekly basis.” (Mila)</i></p>
Therapy as specialized, novel, “external help”	All	Gayle (L61 – 70; 1221- 1224; 1421 – 1439; 1469-1472; Gloria (L314-315; 340-347; 480-481; 931-939); Helen (AL426; 939; 1899); Marian (L417 -418; 950;1586 -1589; 1699-1703); Mel (L40 – 41; 61- 70; 718 -722); Mila (L586 – 603)	<p><i>“I need these people! ... But I really need them to help me.” (Marian)</i></p>

Varied understandings of communication and communication disorders	All	Gayle (L416-419; 432-433; 451-463); Gloria (L123- 131; 442-453); Helen (AL146-148; 285-286; BL239-246; 350 – 359; 366 – 388; 404-408; 410 – 431; 515 – 522); Marian (L1722- 1730; 1999-2033); Mel (L429 – 433; 557 – 564); Mila (L393 – 405)	<p><i>“I’d just love to hear him talking.” (Mel)</i></p> <p><i>“It gave me something, not a ten-minute speech therapy session that I would do as homework. It gave me a way of communicating with him, on a very general level ... And emm ... understanding, getting inside his skin a little bit, somehow. Slowing down. Not trying to put a plaster on all the issues that came up ... But trying to get inside his head a little bit. That’s what I felt it was.” (Helen)</i></p>
‘Wrong’ therapy can do “more harm than good.”	All, except Helen	Gayle (L1545- 1562); Gloria (L767-568; 771); Marian (L1513); Mel (L39 – 40); Mila (L101-102).	<p><i>“Do the <u>right</u> job.” (Marian)</i></p> <p><i>“I could have done more harm than good.” (Gayle)</i></p>

Table 8.2 Overview of the evidence supporting “Understanding and Expectations of SLT.”

8.3.1 Not really knowing what to expect, but expecting to be involved.

Analysis indicated that prior to commencing [SLT](#), participants' expectations of [SLT](#) were extremely loose. For example, when asked about her expectations, Marian said, "Well *emm initially I didn't know what was going to happen. I really didn't have a clue. I had no clue ...*" This is echoed by Mel who had "never really thought about it." Despite not knowing what to expect, there is evidence across participants' accounts that they expected to have some role in therapy. This expectation of being involved in therapy was met for all participants. Many of the participants described processes such as their child's diagnosis, therapy and discharge using the pronouns "we" and "us" (referring to themselves and their child). Helen described her involvement as "quite an all-embracing thing," elaborating:

"It's a big investment of yourself ... You're not passing it on. It's very much, you're involved ... constantly ..." **Extract A11- Helen (BL 512)**

The use of the word "*investment*" coupled with "*yourself*" in Extract A11, points to participation in therapy being experienced as a kind of speculation process, perhaps involving risk to one's own identity. Helen perceived herself to offer up part of herself in the hope that her son would make gains. Participation in therapy involved redirecting time, energy and focus away from some other aspect of Helen's life. Yet, rather than perceiving this through the lens of sacrifice, Helen framed it as an "*investment*," indicating that this was a planned, coordinated, worthwhile risk. The extract suggests that the investment is neither expressed as short-term nor sporadic, but as something constant. Helen's language also pointed to a perception of involvement in therapy in terms of parental duty and responsibility. By not "*passing it on*," she was both doing what was expected of her as a parent and what she judged to be "right." Parental involvement experienced as parental duty was also evident in Gloria's account.

"I mean at the end of the day, he, he- You know, he's my child. I expect ... to have to do-to have to do a certain amount ... But it's just emm - It was- It's sink or swim ..." **Extract A12- Gloria (L568 – 570)**

Extract A12 highlights that for some participants the extent of their involvement in therapy was unexpected. Mila noted *"I didn't think we would need to do as much."* Indeed, Gloria's reference to *"sink or swim,"* emphasises that that involvement sometimes felt overwhelming. Gloria's language suggests that for some participants involvement felt high risk at times and may have been perceived as going beyond their remit as parents.

8.3.2 Expectations and Understandings grounded in Direct, Expert-Led Therapy

Participants' initial expectations of [SLT](#) involved therapy taking the form of direct, expert-led intervention. Participants' expectations involved *"one on one"* (Mila) therapy, and *"they're going to do loads of stuff with him,"* (Gloria). *"They"* are the experts who have the training and skill set that they are *"equipped enough to manage"* (Mila) their children and *"teach"* (all participants) them. Gayle noted that *"Parents understand intervention to be direct therapy."* Mel's account also suggested that she valued therapists working directly with children. Mel's data suggested an interpretation of time spent by therapists talking to parents as *"wasting Stephen's time."* Mel intimated that time spent engaged in direct therapy is a precious resource that they need to maximise. She described warning her husband to refrain from talking to therapists during sessions, saying:

"Don't talk to them. You- You're talking too much. You're wasting his time. He only has 45 minutes so now he only has a half an hour." **Extract A13- Mel (L687 – 688)**

8.3.3 Therapy as Specialised, Novel “External Help”

All participants demonstrated evidence of an understanding of therapy as a form of specialised, “*external help*” (Helen). All participants’ accounts contained descriptions of planned and unplanned ways in which they had helped their children’s communication development, without professional help. For example, Gayle described friendships that she “*engineered*” for her son, and Marian described supporting her son’s involvement in informal social groups for children on the autism spectrum. Analysis suggests that parents understood many things to be therapeutic, but differentiated therapy as specialist, therapeutic help that required an expert and could not be completed by a parent independently. For example, Marian emotionally exclaimed, “*I need these people! ... But I really need them to help me.*” Marian’s repetition and emphasis on the word “*need*” intimated an interpretation of therapy as offering something Marian could never provide alone, despite her best efforts to help her son. Marian used the phrase “*these people*” to refer to the professionals that her son was engaged with. This suggests a view of health professionals as a member of a cohesive group. Indeed, all participants when asked about their experiences of [SLT](#) specifically, gave accounts of their experiences with a range of health and educational professionals, including [OT](#), psychologists and teachers. Nonetheless participants’ accounts also illustrate their recognition of differences between professions. Gayle, for example, stated, “*if it was all mis-mashed into one profession, there would be just one profession then.*”

All participants perceived different professions to involve different specialised expertise. Analysis indicates that participants understood therapy as a platform to provide specialised “*new ideas*” (Gloria) that participants “*would never have thought of,*” as they are “*totally different than what we’re used to,*” (Mel). Analysis suggests that participants sometimes experienced disappointment when the therapy they experienced was perceived

as familiar. Mel stated with frustration, *“I just can't see how playing with toys - Like what she's doing with him, I do all the time. And I'm sure he's doing it at school. So, what is the difference of this?”* Mel views her son's therapy to involve only play, which she identifies as something that he already has access to at home and in school and not as anything specialised or novel. She discussed how her husband eventually stopped attending these appointments with her as they both felt the therapy wasn't worth taking time off work. When describing why she was impressed with the private [OT](#) that her son attended, Mel compared the publicly funded joint [OT-SLT](#) sessions which involved *“playing”* with familiar toys to the private [OT](#) that involved specialist equipment and interacting with her son in unfamiliar ways.

R: This OT is totally different now than (name of publicly funded voluntary agency) now.

I: What's different?

R: In (name of voluntary agency) the man is with this girl and they're playing with toys.

I: Ok ... And what's different with emm-

R: This is a whole big, massive big play centre thing.

I: Ok

R: And he's jumping on trampolines. He's on swings and he's climbing and this deep pressure. She leans on him with all these ... It's very rough like.

Extract A14- Mel (L61 – 70)

Mel's description conjures two contrasting images. One is of an interaction that is so familiar it could happen in the home, while the other involves an interaction that is different or unusual in its content and context. The familiar interaction is perceived as a

“waste of time,” in which nothing new will be learned or tried to help her son. There is some evidence that “new ideas” (Gloria) offer a means of providing and maintaining hope for families. Gloria, for example, described her disappointment when the [SLT](#) she was working with encouraged her to continue working with her son using the interaction strategies that she had previously learned in an earlier therapy episode.

“She would say, ‘You’re doing a great job.’ I don’t want to hear I’m doing a great job. ‘You’re doing a great job. You’re- You’re fabulous. You’re doing this and you’ve got this done and you- This is- You’re doing brilliantly ... Emm there’s nothing more I can teach you.’ ... ‘Ok so what do you suggest? How can I move forward? What else can I do?’”

Extract A15 – Gloria (L340 – 345)

This extract emphasises that for Gloria, new ideas offered the hope of making further progress. Without new ideas, the appointments felt of limited value. While the encouragement was “very nice,” participants appeared to desire a therapy experience that also offered them “new ideas” and reinvigorated hope.

8.3.4 Understandings of Communication and Communication Disorders

Analysis indicated that varied understandings of communication and communication disorders were prevalent across participants’ accounts. There is evidence that many participants’ early understandings of communication and communication disorders were limited to the realm of speech. For example, when asked about what she expected of [SLT](#) before attending, Mel responded:

R: I probably think of older children, you know that can’t pronounce their words. The husband said he did go to speech before. He had a bit of a stutter.

I: Mmm

R: *A stammer or whatever you call it. And like I, I would associate it now with an older child to ... Like sounding out the words. Maybe on a blackboard or a page or ... pronouncing words like.*

Extract A16- Mel (L657 – 664)

Extract A16 refers to overt, audible communication disorders and makes no reference to language or social communication. Mel's uncertainty about the terminology for a stammer suggests a lack of confidence in her understanding of communication disorders. Indeed, Mel's use of the present tense "*think*" to respond to a question about her initial expectations from two years ago, suggests ongoing uncertainty about her understandings. However, there is evidence in Mel's dataset that indicates some changes have occurred in how she understands communication. For example, Mel's descriptions of her son's use of [PECS](#) suggest an emerging broadening understanding of communication to involve more than speech alone. Nonetheless, Mel's data strongly indicates that speech dominates her understandings of communication and communication disorders. Later in the interview, Mel stated, "*I'd just love to hear him talking.*" This utterance tentatively suggests that while changes have occurred in Mel's understandings, she does not recognise the potential role of motivation and communicative intent in her son's communication disorder. This heartfelt statement may also indicate that shifts in rational, knowledge-based understandings do not automatically translate into changes in emotion-driven hopes and dreams for a child's future and the therapies involved.

In contrast to Mel, the other participants accounts are suggestive of a broader understanding of communication. Helen's data indicates that relatively early, she formed an understanding of communication as involving a number of discrete, tangible but interlinked "*elements*." These elements included speech, language and social communication. Therapy involving "*teaching*" the child these specific "*elements*"

individually. There is evidence that Gayle, Gloria, Marian and Mila also held this view of communication as a system made up of discrete “*elements*.” This understanding compartmentalized communication skills as separate and unrelated to the other aspects of a child’s development and well-being. However, Helen experienced a shift in her understanding of communication and therapy that was not evident in the other participants’ accounts.

“And that’s fine if you have a broken leg or a pulled muscle but in, in the texture of somebody on the spectrum, I think ... it’s inadequate because, I think that ... there’s lots- Like there might be four or five different areas. All the OT, speech, physio, all that stuff and psychology ... But they have to blend as well. It’s not like a spoke going to each and everyone does their little bit.” **Extract A17 – Helen (BL 242 – 244)**

Analysis suggests that Helen’s understanding of communication broadened. While she continued to perceive it as a system involving related but discrete “*elements*,” she also viewed it as occurring in the context of her son’s overall development. This gave rise to a greater appreciation of other intrinsic factors that impacted on communication, including emotional regulation. Furthermore, Helen expanded her understanding of communication and communication disorders to appreciate that communication occurs when two or more people relate to one another. This led to Helen seeking out private intervention that was focused on the parent- child relationship (DIR Floortime®.) Helen noted that Floortime® was “*teaching- training for me and - more me than John probably,*” indicating an understanding that therapy could target her behaviours and communication approach, but be helpful for both herself and her son. Instead of a specific communication goal, Helen interpreted this therapy to be more holistic - “*I felt it was it like bringing John out of his cocoon a bit,*” and helped her “*make him blossom.*” This language evokes an image of

therapy acting to reveal competencies and communication strengths, rather than “teach” individual skills.

R: *It gave me a way of communicating with him, on a very general level ... And emm ... understanding, getting inside his skin a little bit, somehow.*

I: *Mmm*

R: *Slowing down. Not trying to put a plaster on all the issues that came up ... But trying to get inside his head a little bit. That's what I felt it was.*

Extract A18 – Helen (BL428 – 431)

Analysis of extract A18 suggests that Helen’s understanding of therapy expanded to include working at “*a very general level*” that differed to the very specific focus of other interventions. This ‘general’ approach moved away from trying to “fix” her son’s individual difficulties by putting “*a plaster on all the issues that came up.*” Plasters are temporary fixes to superficial cuts and wounds. This language hints at a shift in understanding of her son’s communication disorders as occurring within the lifelong context of autism. Helen appeared to perceive the goal of this therapy to be to better understand her son so that she could better relate to him and communicate with him. Helen described DIR Floortime® as providing the “*foundation*” on which other more “specific” therapies work. At the time of the interview, Helen still saw the importance of therapy that took a specific focus, but also approached such interventions with an additional “general” focus too. This “general” focus was evidenced by Helen seeking therapies that she felt were functional. Additionally, Helen looked at what she “*could bring to the home,*” beyond the therapy exercises provided, so that the therapy had meaning in her son’s life.

8.3.5 'Wrong' therapy can do "more harm than good."

Many of the participants described therapy in terms of right and wrong. For example, when discussing their frustration about the limited resources available for publicly funded therapy, Gloria said, "*When you say you're going to work with me, well just give me the right intervention that I need to do,*" and Marian exclaimed, "*Do the right job.*" Gloria, Marian, Mila and Mel perceived therapy to be "wrong" when they viewed it to be of no benefit to their children or their families. For these participants, the consequences of getting the "wrong" therapy were perceived as emotional and related to experiences of frustration, disappointment and sometimes anger about the "waste" (Mel) of time and opportunities. However, one participant, Gayle, understood receiving the "wrong" therapy as having potentially harmful and lasting impacts on her family's life. Gayle appeared to interpret participation in therapy to involve risk. In the extract below, Gayle discusses the risk involved in therapy targeting her son's feeding, which involves "homework" in between weekly sessions.

R: And the thing is sometimes it can all go wrong. Like so - And because we have so few foods to work with, if I try at home and do the Cornflake thing and it doesn't work, I'm better off leaving it.

I: Mmm

R: Letting Mary [private SLT] know- who he's with now, and saying "Listen it didn't work. Do you mind upping the ante here?" She'll do that. Then we try it again at home, rather than me trying it today; doesn't work; backfires. Try it on Thursday- really backfires, and then Cornflakes are gone.

Extract A19 – Gayle (L1545 -1552)

Gayle's use of the term "*backfires*" above suggests her perception that the consequences of taking the wrong approach can sometimes be experienced in a powerful, almost violent way, as well as in the regression of the range of foods eaten. This language captures both the "*meltowns*" it may trigger in her son, and the challenges her family may then face in managing these behavioural outbursts and his increased anxiety. She later expands on this to say, "*I could have done more harm than good.*" Helen was the only participant not to show evidence of this perception of therapy as either right or wrong. While she also experienced frustration and disappointment with her interactions with some therapists, she perceived therapies as on a gradient. Some therapies "*didn't feel like they hit the spot*" but were "*never a complete waste of time.*" Helen viewed these therapies as less helpful as they did not feel "*tailored*" to meet her son's specific needs and were not an "*effective use of time*". However, she understood her participation in less helpful therapies as part of a process in which parents "*try everything*" so "*you see what sticks.*" Eventually Helen "*became a little more selective,*" "*as to what we accepted from the service. In a way we filtered it a bit.*" This more "*selective*" approach involved Helen making decisions about which therapies and goals were the greatest priority for her son. Helen's engagement of private services at this point facilitated this approach.

8.4 Deductive Analysis Results

Evidence was found to support the relevance of both superordinate themes to all participants involved in the deductive analysis. A comparison of the numbers of participants demonstrating evidence of each theme in the [IPA](#) and deductive analysis samples is shown in Table 8.3 below. The greatest difference between groups was found in relation to the theme of 'Wrong' therapy can do "*more harm than good.*" There was a difference of two participants between these groups. Sample evidence gathered during the deductive analysis for each superordinate theme is shown in Tables 8.4 and 8.5 below.

	Theme	Core IPA Study -Number of Participants Involved (n=6)	Deductive Analysis – Number of Participants Involved (n=6)
Understandings & Expectations of Autism	Negative understandings of autism	5	5
	<i>“Autism is kind of consuming me.”</i>	4	4
	In a race against the clock	3	4
	Not <i>“working against the autism”</i>	4	4
	Complex relationship between understandings for autism and hopes for therapies	3	3
Understandings & Expectations of SLT	Not really knowing what to expect, but expecting to be involved	6	6
	Expectations and understandings grounded in direct, expert-led therapy	6	6
	Therapy as specialized, novel, <i>“external help”</i>	6	6
	Varied. understandings of communication and communication disorders	6	5
	<i>‘Wrong’ therapy can do “more harm than good.”</i>	5	3

Table 8.3 Numbers of participants in the IPA study and deductive analysis who showed evidence of “Understanding and Expectations of Autism” and “Understandings and Expectations of SLT.”

Sample Quotes

	Mary	Sarah	Sinead	Susan	Robyn	Trish	
Negative understandings of autism		√		√	√	√	<p>“You can feel a little resentful because you remember what it felt like to before autism came into your life ... when non-verbal autism comes into your life, it is hard.” (Robyn)</p> <p>“I’m still dealing with the idea that there’s something wrong with them. I look at my kids and I don’t see anything wrong with them.” (Mary)</p>
“Autism is kind of consuming me.”			√	√		√	<p>“Emm there’s nothing. Emm like you’re kind of dropped into this ocean of ‘your child has special needs’ and that’s it.” (Robyn)</p> <p>“And I think they try to understand it. But I think unless you actually live it ... It takes over your life a little bit.” (Sinead)</p>
In a race against the clock			√	√		√	<p>“I feel I’ve wasted two years with [name of EIT].” (Trish)</p> <p>“I know like, because ... I, I find ... Like they’re called Early Intervention and the young- Like, you know the younger you catch these things ... the better the prognosis in the long run, like.” (Sinead)</p>

<p><i>Not “working against the autism”</i></p>	<p>√</p>	<p>√</p>			<p>√</p>	<p><i>“Now we’ve been looking up stuff. Say I’ve Temple Grandin’s book, and you know- what’s it called. There’s a huge book that came out now about neurodiversity. We’ve loads of different books about it and we look it up online and so on.” (Trish)</i></p> <p><i>“I think I need to understand him a bit more ... As much as ... I have the knowledge of autism ... living with it is totally different.” (Sinead)</i></p>
<p><i>Complex relationship between understandings for autism and hopes for therapies</i></p>		<p>√</p>	<p>√</p>		<p>√</p>	<p><i>“We don’t expect anyone to kind of take Paul and say we’ll fix this or we’ll do that, like we feel it’s, it’s a journey as well. You know it’s not all going to fall into place all at once.” (Trish)</i></p> <p><i>“I don’t pay for private therapies any more. I used to in the early years because I do think he’s reached a level of ... He’ll do his own thing and develop as he’ll develop and he’ll, you know, kind of reach that stage of- Peter is Peter. He will do- If we get more out of him, great. If- Once he’s happy and healthy and can communicate with people, which is very important, you know.” (Susan)</i></p>

Table 8.4 Sample evidence from deductive analysis for “Understandings and Expectations of Autism”

Sample Quotes

	Mary	Sarah	Sinead	Susan	Robyn	Trish	
Not really knowing what to expect but expecting to be involved	√	√	√	√	√	√	<p>“... I didn't know what to expect. I didn't know what it was.” (Susan)</p> <p>“But emm ... I didn't know what to expect with the first, but ... I think too as well the assessments are so different to the sessions. Because the assessments was just like observations and the parents' interview.” (Sinead)</p>
Expectations and understandings grounded in direct, expert-led therapy	√	√	√	√	√	√	<p>“And a lot of the time I felt – Let's say it was a 40 minute appointment. Three quarters of that was spent talking to me ... and not working with Daniel.” (Sarah)</p> <p>“She did a lot of work with Sarah and a lot of games with Sarah and she was really, really good.” (Robyn)</p>
Therapy as specialized, novel, “external help”	√	√	√	√	√	√	<p>“The specialists know what they're doing because they're trained to do it.” (Mary)</p> <p>“You need a fresh input every so often, I think, otherwise it becomes stagnant and he gets bored and he switches off, you know.” (Susan)</p>
Varied understandings of communication and	√		√	√	√	√	<p>“But emm, I just expected that they'd just keep reinforcing the ... communication to come out. You know.” (Susan)</p>

<p>communication disorders</p>						<p><i>“We actually didn’t know what his voice was like for a long time because ... And then you’d have the odd word and Tom shares a room with Paul so he’d say “Paul said ...” You know I don’t know if I was telling you this the last day, but “Paul can count from Irish. One to ten in Irish.” And we were thinking [laughs] we don’t care if he can speak Irish. All we want him to do is speak and interact with us!” (Trish).</i></p>
<p><i>‘Wrong’ therapy can do “more harm than good.”</i></p>	<p>√</p>	<p>√</p>			<p>√</p>	<p><i>“Even if you get stuff to work on with the child, your daily life, all the other things emm kick in so by the time you go back next month it’s almost like you’re starting again. And I know the reason is probably their books you know they’ve loads of appointments and so on but is it helping anyone at all? Are you actually helping anyone?” (Trish)</i></p> <p><i>“But I think again it’s a lot of like, ‘This is what works.’ And it’s never like, ‘Do you think this would work for you?’ (Sinead)</i></p>

Table 8.5 Sample evidence from deductive analysis for “Understandings and Expectations of SLT”

8.5 Reflexive and Reflective Commentary

Both themes relating to “Understandings and Expectations” challenged and were challenged by my thinking as a therapist. My experience suggested to me that most parents enter therapy with a very abstract understanding of therapy, communication and communication disorders. Before commencing the research, I believed that many parents’ understandings of therapy drew heavily from the medical model, in which they viewed communication disorders as “curable” entities. When engaging with this research, I attempted to maintain an open mind and limit the influence of these assumptions on my analysis. To some extent the study’s findings relating to this theme were congruent with my initial assumptions. However, the findings opened my eyes to the subtle but significant differences between my expected results and those found through analysis. While participants held loose expectations, they expected to be involved in a manner, far beyond that associated with a doctor-patient dyad.

The results also suggested that participants understood therapists as “experts” who would be involved in “teaching” them. This emphasis on teaching prompted further reflection. Teaching suggests work and effort on the part of the student, while also carrying connotations of learning and development, rather than a cure. Yet as a therapist, I had spent much of my career shunning the idea that I was a “teacher” of communication. I viewed myself as a facilitator of communication development, as a therapist who saw parents as my equals not my students. To me, teaching suggested an overly simplified concept of communication and implied a power imbalance. When I approached the analysis of this theme, some parts of me felt compelled to reject this idea of therapists as teachers. Engaging reflexively with this helped me to perceive this likening of therapists to teachers positively, as an indicator of parents’ desire and motivation to learn. I considered my work as a therapist and concluded that some of the work I do does indeed involve teaching. Furthermore, I recognised that it is naïve to

pretend that power imbalances do not exist between therapists and parents, particularly in publicly-funded systems.

The theme of “Understandings and Expectations of Autism” raised some surprising questions for me personally and professionally. I was saddened by the largely negative understandings of autism that were evident in the data, while also understanding that as a parent if my son was given an autism diagnosis, I would feel worried and fearful. Analysing this theme provoked me to consider my views on autism and reflect on how compatible being a therapist is with valuing neurodiversity. My thoughts on this topic continue to evolve, however it helped me to understand to a greater degree the complexity of this issue and the many paradoxes in my own philosophy of autism. This in turn helped me with the analysis of the theme, ‘Not *“working against the autism,”*’ as I recognised the “muddy” approach that I had taken to try and find a way forward in my understanding of autism, that some participants may have taken too.

8.6 Summary

This chapter discussed the superordinate themes relating to understandings and expectations of autism and [SLT](#). These two themes help to address how participants in the study made sense of their role in [SLT](#). Participants’ initial understandings of autism often inspired feelings of fear and loss, which for some became all-consuming and acted as a barrier to participating in therapy. Sometimes this fear created a sensation of urgency, compelling participants to act quickly and require professionals to act quickly, particularly in the years following the diagnosis. While some participants’ relationships with their particular child’s autism became more accepting, understandings of autism in general remained complex, with analysis suggesting that many participants held hopes that therapy that might ‘normalise’ their child.

The superordinate theme of “Understandings and Expectations of [SLT](#)” highlighted the challenging context in which participants attempted to make sense of their roles in [SLT](#). Participants held loose but heightened expectations of [SLT](#) as a form of novel, “*external help*,” which offered hope for the future. Analysis suggests that participants held understandings of therapy that were grounded in direct, expert-led interventions. Additionally, many participants held binary evaluations of therapy as either “*right*” or “*wrong*,” with some perceiving “*wrong*” therapies to be harmful. These understandings may have contributed to amplified but narrow expectations of therapy and therapists, that may be problematic in the context of how therapy is often delivered in practice in Ireland. Furthermore, participants’ understandings of communication and communication disorders varied, but most participants viewed communication as an isolated system of separate but related “teachable” components. This understanding is more compatible with therapy approaches that focus on the “teaching” of specific discrete skills, and may pose challenges for interventions that adopt a more holistic focus. The next chapter discusses the superordinate theme of “*Therapy Mother*.”

Chapter 9: IPA Findings – Spotlight on “Therapy Mother”

9.1 Introduction

This chapter addresses the question of how participants perceived their role in [SLT](#), through a discussion of the superordinate theme of “*Therapy Mother*” (Helen). Analysis suggests participants understood their role in [SLT](#) to involve therapy implementation. Two categories of the implementer role were depicted. Participants expected to be involved as “Apprentice Builders,” working under the direction of an expert [SLT](#), learning how and what to do to help their child’s communication development. However, analysis also pointed to involvement in implementation in unexpected ways, as a case “*manager*” (Marian) and “*therapist*” (all except Mel). There is evidence that these unexpected roles may sometimes have been perceived as conflicting with participants’ identities as mothers, contributing to negative self evaluations. An overview of how the superordinate theme of “*Therapy Mother*” is constructed is shown below in Figure 9.1. The chapter begins with a discussion of the ‘Apprentice-Builder’ role, before presenting my analysis of the “Manager-Therapist-Mother” role.

9.2 Apprentice Builder

As discussed in Chapter 8, participants entered therapy with an expectation of being involved in therapy, albeit in a loosely defined manner. Analysis suggests that participants perceived their role as a “builder,” of their child’s communication. Gloria spoke of “*constantly trying to build*” her child’s existing communication skills, by using the strategies and exercises recommended by therapists. The connotations evoked by this language of “*build[ing]*” captures participants’ understandings of their role as one involving hard work and effort, and some skill but not at a specialist level, signalling that support from experts

is necessary for the builder to perform their role well. Table 9.1 below (format adapted from Larkin & Thompson, 2012) provides a summary of the participants involved in this theme and some of the evidence supporting the component subthemes. An overview of this theme is shown in Figure 9.2 at the end of this section of the chapter.

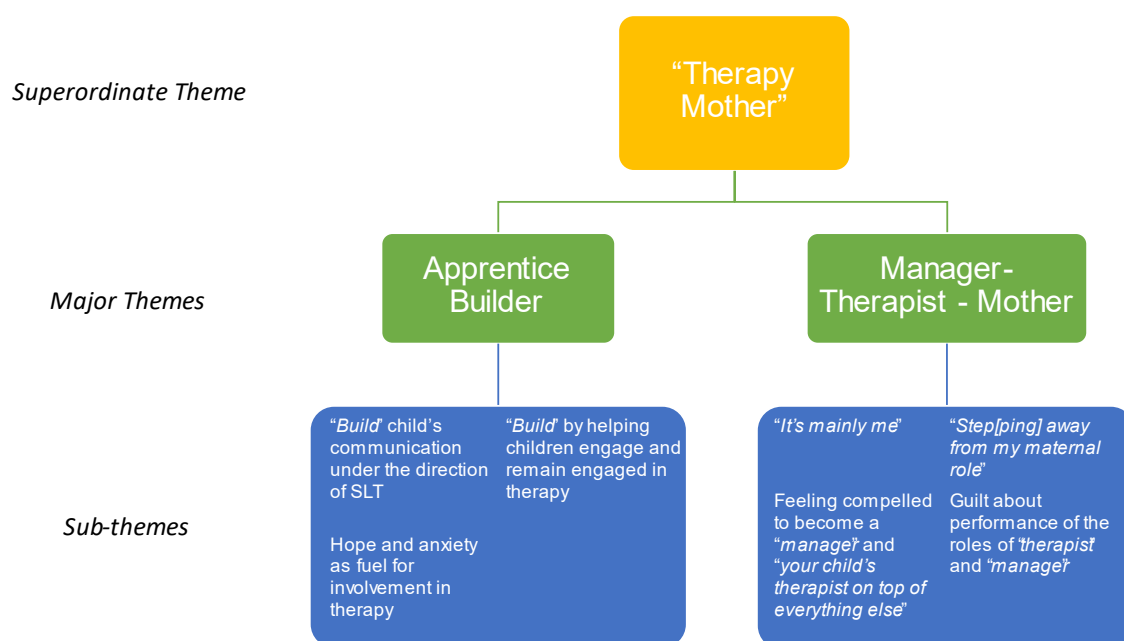


Figure 9.1 Superordinate theme of "Therapy Mother"

Superordinate Theme	<i>Therapy Mother</i>		
Component Major Theme	Apprentice Builder		
Participants Involved	All		
Subthemes	Participants involved	Supporting Evidence	Indicative Quotes
<i>"Build"</i> child's communication under the direction and/or guidance of SLT	All	Gayle (L1484-1488; 1513 – 1515; 1531- 1537); Gloria (L:523- 525; 875-881; 1409-1420); Helen (AL: 169-174; 342; 1554); Marian (L655 – 662; 670-672; 1427- 1434; 1455-1463); Mel (L665 – 671; 734-736); Mila (L98-99; 417 – 421; 434 – 437)	<p><i>"And so- What I felt my job- I mean, the thing is that what I felt my job and what I feel my job is all along, is to follow up whatever ... is established with the professional ..."</i> (Gayle)</p> <p><i>"She'd be teaching me and she would write down what she's doing and ... she would tell me what I have to do at home. And this is all homework."</i> (Marian)</p>
<i>"Build"</i> by helping children engage and remain engaged in therapy	Helen, Marian and Mila	Helen (AL179-180); Marian (L1436 – 1454; 1810-1819); Mila (L410 – 416; 423-424; 432; 521-529)	<p><i>"So emm, emm I'm here and obviously for emm cheering if you know- An extra cheer when she is doing great."</i> (Mila)</p> <p><i>"But I have to sort of- And I, I- Emm you're the expert. I have to go with they're doing and great, but emm ... yeah that's fine. And I sort of say, "Well actually I don't think that's going to work or-" And it's nice that you have this sort of feedback. I get on very well with all his therapist now."</i> (Marian)</p>

<p>Hope and anxiety as fuel for involvement in therapy</p>	<p>All</p>	<p>Gayle (L: 689-694; 785-786; 1755 -1758; 1813-1822); Gloria (L:857-862; 864-867); Helen (AL: 538); Marian (L: 403-409; 696-708; 1464-1472); Mel (323-329; 846-851); Mila (L810-814; 923-924)</p>	<p><i>“And I, I always go in with this sense of it’s going- You’re going, he’s going to improve now. From the time you see him, in six weeks’ time, there will be- he will have learned something.” (Marian)</i></p> <p><i>“Well, all the appointments ... They just ... They stress me out all these appointments he’s to go to, you know, but ... It’s just if I could see it working like ...” (Mel)</i></p>
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Table 9.1 Overview of evidence supporting major theme of “Apprentice Builder.”

9.2.1 “Build” child’s communication under the direction of the SLT

Analysis of all participants’ data points to a shared, core interpretation that their role in therapy was to help “*build*” (Gloria) their child’s communication skills with the support of the therapist. All participants viewed building as an active, intentional activity that involved “*hard work*” (Gloria) and an attitude of openness to learning from therapists. Building involved working “*in tandem*” (Gayle) with therapists, but with the therapist acting as the lead. Participants appeared to understand the therapist role to involve directing them about what and how to build, as well as getting involved in laying the foundations and scaffolding so that participants could build effectively and securely. Building for the participants involved “*follow[ing] up whatever ... is established with the professional*” (Gayle) and following the therapist’s “*plan*” (Gloria) with support from the therapist. The importance of having “*a plan*” was particularly important for Gloria, who referred to it six times in her interview. “*A plan*” for Gloria provides parents with “*something to do*” as well as the security that that “*something*” will bring them closer to both a short- and long-term goal. For Gayle, support from therapists was defined as the therapist working directly with the child, as well as providing guidance and problem-solving. All other participants held a broader definition of support which involved the therapist providing guidance and direction through therapy sessions, without specifying if that support involved direct or indirect intervention approaches. The “*follow up*” building work of participants involved trying to “*copy*” (Mel) interaction styles of the therapist, “*mirror*” (Mila) the activities completed in direct therapy sessions, while also completing specific “*homework*” (Helen and Marian) exercises and strategies that were prescribed by therapists. All participants demonstrated comparably high levels of motivation and commitment to help “build” their child’s communication, yet this manifested in different ways of being within therapy sessions.

All participants understood the builder role to encompass openness to learning from therapists, with most using terms that indicated a perception of a student-teacher relationship. When summarising typical sessions, Marian said, *“She’d be teaching me and she would write down what she’s doing and ... she would tell me what I have to do at home. And this is all homework.”* Helen also referred to therapists *“teaching”* her, while Gloria described going to therapy to *“learn X, Y, Z and come home and try and implement some of those ideas.”* Helen and Mel also used the term *“homework,”* and conveyed a similar interpretation to Marian, that homework related to what they had been told was obligatory to do at home. These interpretations indicate an understanding of the therapist as the expert, authority figure. Participants described different preferences, beliefs and opportunities for learning from therapists. All participants, except Helen, strongly valued observing and watching the therapist either working with the child or demonstrating strategies for the parent to use. Participants engaged in active observations of the therapists with a view to learning what *“to do”* to help their child (Gloria). Participants watched for concrete things they could *“mirror”* at home (Mila). Sometimes participants attempted to *“copy”* (Mel) therapists despite not fully understanding the rationale or the specifics of what the therapist was doing, and not feeling confident that, *“it’s doing any good,”* (Mel).

“I know the reason she’s talking so loud- Like she does explain anything like. Like she wouldn’t just say, “We’ll pick up this plate.” She’d say, “Stephen, we’re going to pick up this green plate. Hand it to Stephen [said in an animated tone of voice]. Stephen pass it back to Gemma.” Like she’s shouting words and colours all the time now.” **Extract B1- Mel (L665 – 669)**

Extract B1 highlights how Mel engaged in active observation of the therapist in sessions, noticing her tone and volume. However, Mel's explanation that the therapist is "*shouting words and colours all the time,*" suggests a partial understanding of what the therapist was doing and how this might help her son's communication. Despite this partial understanding, and despite her uncertainty about its value, Mel reported, "*I do just copy her like,*" depicting how she tried to "*copy*" the therapist when interacting with her son at home. This is suggestive of Mel's dedication to helping her son by whatever means possible. Analysis also suggests that understandings of therapists as experts with greater and more effective skill-sets, also contributed to some participants' apparent preference to observe therapists at work. Mel, Mila and Gayle's data suggests that their preference for learning through observation may be influenced by such understandings, as well as their confidence about their skill level. For example, Gayle explained her preference for direct therapy, led by a therapist, saying, "*it has more effect if it comes from a professional.*" Mila's data hints at a similar belief. For example, Mila described how she does "*sessions at home.*"

I: *And what do they look like?*

R: *Emm well I wouldn't be as creative and I wouldn't have the lily pads, but emm yeah, no, I would print loads of stuff as well.*

I: *Mmm*

R: *You know whatever I'm trying.*

Extract B2- Mila (L537 – 541)

Mila answered my question about her "*sessions at home*" by first discussing herself and her shortfalls when compared to the therapist. Despite perceiving herself to be doing

“*the same*” as the therapist, she emphasised that she is not as skilled, “*creative*” or well-equipped as the therapist. Her choice of the word “*trying*” and use of the modal auxiliary “*I wouldn’t*” twice, points to the apologetic nature with which she describes her skill-set. Following this extract, Mila gave an example of a therapy session she had observed, detailing the aim of the activity, the approach taken by the therapist and the resources used. She talked about how she “*did the same*” at home, as well as taking efforts to generalise the target into real life contexts. She showed clear evidence of having closely observed and learned from the therapist, and high levels of engagement with the therapy process despite not partaking in activities during the session.

Gloria and Marian’s cases demonstrate evidence of a preference to learn by both observing and getting involved in activities during direct therapy, in order to “practise” and get feedback from the therapist. Marian emphasised, “*so it’s very important that a parent does it in the therapy with the therapist ... You have to do it with them. Because then you realise what they’re doing and you can do it at home.*” For Marian, the opportunity to practise with the therapist present was “*essential*” for her learning, helping her to understand fully what and how the therapist was working and what they are hoping to achieve. Marian’s affirmation that by practising then “*you can do it at home,*” hints that her participation within sessions helped to raise her confidence in her own abilities to “build.”

Helen’s preferences regarding learning how and what to “build” was unique in comparison to other participants. Helen rated her participation in an indirect therapy approach called Floortime® as her best and most valued experience of therapy. She valued the learning through coaching involved in this therapy approach which she perceived as “*at a different level*” to the direct therapy sessions she had experienced. However, despite the value Helen placed on participatory learning in indirect therapy sessions, analysis indicated she preferred to adopt a different type of role within direct

therapy sessions that could have potentially been interpreted as “passive.” Helen described how in direct therapy sessions she primarily observed the therapist at work, but as her son increased in age, Helen developed a preference for sitting outside sessions when possible. In this context, Helen described learning from the therapist through receiving verbal instructions at the end of session. Analysis suggests that Helen’s preference to learn in this way was influenced by a number of factors. Helen explained that initially she was present during direct therapy sessions with her son, John, but that as he got older, she “*withdrew ... over time as ... John got confidence, I suppose, and was able.*” This potentially points to a perception that “withdrawal” from the therapy room was a marker of success, indicating her son was now confident and competent enough to work alone with the therapist. Helen’s data also suggests that self-confidence may have impacted on her preference to learn through verbal instruction only. When explaining her decision-making regarding her involvement with services in general, Helen states, “*I did feel I had the skills to do a reasonable job.*” She noted that her professional background gave her both experience and confidence in completing the “*homework*” provided.

9.2.2 ‘Build’ by helping children engage and remain engaged in therapy

Half of the participants (Helen, Marian and Mila) demonstrated evidence that they perceived part of their role in direct therapy sessions to involve helping their child engage and remain engaged during the therapy sessions. For Mila, this role involved an attitude of feeling responsible for her daughter’s engagement in therapy, marked by the behaviours of monitoring and managing her daughter’s behaviour and attention. She described herself and her husband as “*the refocusing [laughs] ones*” who had to physically, verbally and emotionally respond to their daughter “*so she wouldn’t climb on the walls,*” during early therapy sessions. Mila also identified the role she played in praising her child’s efforts and celebrating her successes.

I: And what about you in the session?

R: Emm so again emm, emm, emm I am, I am here as well. And it's just, you know again, I'm just watching –

I: Mmm

R: And, and you know and if Nina needs to be refocused a, a little bit- Emm just a prompt. So emm, emm I'm here and obviously for emm cheering if you know-

I: [laughs] Oh ok.

R: [laughs] An extra cheer when she is doing great. And you know- Yeah. You know, I am not involved.

Extract B3- Mila (L521 – 529)

Extract B3 indicates that while Mila was aware of her actions in sessions, she did not fully appreciate the potential importance of this role. I interpreted her dysfluency, as well as her use of the words “*just*” and “*obviously*” as mechanisms used to downplay the significance of her role. Indeed, despite discussing all that she did in sessions, Mila summarised her in-session role with the statement “*I am not involved.*” The extract above was provided in response to the prompt, “*what about you?*” Prior to this Mila discussed in depth her observations and perceptions of the therapist and her daughter’s involvement in therapy sessions, with very little reference to herself. Analysis tentatively suggests that Mila viewed her role in therapy sessions as of secondary importance to that of her daughter and therapist. The word “*obviously*” may intimate a perception that her actions were a routine and perhaps automatic part of parenting and not something that she perceived as a significant contributor to the success of the therapy sessions.

In contrast to Mila, Marian and Helen identified the importance of their expertise as parents, who “*know best*” (Helen) about their children as individuals and their children’s “*comfort levels*” (Helen). As discussed above, Helen viewed her role in direct therapy sessions as largely centred around managing her son’s behaviour and engagement, and when he began to consistently engage in sessions without difficulty, Helen was keen to withdraw. Marian, like Mila, described her attempts to motivate her son with praise and also by bringing a high energy and fun atmosphere as she joined in therapy games. Unlike Mila, both Helen and Marian provided “*feedback*” (Marian) and suggestions to professionals about how to approach working with their children to support their children’s engagement in therapy.

R: You know I would be very, very much watching what they’re doing.

I: Mmm

R: Emm [laughs] Critical [laughs] You know what I mean. Looking and saying, “Ok yeah that’s good,” or I’m thinking “No, that’s not going to work! But anyway, let her go on.” [laughs] You know, but I- You know

I: Mmm

R: But I have to sort of- And I, I- Emm you’re the expert. I have to go with they’re doing and great, but emm ... yeah that’s fine. And I sort of say, “Well actually I don’t think that’s going to work or-“ And it’s nice that you have this sort of feedback. I get on very well with all his therapist now.

Extract B4- Marian (L1810 – 1819)

The extract above suggests that Marian has self-confidence in her expertise in engaging her son and is aware of the importance of sharing this knowledge. Nonetheless

the extract suggests less confidence in the act of sharing this knowledge with therapists. Marian was hesitant about discussing her thoughts and considered if she should “*let her go on.*” This hesitancy appears to point to a tension between viewing the therapist as the expert, authority figure, while also recognising her own expertise. Marian became dysfluent as she appeared to attempt to signal her respect for the perceived power and authority of the therapist, while speaking to them in a way that revealed both her own expertise and recognition of their expertise. Marian’s language here adopted a heightened sense of politeness, as she used terms like “*great,*” “*that’s fine,*” “*it’s nice,*” and concluded with the sentence, “*I get on very well with all his therapists now.*” This language suggested to me that despite her self-confidence, talking to therapists in this manner perhaps felt uncomfortable as Marian considered it may be misunderstood as disrespectful of the therapist’s perceived expertise. Nonetheless, Marian persevered through the discomfort to share her expertise, suggesting that she recognised it as important for therapy.

9.2.3 Hope and Anxiety as fuel for involvement in therapy

Participants accounts suggest that hope and anxiety may help to fuel their involvement in therapy. Participants all hoped for a positive future for their children and families and perceived therapy as the vehicle that could bring them closer to this positive future. For some participants, like Gloria, Marian, Helen and Mila having hope for therapy helped them to remain hopeful for the future in general. For example, in the extract below Gloria described her feelings about an upcoming [SLT](#) session with a new therapist in a new service.

“So, I have great hope for Friday. I’m going in with great hope for Friday, say ... you know that she’s going to be able to do something emm and that she’s not going to say ‘You need a multidisciplinary team. Sorry I can’t help you.’ You know, she sounded like she, she wasn’t put off- You know she didn’t- She wasn’t like ‘Oh right ... Ok.’ She just said, ‘Look

*Gloria, our goal might be trying to get him in and' – You know she was just I suppose positive about it." **Extract B5 -Gloria (L857 – 862)***

Gloria was emphatic about her hopeful stance about this upcoming therapy episode. She moved between present and future tense to describe her feelings of hope, intimating, perhaps, that feeling hopeful about therapy may spill over into feeling more hopeful about life in general. Gloria's feeling of hope appeared to be measured. When describing what she was hopeful for Gloria used the modal verbs "*might*" and "*could*," suggesting that her hope is based on a perception that change and progress are a possibility rather than a certainty. Feeling that positive change was possible was enough to help Gloria feel motivated and hopeful about her own abilities and those of the therapist. She contrasted the experience of hope outlined above to other experiences with professionals who raised concerns about their abilities to "*help*" her son because they were not based on multi-disciplinary teams. Perhaps previous disappointing encounters with professionals had contributed to Gloria's hope becoming depleted in the past. If so, this may underlie why having any hope at all appeared to be a cause for celebration for Gloria. While hope for Gloria manifested as possibility, Marian viewed hope through the perspective of certainty. When discussing beginning episodes of [SLT](#), Marian said:

R: And I, I always go in with this sense of it's going- You're going, he's going to improve now. From the time you see him, in six weeks' time, there will be- he will have learned something.

I: Mmm

R: And we're going to see this.

I: Mmm

R: And we're going to work together.

I: Mmm

R: ... No I'm very ... When I, I go in there, I, I'm positive.

Extract B6- Marian (L1464 – 1472)

Marian depicted herself to “*always*” enter therapy with hope. Marian, like Gloria, had interactions with therapists which she perceived as disappointing and frustrating. Analysis suggests that Marian responded to such interactions by approaching new relationships with a deliberate and confident hopeful stance. Marian’s belief in her son appeared closer to a certainty than a hope. Her language hints that this level of hope may be designed to convince professionals to believe in her son’s potential. Marian’s dysfluency regarding the subject of the utterance, “*it’s going- You’re going, he’s going to improve now,*” raises some questions about what her hope is grounded in. Initially it appears she may have attributed her hope to the therapy process in general, but she quickly revised this to the pronoun “*you,*” referring to the therapist. Her intonation suggested that this utterance was then conjoined to the statement about her son, suggesting that both the therapist and her son would be “*improving.*” I interpreted this statement to intimate that Marian hoped that by working with her son, therapists would learn and “*improve*” their practice. Marian’s hope appears to relate to both hope of seeing progress in her son’s communication skills, but also hope of a positive therapy experience, characterised by a positive therapeutic relationship. Her statement “*we’re going to work together,*” acts as both a directive to therapists and an affirmation for herself that this therapeutic relationship was going to work well. Analysis of other extracts in Marian’s dataset point to the possibility that the certainty and confidence surrounding her experiences of hope, may partly relate to her ability to recognise and celebrate her son’s progress to date. She described her son as “*a complete success*” and “*a success story,*” and at a separate point stated:

R: *But if you see him now, you'd realise, "Gosh, you know, he's come an awful long way."*

I: *Mmm*

R: *From a child who was on the floor, in a corner, just, you know playing with, with a pen or something, would not even look at toys*

I: *Mmm*

R: *To where he is now ... Is amazing ...*

Extract B7- Marian (L403 – 409)

Marian's description above illustrates her sense of pride and awe at all that her son has achieved. Her language suggests an interpretation of his progress as a journey, of which the longest and hardest parts are now over. This extract hints that Marian's hope may not have always been experienced with such certainty, but reflecting on and celebrating her son's progress have solidified her hope and confidence in his abilities and his response to therapy. The potential relationship between recognising and celebrating progress and experiencing hope is also illustrated in the contrastive case of Mel. Mel was being treated for depression at the time of her interview and this was likely a factor in the hopelessness that was prominent in her data. Analysis suggests that Mel perceived her son's apparent lack of progress as contributing to her feelings of hopelessness.

"It's just if I could see it working like ... It's just that when you're going and you just think, 'This is ridiculous. This is- This is just ridiculous.' ... It's just it's very disheartening like. Like your one, the private OT now said she can see some change already now ... I don't know maybe they just say that, but ... Like ... if I could get him to calm down and sit down. Sit down. He won't sit down at all now." **Extract B8- Mel (L324 – 329)**

Mel suggested that if she “*could see it working*” then perhaps she could feel more confident and hopeful about therapy. Mel attributed not seeing any progress to the more general feeling of being disheartened. The extract above suggests that progress is a subjective phenomenon whose power may stem from the act of being noticed. Mel’s statement about the [OT](#) raises the possibility that Mel defined progress differently to the professionals she works with. Mel’s focus appeared to be on functional but longer-term goals. Progress for Mel in the area of [OT](#) appeared to be characterised as being calm and still for periods. In a separate extract, Mel described again how she didn’t “*see a difference*” and she elaborated on this, by stating, “*He’s not talking like ... He goes into school. He comes home. He’s ... He’s not even any more independent.*” Mel appeared to define progress both broadly and in relation to major milestones. Her thoughts appeared dominated by all that her son couldn’t do.

Despite not recognising any progress and feeling without hope in the time prior to the interview, Mel continued to attend direct therapy appointments and as discussed above (see theme: “Build child’s communication under the direction of the [SLT](#),”) attempted to “*copy*” how the [SLT](#) interacted with her child and followed recommendations about encouraging [PECS](#) at home. Her involvement despite this context of limited hope appeared motivated by her anxieties and fears for her son’s future. Gayle also experienced limited hope for therapy at times, albeit for different reasons. As discussed previously, Gayle did not perceive indirect interventions such as the Hanen® programmes as “*effective*,” and overtly discussed her lack of belief in such approaches. Yet, despite not believing in these interventions, Gayle continued to attend appointments, and read the material given. Her relationship with the therapists sometimes appeared challenging and on occasion “*hostile*” (discussed further in the next chapter), yet Gayle did not withdraw from these interventions. Analysis indicates that for both Gayle and Mel, anxieties and

fears about their children’s futures were such that they were willing to try anything, even things they didn’t believe in, to try and help their children. Despite Gayle’s son successfully starting school without requiring additional supports, Gayle forecast a challenging future for him in which her son would “*always*” require some therapeutic involvement. Gayle predicted a future for her son that involved “*mental health problems, in terms of anxiety,*” that she anticipated would require medication and “*an eating disorder.*” She described how she understood the only way of protecting against this future was to access “*intervention.*” When describing these predictions, Gayle concludes by saying “*I suppose forewarned is forearmed and all that kind of stuff.*” I interpreted this to signal that Gayle attempted to use her anxieties as a positive force that allowed her to try and address some concerns preventatively. Her anxieties about the future may have “forearmed” her by motivating her to do all that was possible to help her son.

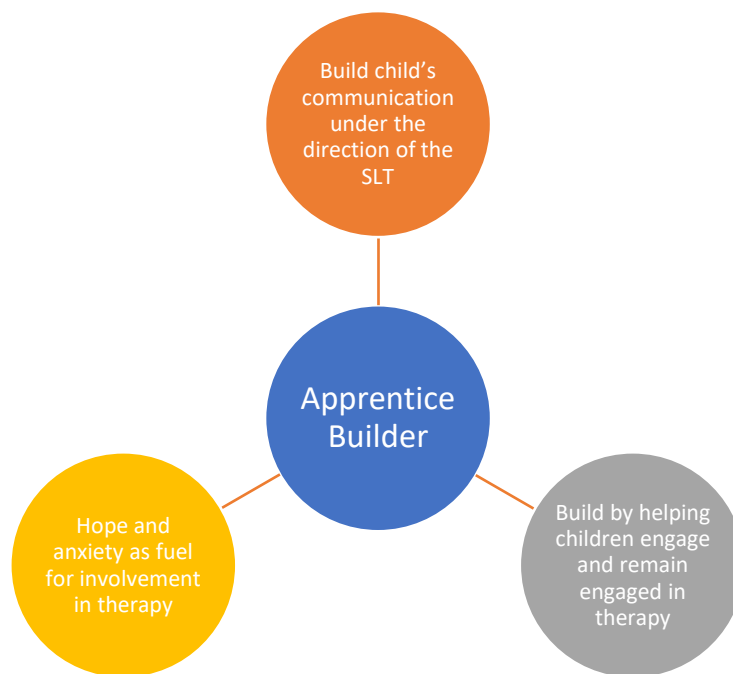


Figure 9.2 “Apprentice Builder” Theme

9.3 Manager-Therapist-Mother

While the Apprentice-Builder role aligned somewhat with participants' early expectations of their role in therapy, most participants also experienced being involved in unexpected and often isolating ways. Participants felt compelled by the organisation of services and practices of professionals to take on roles as multiple "*therapists*," (all except Mel) as well as a case "*manager*" (Marian). Adopting these unexpected and unwanted roles was sometimes experienced as threatening to their identities as mothers (see "*Step[ping] away from my maternal role*" theme.). These additional roles involved attitudes of being solely responsible for their child's communication development, with no or limited "*back-up*" (Mila) from professionals and partners (see "*It's mainly me*" theme.) Instead of acting within the skill set of an apprentice-builder, participants felt that services and interventions were provided in such a way that they were required to do the "*impossible*," in acting as multiple therapists for their children, without feeling skilled or supported and while also trying to maintain their other roles and responsibilities ("*Feeling compelled to become 'a manager' and 'your child's therapist on top of everything else'*" theme). While the motivation for participants' taking these roles was grounded in their desire to help their children, performance of the role contributed to significant guilt. Table 9.2 below (format adapted from Larkin & Thompson, 2012) provides a summary of the participants involved in this theme and the evidence supporting the component subthemes. An overview of this is also presented in Figure 9.3 at the end of this section.

Superordinate Theme	<i>Therapy Mother</i>		
Component Major Theme	Manager-Therapist-Mother		
Participants Involved	All except Mel		
Subthemes	Participants involved	Supporting Evidence	Indicative Quotes
<i>"It's mainly me"</i>	All except Mel	Gayle (L117-118; 841- 845; 1540-1541) Gloria (L1097-1100; 1334-1355; 1848-1859), Helen (BL:848-863), Marian (L993-995, 1688-1690) Mila (L287-288; 293-295; 559-561)	<p><i>"The HSE approach was to basically bat the ball back into the parents' court. To try and train up the parents expecting the parents to run home programmes with very, very limited support from them."</i> (Gayle)</p> <p><i>"I need back-up and I need to know- That if I - we need help, it's going to be there and I don't <u>want</u> to be chasing anybody. I want it to be there and if emm there will be a problem or <u>somebody</u> will be telling me, 'Ok we will touch base with you.'"</i> (Mila)</p>
Feeling compelled to become <i>"a manager"</i> and <i>"your child's therapist on top of everything else."</i>	All except Mel	Gayle (L1679-1683; 1695-1699); Gloria (L547-560; 569-573); Helen (AL311; 355-356; 1511; 1839-1844); Marian (L1160-1165; 1583-1591; 1606-1607); Mila (L210-214; 290-291; 674-676; 724-727; 774-775)	<p><i>"But if you take every element of the child's needs, like psychology, speech therapy, OT, physio ... whatever, educational, all of that ... emm, there is nobody orchestrating events. You, as a mother, have to take it on, really, and make decisions as to which-what is made and when."</i> (Helen)</p> <p><i>"Not just one therapist. You've to be 4 rolled into 1 ..."</i> (Gayle)</p>

Guilt about performance of the roles of “therapists” and “manager”	Gloria, Helen, Marian and Mila	Gloria (L399-400; 454-468; 495-497; 954-964; 1044-1046); Helen (AL 1916-1920; 1866-1871; BL 101-108; 559-563); Marian (L761-762; 1705; 1899-1905); Mila (L677-680; 720-724)	<p><i>“Because it's always here [points to her head] at the, at the back of my emm, emm head. ‘Ok, we didn't do this and we didn't, we didn't do anything for the last two days.’” (Mila)</i></p> <p><i>“If I'm doing such a great job then why is his speech not coming on?” (Gloria)</i></p>
“Step[ing] away from my maternal role”	Gloria, Helen, Marian and Mila	Gloria (L1420-1474; 1496-1499); Helen (AL 310; 1425-1427; 1601; 1858-1864; 1963-1971; BL 304-305; 344-351; 554 -555); Marian (L1002-1013; 1598-1599; 1659-1660); Mila (L716-717; 736; 742-763)	<p><i>“There's always an agenda and that's what I don't like. I can't just sit down and play with him” (Gloria)</i></p> <p><i>“Emm ... and I felt to a large extent I could step away from my ... maternal role into ... kind of a ... therapy role- I could jump.” (Helen)</i></p>

Table 9.2 Overview of evidence supporting major theme of “Manager-Therapist-Mother”

9.3.1 “It’s mainly me”

Apart from Mel, data suggests that participants perceived themselves to carry the responsibility for their children’s communication development largely alone, with limited or sometimes no support from professionals and services. Additionally, participants’ accounts suggest that they took the chief parental role in therapy, carrying the dominant share of the work involved when compared to their spouses.

Intentionally “Batting the ball back into the parents’ court”

Gloria and Gayle appeared to view the organisation and operation of public services and professionals as attempting to transfer all responsibility to parents. Both participants experienced publicly-funded therapy that almost exclusively took the form of manualised parent-mediated intervention approaches. In both cases, the services utilised single channel pathways of care. In Gayle’s case, the service discharged all children when they turned 5 years of age, while in Gloria’s case the service discharged all children 12 months after their cases were opened, regardless of ongoing need. Gayle summarised her experience as, one where the approach of the health service “... was to basically bat the ball back into the parents’ court. To try and train up the parents expecting the parents to run home programmes with very, very limited support from them.” This game-playing metaphor signals a view that the experience of working with the [EIT](#) service and the professionals involved, felt like being on opposing teams rather than the same team. The language also suggests an interpretation that the actions of the health service and professionals were deliberate and planned, and designed around an understanding and expectation that parents could and should work alone once “*train[ed] up.*” Gloria’s account suggested a similar interpretation. For example, the extract below relates to Gloria’s experience of reading her son’s discharge report from the [EIT](#).

“Don’t just say, ‘Well we’ve shown you this now,’ and it’s all back on the parents and it actually says that in the reports, you know. And I read it down and I’m just thinking you know it’s so ... It is definitely a ‘It’s your fault. It’s on your shoulders if anything goes wrong here.’” **Extract B9- Gloria (L1097 – 1100)**

Gloria and Gayle interpreted their experience to signal that the responsibility was theirs alone. Furthermore, as they had now been “*train[ed] up*” and “*shown*” what to do, if their child did not progress it was their “*fault*.” Gloria’s phrase “*it’s on your shoulders*,” hints at the perception that “*the huge burden*” (Gloria) of responsibility for her son’s development was hers alone. Extract B9, points to a sense that the weight of responsibility carried by Gloria increased following her engagement with [EIT](#), as she now perceived herself as both responsible for her son’s progress, as well as being responsible for preventing future “*wrong[s]*” in his development.

Not having Reliable or Consistent “back-up” from Professionals and Services

Marian, Helen and Mila also felt that they received limited support. However, they appeared to primarily understand their experiences with professionals as akin to playing on the same team, but with many team mates and clubs on whom they could not consistently “rely” (*Marian*). These participants described service factors and professionals’ practices that contributed to their sense of having limited and unreliable support. These challenges are discussed in detail in the next chapter, but involved long waiting times for services and caps on the amount and type of therapy available. While all three participants described positive experiences with many, individual professionals, these experiences were time-limited and usually occurred while they were involved in a scheduled block of intervention. The time following these blocks of intervention was often characterized by feeling “*isolated*” (*Helen*), “*in limbo*” (*Marian*) and by a pervasive sense of uncertainty, as participants were unsure when they would receive therapy again and often

who that therapy would be with. In the extract below, Mila described her “need” for “back-up” and what “back-up” meant to her.

R: *I need back-up and I need to know-*

I: *Mmm*

R: *That if I - we need help, it's going to be there and I don't want to be chasing anybody. I want it to be there and if emm there will be a problem or somebody will be telling me, "Ok we will touch base with you." ...*

I: *Mmm*

R: *"And we will see how she's progressing and emm we will re-jig the programme for her and- or we will just work on it and she will have more sessions ... as much as she will need."*

Extract B10- Mila (L293 – 302)

“Back-up” for Mila and the other participants was perceived as coming from a “need,” rather than what they desired in an ideal world, or what the service was resourced to offer. Mila’s correction of her pronouns, from “I” to “we” hints that she perceived the support as necessary for both herself as well as for her daughter and family as a whole. Mila’s use of the term “back-up” is also suggestive. The term evokes a sense of temporary, but timely support in scenarios in which the person cannot succeed (or escape disaster) if they remain alone. Mila characterised “back-up” as support that was readily available without delay and the need for “chasing” professionals. The term intimates an expectation of continued involvement, as “back-up” provides enough support to help parents to continue “building.” The extract above suggests that back-up can take many forms, it may

be further therapy, or a home programme, or advice. Further evidence that “*back-up*” (Mila) was viewed as a necessary support for ongoing parental involvement is found in Helen’s account in the extract below, in which she described the support she felt was missing from her experience.

R: I just felt that ... Not to hold your hand, but just to understand the nuances of the condition, and to understand the needs, and to advise me as a parent who was prepared to take on a fair bit-

I: Mmm

R To have somebody ... even to brainstorm with or talk through stuff with. So ... It takes a lot of energy to work through the process by yourself to a large extent ... and to feel that you're making the right decisions

Extract B11- Helen (BL848 – 852)

Similar to Mila’s extract B10, extract B11 signals that support did not necessarily involve direct therapy sessions; instead, Helen chose to emphasise the important role that professional advice, information-giving and sign-posting could play. Indeed, all participants with the exception of Gayle appeared to interpret support in a broad manner. Extract B11 points to the potential isolation, self-doubt and fatigue that may stem from feeling inadequately supported. The use of the term “*not to hold your hand,*” appears to carry multiple meanings. I understood it to signal that professional support was perceived to be needed, not desired, and related to practical not emotional reasons. I also interpreted this to emphasise that Helen was willing and able to do a certain amount alone, and she did not expect involvement of services and professionals at all times. Further interpretations of the phrase “*not to hold your hand,*” arise when the term is analysed in the context of how participants were supported by their spouses, as discussed below.

Spouses Primarily Provide Emotional Rather than Practical Therapy Support

Analysis suggests that Mila, Marian, Helen, Gloria, and Gayle took the primary parental role in therapies and engagement with services. Their accounts suggest that their spouses were seldom involved at a practical level. The support provided by spouses appeared to be largely restricted to providing emotional supports to their wives (or “hand-holding”) as they coped with feeling of frustration, anxiety and sometimes anger about their involvement with services. All participants’ data indicated that they viewed themselves to be in a loving, supportive relationships and viewed their spouses as committed, involved fathers. For example, Marian, referring to her husband said, “*Brian had supported me in everything.*” Gayle described her husband as, “*a rock for me, when something's going wrong,*” and described how her husband and son have “*a super relationship.*”

While participants viewed their spouses as supportive, analysis suggests that this support seldom extended to practical involvement in therapy. Participants discussed how their husbands joined them for all initial therapy appointments, particularly at the time before or during the diagnostic process. However, the content of the participants’ datasets indicated that by the time of the interviews, most participants’ husbands’ attendance at therapy appointments was irregular, with work commitments often cited as the reason. The involvement of spouses was typically described as restricted to receiving updates from the participants about when therapy was occurring. Two participants, Mila and Gloria, reported that they tried to “*pass on*” (Gloria) their learning from therapy sessions so that their husbands could be involved in the implementation of therapy at home. Yet the limited practical involvement of spouses was never raised as a concern by participants during interviews. Data relating to the support provided by spouses was almost exclusively obtained in response to questioning and prompts by me. For example, in the extract

below, I directly prompted Marian about her husband's involvement, during a period in which Marian felt unsupported by the [EIT](#) and was particularly anxious about her son.

I: And where was your husband for this? Was-

R: Oh he was here. He was here as well. Like I mean it sounds like- I, I did everything though because I was here.

Extract B12- Marian (L993 – 995)

Marian emphasised that her husband was “*here*,” twice, suggesting that she did not feel alone, as her husband felt present with her in what was occurring. However, the language of the next sentence appears paradoxical. The explanation Marian offers for why she “*did everything*” was because she “*was here*.” Yet her previous sentence indicates her husband was “*here*” too. Despite having a spouse who was an involved husband and father, Marian appeared to understand herself as more responsible for “doing” “*everything*” as she was not employed and was at home. Helen and Mila also suggested that the distribution of the therapy workload was at least partly related to their husbands' work and their own position at home with their children. For example, when asked “Do you share the responsibility for therapy?” Mila stated, “*It's mainly me. It's mainly me who, who does that as he is self-employed and you know, so because I'm home more.*” Participants such as Gloria, Gayle and Helen also suggested that differences in personalities and skills-sets helped to explain why they took the primary role in therapy and engaging with services. For example, Gloria's husband briefly entered the room during the interview and they engaged in a brief, light-hearted discussion about how they share their responsibilities. Gloria's husband noted that he no longer attended therapy sessions, and didn't read the information sent by the therapist, instead asking Gloria to “*sum it up.*” While their interaction appeared jovial, I also interpreted it to carry an undercurrent of mild tension.

Gloria noted that by asking Gloria to “*sum it up*,” her husband “*doesn't have to read the stuff*.” Gloria appeared to interpret her husband’s workload to have reduced while hers had increased. She explained that by approaching therapy in this way, her husband wasn’t “*getting the whole thing*,” hinting that she perceived it as less effective than if her husband were to attend or to read the materials himself.

Gayle depicted the responsibilities for the therapy workload as influenced by gender and perceived differences between mothers and fathers.

R: Emm but emm in terms of dealing with services, no. Emm, like it's anecdotal, but I can say- I would say if you polled a load of parents, 9 times out of 10, 9 families out of 10, it's the Mammy that deals with everything anyway-

I: Mmm

R: Emm and that's the same in our household

Extract B13- Gayle (L841 – 845)

Gayle’s inclusion of the word “*anyway*” intimated an understanding that the experience of being a mother in general involved taking the larger share of the practical responsibilities and tasks involved in parenting, and this extended to the division of labour involved in therapy. This interpretation may help to explain why none of the participants appeared to perceive their spouses as unsupportive. The lack of reference or discussion of this may point to an assumption that the role of mother involves doing the lion’s share of work with children, and thus their husbands were providing the level of support expected. Alternatively, the lack of discussion of this topic may have stemmed from its personal nature. Nonetheless, the lack of reference to this topic appears stark when compared to

the volume of extracts relating to participants' perceptions of the support received from professionals and services.

9.3.2 Feeling Compelled to Become “*a manager*” and “*your child’s therapist on top of everything else.*”

With the exception of Mel, all participants' data suggests that they felt compelled to adopt a role akin to a case manager, in addition to feeling required to act as their children's therapists, but without the necessary skills and experience. Gloria and Gayle interpreted services and professionals as overtly demanding them to act as “*not just one therapist. You've to be four rolled into one,*” (Gayle). Helen, Marian and Mila felt compelled to reluctantly take these roles not because they were directed to do so, but because they perceived the “case manager” work as not being done and the therapist work as only completed sporadically due to difficulties with funding and resources. These participants felt that if they didn't take these roles, their children would be negatively impacted; assuming the role was perceived as a necessity rather than a “choice”. Mila summarises this as “*I would love not to do it, you know but how I look at it is, 'Well it needs to be done.'*”

Being a Manager

All five participants discussed feeling compelled to adopt the role of case “*manager*” (Marian) as they perceived it as an essential role that no one else was doing. Helen described, “*But if you take every element of the child's needs, like psychology, speech therapy, OT, physio ... whatever, educational, all of that ... emm, there is nobody orchestrating events.*” This role encompassed arranging and coordinating appointments, trying to keep communication open between the clinic and the school, as well as between different health professionals, researching different therapy approaches and discussing these with professionals, as well researching and planning for future service needs. All

participants expressed their dislike of this role. For example, Helen described how she would be “*delighted*” to “*hand it over*” to a professional, but she “*can’t see any person who would do that.*” Marian similarly described how she “*really did not want that job.*” However, analysis raises questions about how easily or gladly participants may have been willing to “*hand it over.*” As detailed in the next chapter, participants experienced considerable mistrust of services and some professionals. When describing the role of “manager” (Marian), Marian became dysfluent: “*You know, so I’ve got to get - make sure they do this. And get- And you know- I have to get what I- You know, I need this.*” Her dysfluency indicates the emotion that was intertwined with her performance of this role. Marian’s final phrase hinted that the role of “manager” may have offered Marian reassurance and helped her to regain some sense of control.

Trying to be Professional Therapists

Many of the participants described acting as therapists at home during the periods in between their children’s blocks of intervention. Mila described doing daily “sessions” of [SLT](#), [OT](#) and physiotherapy. Mila’s choice of the word “*session*” intimated an interpretation that she was acting as a therapist. Helen described her work as “*a formal sit-down with your own child,*” further suggesting a professional-type interpretation of this role. For other participants, work at home involved using naturalistic strategies, rather than prescribed exercises, yet this was also perceived as “therapy work.”

R: *And it's a huge burden to carry, you know that I'm responsible for his speech and language or his OT or his physio. That I have to ... you know, I have to make-walk up the front of the slide so that I can get him to put his foot down because he's a toe walker. You know, that all these- trying to get these physio things done. Emm and even from an OT point of view, to try and do that and then to*

try and bring his language on by saying, "We want to climb ... up." We start with up and then we're trying to ... trying to "climb up. We're trying to go 'uh' - "

Waiting for him to say 'up.'

I: Mmm

R: You know. All this.

I: Mmm

R: This was all the time. And I know the research proves that, that home maybe is where a lot of the learning goes on, but you, you are very much by yourself and you're on your own ... you know ...

Extract B14- Gloria (L547 – 560)

Gloria's language in the extract B14 illustrates the sense of obligation that surrounds adopting the roles of "therapists". She talked about it in terms of "responsibility" and repeated the modal verb "have to" twice. The extract also suggests a perception that attempting to be responsible for multiple therapies when you are one person without any of the relevant qualifications is an impossible feat. Her repetition and emphasis of the word "all" in relation to both time and the volume of responsibilities suggests a view that no one person could do all that she feels is demanded of her. Indeed, in a separate extract Gloria described her experience as "sink or swim." Gloria's reference to "the research" hints that she has perhaps been informed that this approach is possible and will work. Yet the extract may be interpreted to imply that Gloria doubts this. It is unclear if she perceived herself as the reason this approach might not work, or that she interpreted the intervention to be effective only if the parent isolated themselves from all other aspects of their life.

Trying to do the Impossible

Other participants, also viewed the work involved in being their children's "therapist" (Mila, Gayle, Gloria, Marian) through the lens of striving for the impossible. Being their children's "therapist" was perceived as mentally and physically exhausting. Mila described "*busting my bum*," while Marian and Helen referred to difficulty sustaining the "energy" involved in this type of work. Mila, Helen and Marian cited the volume of work as problematic. For example, Mila referred to "*trying to cram everything*," and "*there is only as much you can fit in a day*." For Gayle, the impossibility of this work appeared to stem from her perception that parenting a child with autism involves additional work that had left her no capacity to take on further "therapist" work. She stated, "*It's hard enough parenting a child with additional needs, when that's all you've to do*," and in a separate extract described her frustration that she is "*expected to be your child's therapist on top of everything else*." Gloria, Mila and Gayle's perception of impossibility also appears to relate to not feeling adequately skilled to take on this role without regular support from professionals. For example, Mila discussed how during breaks from therapy she did therapy work at home with her daughter, but would ultimately always reach "*a certain point and it's like "Ok, what's, what's next?" I am not speech and language therapist*."

9.3.3 Guilt about Performance of the Roles of "therapists" and "manager"

There is strong evidence in four of the participants' accounts (Gloria, Helen, Marian and Mila) that the roles of 'therapist' and "manager," were perceived to contribute to feelings of guilt. This guilt related to participants' perceptions about their performance of these roles - that they were not good enough or did not do enough. For example, Gloria stated, "*You always think you should be doing more*," and Helen described how she sometimes felt she had, "*failed John a little bit*" as "*all the decisions weren't perfect ...*" Gayle's account differed as she described engaging in large amounts of privately funded direct therapy that

was delivered on a weekly basis. With this level of private support, Gayle felt in a position to reject the therapist roles. She noted that *“the reality is if you're seeing a professional on a weekly basis ... there's not a huge amount of follow up you have to do, because they're going to be seeing them again anyway.”* This appeared to lessen the weight of responsibility experienced by Gayle and may account for the absence of guilt-related data in her interview. However, for participants such as Mila and Gloria, analysis suggests guilt was experienced as a permanent *“niggly feeling”* (Gloria) that was always with them.

“Because it's always here [points to her head] at the, at the back of my emm, emm head. ‘Ok, we didn't do this and we didn't, we didn't do anything for the last two days.’” **Extract B15- Mila (L720 – 722)**

Mila's language points to guilt having a physical presence, evoking a sense that it may further add to the weight or *“burden”* (Gloria) that some participants felt they carried with them in everyday life. Marian and Helen's experiences of guilt appeared to fluctuate more and involved descriptions of specific events relating to the roles, for example specific decisions made, rather than the general experience of performing these roles.

Benchmarks for Guilt

Helen and Marian's accounts were tempered with language suggestive of some degree of self-compassion. Helen used the language *“reasonable”* and *“do enough”* to describe her skill set and effort level. Marian similarly appeared to strive to focus on doing her best, rather than perfection. When asked about what advice she would give to [SLTs](#) in general, Marian stated:

“What would I like them to know emm ... To know that a parent is doing their best. That they can't always do therapy every day that they want to, but that they're trying ... Emm is

*that, you know to be patient as much as possible ... emm with a parent who might be ... under a lot of pressure and struggling.” **Extract B16- Marian (L1899 – 1903)***

Marian’s extract above suggests that she attempted to mitigate feelings of guilt by acknowledging that she was doing her best, and her “best” may fluctuate depending the other pressures. The extract intimates that Marian has perceived herself to be judged by professionals in the past as not doing enough. Her use of the word “*can’t*,” when contrasted to Mila’s use of the word “*didn’t*” in extract B15, suggests a more sympathetic framing of times when therapy work was not done at home. Marian’s focus in extract B16 is on the intent and attempt. Mila and Gloria appeared to judge themselves more harshly, focusing more on how often and how well something was done, and sometimes using their child’s progress as a benchmark for their abilities in the roles of therapists and manager. For example, Gloria recounted her frustration when an [SLT](#) she was working with advised her to continue using the given strategies and attempted to compliment her by saying, “*Oh you’re doing a great job.*” This compliment appeared disingenuous to Gloria, who noted:

R: You know if I was doing a great job, I wouldn't still need to bring my child here ...

I: That's what it felt like?

R: Yeah.

I: Ok

R: Yeah. He- If I'm doing such a great job then why is his speech not coming on?

I: Mmm

R: Do you know what I mean? Why is his language - Why is his comprehension not

coming on?

Extract B17- Gloria (L954 – 962)

Gloria appeared to be holding herself to an impossible standard, perceiving herself as the only factor that was influencing her son's rate of progress. Extract B17 illuminates the weight of the responsibility and guilt that Gloria carried. When the different manifestations of guilt are compared across the participants involved, it suggests that the benchmarks against which parents compare themselves and measure their success may contribute to the degree of guilt experienced.

9.3.4 "Step[ing] away from my maternal role"

Four of the participants, Gloria, Helen, Marian and Mila, retained the roles of "*therapists*" and "*manager*." Each of these participants' accounts showed evidence of experiencing tension and conflict between these new roles and their role as a mother. The role of mother dominated across all participants' accounts and was characterised by significant emotional involvement connected to the happiness and well-being of their children and a drive to both protect and nurture their children's development. However, the maternal desire to protect sometimes contributed to challenges in performing the role of manager.

"Emm ... Probably nobody knows him as well as I do ... and, emm, that I'm in tune with him. And the problem is I'm his mother and therefore I have an emotional- stuff going on myself. And maybe I'm not the best [laughs] now that we're talking about it. Hey this is my talk therapy now [both laugh]... But maybe, you know, maybe I'm not the best person but I kind of ... " **Extract B18- Helen (AL 1425 – 1427)**

Helen perceived the role of manager to require being "*objective*" (Helen), which she identified as challenging when you are the mother of the person being managed. For Helen, being a mother was sometimes viewed as a "*problem*" in her ability to make

decisions in her capacity as manager. For example, Helen and her husband initially declined a diagnostic assessment for autism for their son, as they were “*protecting John from having a label.*” However, at the time of the interview, Helen reflected on this decision with regret, “*And we lost a bit for that. Certainly really. We lost a chunk and I don't know whether it was worth it now, looking back.*” Similarly, Helen found adopting the therapist role difficult because she understood it to involve shifting how she related to and interacted with her son. She noted, “*It's hard to do a formal sit down with your own child.*” Helen’s language suggests that a key challenge for her was not her ability to do the work but that the work involved interacting with her son in a way that felt “*formal*” or professional. For all participants, performing the role of “*therapist*” impacted on how they performed and conceived their role as mothers.

Parenting with “an agenda”

Gloria depicted her role as a therapist to involve parenting with “*an agenda behind it.*” Gloria described feeling compelled to consider all interactions with her son as learning opportunities, in which she had to behave and communicate in the way learned in therapy. She described how this style of communication was now “*second nature,*” but it still didn’t feel “*normal*” as she felt there was an ulterior motive behind every interaction and she “*can't just sit down and play with him.*” When talking about how “*there's always an agenda,*” Gloria explained, “*you can't just interact with your child normally.*”

R: *You have all these in your head ... You know. The professionals say you have to do, you have to do, you have to do ... and because you have to, you know - you want to help your child, you know it's second nature then but it's, it's - And I do it, and I'm fine with it -*

I: *Mmm*

- R: ... To a degree but you know out of everything that it probably something that- You know there's always an agenda ... behind everything you do with him ... you know. The child asks for a biscuit, right and I've to go 'Biscuit. Oh I want a ...' Do you know like?
- I: Mmm
- R: I would never have just handed him a biscuit.
- I: Yeah
- R: Emm not even - It wouldn't even occur to me to go in and hand him a biscuit. Do you know what I mean? ... Because he has to ask for it so he can bring on the language.
- Extract B19-Gloria (L1460 – 1474)**

The extract above suggests that Gloria was primarily motivated by the maternal desire “to help your child.” However, to fulfil this desire, Gloria perceived herself as needing to change how she communicated and acted as a mother. She chose to use the example of giving her son food to illustrate how things changed. I interpreted her use of this example to suggest that Gloria perceived the basic defining tasks of being a mother as having fundamentally shifted by taking the role of therapist. Gloria’s extract emphasises her perception that that the “naturalness” of her interactions and perhaps relationship with her son has been reduced. Her repetitive use of the modal “have to” in the temporal context of “always,” suggests that she perceived herself to be constantly “acting” rather than being herself. I understood the emphasis on her statement “it wouldn’t even occur” as an attempt to illustrate her sadness and sense of loss, that how she related to and communicated with her son had fundamentally shifted, and this perhaps contributed to concerns for Gloria that her identity as a mother has also shifted too.

Becoming “the bad cop and the pushy one”

Mil depicted herself as becoming the “*the bad cop and the pushy one*,” and the parent who says “*Oh no. We have to do this.*” Mila described how her daughter found school work challenging and it took a long time to complete the homework given by school. In addition to this Mila attempted to do daily “*home sessions*” with her daughter, which her daughter often resisted, sometimes triggering tantrums. To fulfil her role as therapist, Mila felt compelled to reluctantly adopt an authoritarian style of parenting that she felt uncomfortable and guilty about. When discussing what it would mean to her not to be involved in this therapist role, Mila said, “*We could - We could have more fun. We could, we could do different things.*” Her language here was suggestive of a sense of loss about her relationship with her daughter. While the question related to Mila, she answered using “*we*” suggesting that the perceived impact was on both Mila and her daughter. In the same interview segment, Mila stated in a regretful tone, “*But then you want her to be a child as well ...*” suggesting a concern that in being the bad cop and the therapist, Mila was contributing to the premature loss of her daughter’s childhood. Mila’s guilt about this role was perpetuated by a concern that her daughter didn’t and wouldn’t ever “*appreciate*” and “*understand why I was the ... the, the bad cop and the pushy one.*” The connotations of the term “*bad cop*” may be relevant here, as often the term is used as part of the pair “*bad cop*” – “*good cop.*” As discussed above, Mila’s husband while involved in doing therapy exercises did so less often. Reflecting on the apparent distribution of the therapy workload in her household, I questioned whether Mila’s choice of the term “*bad cop*” might also suggest a perception that taking the lead role of therapist positioned her as the less preferable parent.

I: And what does that mean to you, feeling that you’re the bad cop?

R: Emm, look she loves me-

I: Mmm

R: And I love her ... And emm ... yeah. Like it needs to be done, it needs to be done.

Extract B20-Mila (L759 – 763)

When asked about the meaning of this role, Mila responded by referring to “love.” Love was not mentioned before this point. This seemingly abrupt reference may suggest that perhaps Mila had previously worried that taking this role might lead to her daughter feeling less loved or loving Mila less. She appeared to be attempting to reassure me, and potentially herself, that the emotional bond between mother and daughter remained intact despite the challenges associated with this role. Her repetition of the final utterance in this extract also intimated that despite concerns about the impact on their relationship, Mila was motivated to continue adopting this role in order to fulfil her greater motivation of protecting and securing the best possible future for her daughter.

Impact on Other Children in the Family

Helen, Marian and Gloria also perceived the therapist and manager roles to impact their parenting of other children in the family. Marian questioned the impact of time spent enacting these roles, noting that “a lot of things come to the wall then. Like when do you spend time with Felix?,” referring to her younger son. Gloria and Helen noted their other children’s tendency to mimic the use of naturalistic language learning strategies with simultaneous pride and concern that their other children are prematurely adopting adult-like responsibilities. Gloria in particular appeared concerned that these behaviours indicated that her older son was losing part of his childhood and appeared to blame herself for this.

Heightened Impact in the Context of the Volume of “sacrifices” Already Made

The impact of the roles of therapist and manager on the role of mother may have been experienced through heightened sensitivity, as many of the participants indicated that they already perceived themselves to have made significant sacrifices because of their role as mothers to children on the autism spectrum. Often the “*sacrifices*” (Marian) made were in areas that may be core to one’s identity, such as employment. For example, both Helen and Marian reported giving up work because of the demands involved in attending therapy appointments and doing the “*therapist*” work at home.

Gayle resisted taking on the role of therapist and instead engaged in weekly private interventions, and remained in full time employment. Gayle spoke about her work with pride. She discussed, with overt signs of anger, her perception that the publicly-funded [EIT](#)’s operations and practices assumed that at least one parent wasn’t working. Gayle perceived the [EIT](#) to expect her to give up work, a demand she understood as “*unreasonable*.” Analysis suggests that the potential loss to her identity associated with giving up work was experienced as threatening to Gayle’s mental health. She described work as “*respite*,” and a break “*because you’re not doing it, you know every second of every day*.” Gayle’s family were in a financial position to access regular private therapy. Gayle appeared to interpret this as facilitating her rejection of the “*therapist*” role. While the four other participants also accessed private interventions, it was less frequent and they continued to perceive the roles of “*therapist*” and “*manager*” as necessary.

9.3.5 Trying to “*do as little as you possibly can ... outside your parenting norm*.”

Of these four participants, only Helen overtly discussed how she coped with playing the sometimes-conflicting roles of mother, therapist and manager. Helen described using two approaches to managing this. She noted making an effort to “*do as little as you possibly can ... outside your parenting norm*.” This suggests that Helen perceived her role as

mother as the priority role and so endeavoured to perform the role of therapist and manager in such a way that it had minimal impact on the role of mother. Helen noted that when performing the role of therapist or manager, she deliberately attempted to “*step away from ... my maternal role,*” and “*separate myself off.*” This “*compartmentalising*” of herself appeared designed to allow her to perform the roles of therapist and manager with more “*objectivity*” and less protectiveness. In doing so, Helen may also have been attempting to protect her identity as a mother by endeavouring to keep all roles as distinct and distant from one another as possible.



Figure 9.3 Themes of "Manager-Therapist-Mother"

9.3.6 Mel's Divergent Experience

While all other participants' accounts discussed the roles of "*manager*" and "*therapist*," Mel's account showed no evidence of this. Mel's experience of depression may have contributed to her differing experience to other participants. Similar to the other participants, Mel perceived her son's therapy services and professionals as providing inadequate levels of support. However, in contrast to the other participants, Mel's case was characterised by a large degree of sharing of the responsibility for her son's healthcare needs between Mel and her support network, consisting of her husband and friends. Mel appeared to perceive herself as less capable than those who supported her in relation to accessing and navigating therapies for her son. Mel is the only participant who reported that her husband had opted to go to an entire block of therapy without her, as she "*wasn't able for it.*" Some of Mel's data suggests that she found being involved with services sometimes overwhelming and triggering for her depression. For example, she reported crying completing certain forms "*because it's just a book about your child and the things you have to write down, like it's ... It's terrible to even have to write that down. You don't think he has this many needs until you start filling out these answers like.*" On a number of occasions, Mel compared herself to her friend, Siobhan who also had children with autism. Mel described the number of activities and private therapies that Siobhan brought her children to and noted that she "*should*" bring Stephen and his sister to more activities, but didn't have the "*energy.*" She also compared her advocacy skills to Siobhan's in the extract below:

"Like emm, I did latch onto a friend of mine ... you met her yesterday, Siobhan. She's emm ... She's a great one now for fighting. She'd know everything now. She'd be on to this, that and the other and she just- She's just so great- I'm no good at this now." **Extract B21- Mel (L1063 – 1066)**

Analysis suggests that Mel's support network appeared to recognise the additional challenges Mel was experiencing, and offered her "advice," encouragement and practical support. In the context of Mel's openness about her depression with her support network, it is perhaps unsurprising that her experience contrasts so dramatically with the experiences of the other participants.

9.4 Deductive Analysis Results

Evidence was found to support the relevance of the superordinate theme of "*Therapy Mother*" to all participants involved in the deductive analysis. A comparison of the numbers of participants demonstrating evidence of each theme in the [IPA](#) and deductive analysis samples is shown in Table 9.3 below. The greatest difference between groups was found in relation to the themes of "Build by Helping Children Engage and Remain Engaged in Therapy," and "Guilt about Performance of the Roles of *'therapists'* and *'manager.'*" There was a difference of two participants between these groups. All other themes involved the same number of participants, or differed by only one participant. Sample evidence gathered during the deductive analysis is shown in Tables 9.4 below.

Superordinate/ Major Theme	Theme	Core IPA Study -Number of Participants Involved (n=6)	Deductive Analysis – Number of Participants Involved (n=6)
Therapy Mother: Apprentice Builder	“Build” child’s communication under the direction and/or guidance of SLT	6	6
	‘Build’ by helping children engage and remain engaged in therapy	3	1
	Hope and anxiety as fuel for involvement in therapy	6	5
Therapy Mother: Manager-Therapist-Mother	<i>“It’s mainly me”</i>	5	5
	Feeling compelled to become <i>“a manager”</i> and <i>“your child’s therapist on top of everything else.”</i>	5	6
	Guilt about performance of the roles of <i>“therapists”</i> and <i>“manager”</i>	4	6
	<i>“Step[ing] away from my maternal role”</i>	4	4

Table 9.3 Numbers of participants in the IPA study and deductive analysis who showed evidence relating to “*Therapy Mother.*”

Sample Quotes

	Mary	Sarah	Sinead	Susan	Robyn	Trish	
“Build” child’s communication under the direction of SLT	√	√	√	√	√	√	<p><i>“You’re just there to observe and see and sometimes it’s just to observe where the difficulties are but to see it and then think ok how can we work on it.” (Trish)</i></p> <p><i>“I know you see it when you go to the classes with them, with the speech therapist. You’re sitting there and the speech therapist is doing the stuff with them and they do it no problem but when you go home and do it at home it’s [laughs] it doesn’t work the same way.” (Mary)</i></p>
“Build” by helping children engage and remain engaged in therapy			√				<p><i>“So I do my best to ... have a babysitter for an hour after that ... be it McDonalds or ... a car in the toy shop or the pound shop, whatever, that, that’s part of it as well ... So ... it’s not as if I go, ‘Right we have the appointment, then we’re going home,’ so he does get a bit of ... time out with it as well; something he likes doing. So normally it’s McDonalds ... so ...” (Sinead)</i></p>
Hope and anxiety as fuel for involvement in therapy		√	√	√	√	√	<p><i>“it can take up a lot of your time, but I feel if, if you can see the jumps forward and you can see you know it’s worth it definitely- You’d go anywhere if you thought it would help.”(Trish)</i></p>

							<i>"I do fear for the future... That he won't be reliant on his sisters." (Robyn)</i>
"It's mainly me"		√	√	√	√	√	<p><i>"The service is very few and far between ... I ... It's a purely numbers game. And she would come out and do something with him and it would be a couple of months then and she'd do something else and then it was just like ... You're kind of left with all the work then." (Robyn)</i></p> <p><i>"... I, I don't have any input from them only sheets, you know." (Susan)</i></p>
Feeling compelled to become a "manager" and "your child's therapist on top of everything else."	√	√	√	√	√	√	<p><i>"You don't want to be your child's therapist. You don't mind doing exercises and all that but you don't want to be their therapist. You have enough going on." (Susan)</i></p> <p><i>"I do my best but I'm not a teacher. I'm not an OT. I'm not a speech therapist and I'm not a psychologist." (Sarah)</i></p>
Guilt about performance of the roles of "therapist" and "manager."	√	√	√	√	√	√	<p><i>"You're assessing yourself thinking am I doing it right?" (Mary)</i></p> <p><i>"Maybe it's just a mother thing I don't know but you tend to say, if I did ten more minutes at the table with that exercise, maybe that would make a huge difference." (Trish)</i></p>

<p>“Step[ping] away from my maternal role”</p>	<p>√</p>		<p>√</p>		<p>√</p>	<p>√</p>	<p><i>“It affects your relationship ... because he’s not your son. He’s your patient then. Everything around is his therapy.” (Robyn)</i></p> <p><i>“I see my kids are doing more work than kids not in speech therapy because while the kids are out playing, they’re inside doing more work. They’re not getting outside.” (Mary)</i></p>
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Table 9.4 Sample evidence from deductive analysis for "Therapy Mother."

9.5 Reflexive and Reflective Commentary

I found my identities as a mother and a therapist sometimes spilled over into my reflections about the theme of “*Therapy Mother*.” In particular the aspects of my analysis that related to “*Step[ping] away from my maternal role*,” challenged me. As a mother, I identified with Mila’s fear of always being the “*bad cop*,” particularly in the context of the other parent being perceived more favourably by the child. However, my experience of becoming a mother also tested some of my original thoughts. In my experience, parenting can often involve doing things that are hard, that your children don’t want you to do, and that you feel compelled to do for the greater good of the child. While in my case these “things” are often small and usually quickly forgotten, for example brushing an unwilling toddler’s teeth, they led me to question if perhaps the role of parent includes doing things that you and the child don’t want to do but are done for the longer-term benefit of the child. Originally in my analysis I considered the amount of this “reluctant work” as of great significance. However, by reflecting on how I understood my own experience as a mother and the frequency with which I felt engaged in “reluctant work”, I perceived the nature of the work to be of greater importance. When the type of work triggered connotations of a non-parent role, or a non-parent-child relationship this appeared to be of greater significance. This helped me to evaluate participants’ apparent shifts in how they perceived their identities as mothers and their relationship with their children in greater detail.

From my perspective as a therapist, I feel horrified that my therapy might inadvertently have changed how mothers relate to their children or view themselves as mothers. During write up, I reflected on the discourse that I have previously used as a therapist to explain my rationale for using indirect therapy approaches or for breaks in therapy, during which I have asked parents to continue completing intervention at home. I often framed this as a means to “empower” parents. In my reflections, I frequently grappled with this concept of the empowered parent. I came to the

conclusion that empowering a parent should add to, not take away from parents' identities. I also wondered about where this concept of "empowering" parents had come from and what, if any, input parents had had into professionals' definitions of empowerment. I believe these thoughts and considerations helped me to analyse participants' accounts with greater empathy.

9.6 Summary

This chapter sought to address the question of how participants perceive their roles in [SLT](#), through a discussion of the superordinate theme of "*Therapy Mother*." Analysis suggests that participants perceived themselves to adopt two broad categories of roles in therapy. In the role more closely aligned with participants' expectations, participants adopted a role that I interpreted as akin to an "apprentice builder." This role involved building their child's communication skills by learning from therapists and following the directions and plans provided by expert therapists. Different participants demonstrated different preferences and opportunities for learning, including observation of the [SLT](#) and joining in therapy activities. Participants generally understood this role to involve working with the direct or indirect support of therapists to use strategies and/or do activities largely designed by therapists but implemented by parents for the goal of developing their child's communication skills. Analysis suggests that anxiety and hope for their children's futures contributed to participants' commitment and motivation in this role.

Five of the six participants' accounts pointed to a second category of roles which involved acting as a "*manager*" and "*therapist*." These roles were removed from participants early expectations of what their role would involve. Participants felt compelled to take these roles, often to fill perceived gaps in service. The roles were perceived to signal and be characterised by a sense of isolation and lack of adequate support from services and professionals. Participants viewed the roles as challenging and sometimes "*impossible*" to perform. Adopting these roles also contributed to the

experience of significant guilt for the participants involved and was sometimes experienced as threatening their role and identity as mothers. The next chapter returns to my attempts to address the participants' sense-making of roles, through a discussion of the theme of "Navigating Therapy Services: A Game of Survival." It also introduces an additional role that participants perceived themselves to hold in therapy – advocate.

Chapter 10: IPA Findings – Spotlight on “A Game of Survival”

10.1 Introduction

This chapter addresses the final superordinate theme of the IPA study - “Navigating therapy services: a Game of Survival.” The components of this superordinate theme are shown in Figure 10.1 below. Linguistic and descriptive analysis of participants’ accounts suggest that participants made sense of their experiences interacting with services and professionals using the metaphor of game-playing and through these experiences constructed roles in advocacy. The chapter begins with a focus on the sub-theme “Therapy is a Precious Commodity Guarded by Individual Services,” discussing the challenges faced in accessing publicly-funded services, and the perception by participants that many of these challenges represented deliberate measures taken by services to protect and limit access to therapy. The chapter then discusses participants’ experiences with individual therapists, which were interpreted to be involve a mix of positive encounters and negative encounters. The sub-theme of “Mistrust as a Reaction to Feeling ‘let down,’” is then presented, followed by a discussion of how these perceived experiences and feelings of mistrust influenced participants’ engagement in advocacy roles. Table 10.1, below (format adapted from Larkin & Thompson, 2012) provides an overview of the data supporting each component theme. The chapter ends with reflexive and reflective commentary.

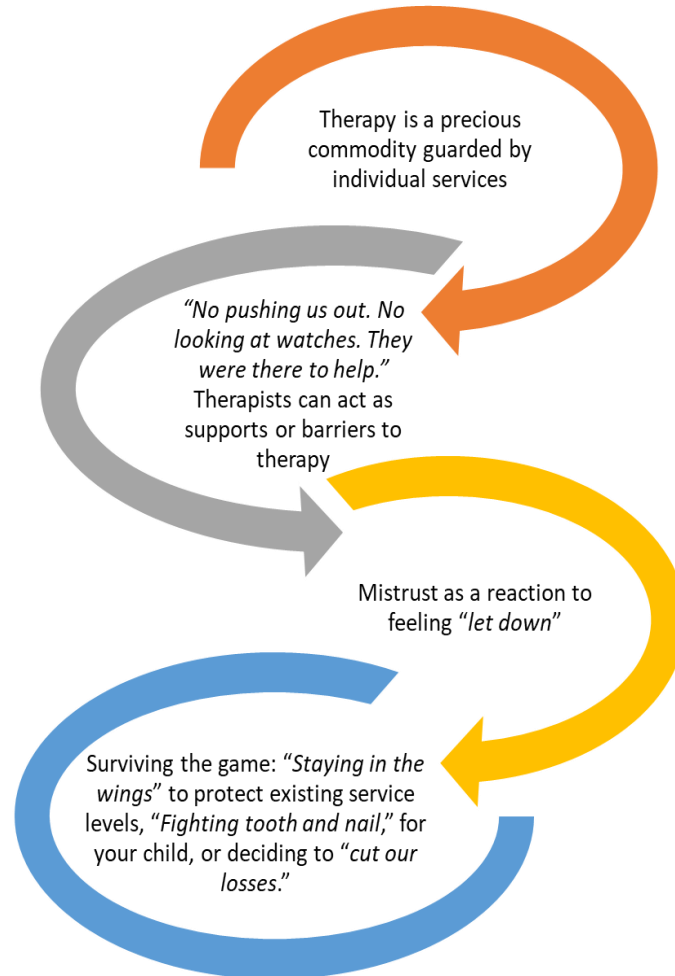


Figure 10.1 Superordinate Theme of "Navigating therapy services: A Game of Survival."

Superordinate Theme	Navigating Therapy Services: A Game of Survival		
Participants Involved	All		
Subthemes	Participants involved	Supporting Evidence	Indicative Quotes
Therapy is a precious commodity guarded by individual services	All	Gayle (L193-197; 291-292; 297-300; 1563-1572; 1580-1599); Gloria (L505; 742-746; 1891-1896); Helen (AL 235-238; 1644-1646) Marian (L270-277; 283-309; 336-342; 423-433; 850-867; 1510-1513; 1763- 1767); Mel (L140-154; 450-456); Mila (L43-49; 127-130; 878-890)	<p><i>“Because -I don't miss anything because I cannot afford to. Because they're like gold dust, or like hen's teeth ... you know they really are. You go. When you get them, you go... And don't squander your chance...” (Marian)</i></p> <p><i>“And then when we tried to get help for the oppositional stuff ... CAMHS wouldn't do it. And the ... community haven't got the ... resources. They weren't happy to do it either, really.” (Helen)</i></p>
<p><i>“No pushing us out. No looking at watches. They were there to help.”</i></p> <p>Therapists can act as supports or barriers to therapy.</p>	All	Gayle (L177-180; 189-192; 213- 220; 369; 1854-1860; 1866-1872; 1887-1889; 1895-1901); Gloria (L112-119; 508-512; 533-535; 584-585; 593 – 596; 613-629; 715-725; 753-756; 808-812; 1059-1079; 1083-	<p><i>“There was no pushing us out, no looking at watches. They were there to help. I said, ‘God!’ So when - I feel that when you’re in the service, it's probably going to be ok.” (Gloria)</i></p> <p><i>“And she's somebody I would never like to go and see again ... She's <u>very</u> knowledgeable but emm ... Ah</i></p>

		1086; 1543-1550; 1604-1613); Helen (AL582-583; 1479-1487; BL 203-235); Marian (L94-104; 188-196; 850-867; 972-987; 1104-1109; 1819-1828); Mel (L196-217; 448-449; 458; 1568-1570); Mila (L164-165; 480; 804-805; 898-920; 1013-1019)	<i>[exhales loudly] I didn't get on with her ... And she was very cold, I felt as a therapist ..."</i> (Marian)
<p><i>"It has coloured my view of the HSE generally and of the service that Liam will get."</i></p> <p>Mistrust as a reaction to feeling "let down."</p>	All	<p>Gayle (209-210; 244-245; 250-255; 915; 941-946; 1932-1935); Gloria (L43-67; 599-604; 758-768; 1726-1781); Helen (AL 816-829; 1315-1324; 1437-1438; 1443; 1427-1433; 1569; 1896-1907); Marian (L158-159; 246-250; 325-334; 353-368; 388-389; 397-404; 731-738; 883; 922-952; 1250-1255); Mel (L43-51; 1249-1256; 1271-1293) Mila (L240-249; 258-259; 371-372; 380-389; 667 – 669; 683-689; 890-893; 968-970; 1020-1023)</p>	<p><i>"I felt he was ignored and there was- They told me there was nothing <u>wrong</u> and then was- left me on these huge, big waiting lists ... Emm I'm, I'm just afraid that he's just going to be ... <u>neglected</u> ...again."</i> (Marian)</p> <p><i>"as long as you have money your child will be fine ... Emm and if you don't, your child is thrown on the scrap heap effectively, I think."</i> (Gayle)</p>

<p>Surviving the game: “<i>Staying in the wings</i>” to protect existing service levels, “<i>Fighting tooth and nail</i>,” for your child, or deciding to “<i>cut our losses</i>.”</p>	<p>All</p>	<p>Gayle (L116-117; 175; 240-242; 944-955; 972; 1187-1193; 1603-1609; 1723-1725; 1907-1909; 1968-1969; 2020-2038); Gloria (L63-67; 156-165; 342-247; 497-501; 512-515; 532-533; 645-660; 697-712; 730-736; 1019-1022; 1673- 1678; 1700-1704); Helen(AL93-96; 1465-1477; 1959; BL326-341; 563-578; 725-750); Marian (L342-347; 391-397; 489-498; 576-578; 771-778; 1136-1153; 1217-1232; 1263-1291; 1480-1483; 1541-1564; 1603-1605; 1609 - 1622 ; 1918-1937; 1971-1977); Mel (L1040-1047; 1067-1074; 1184-1197; 1089-1099; 1371-1374; 1728-1731); Mila (L223; 296-298; 305-317; 667)</p>	<p><i>“Your name has to be mentioned. You <u>have</u> to be in there all the time. You know, if you're not mentioned ... you fall off the list.” (Marian)</i></p> <p><i>“Ok when we give out, that ok they come out afterwards with ‘You’ll have a block of this. Then you’ll have this and this.’ But that should have all been done.” (Gloria)</i></p>
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Table 10.1 Overview of evidence supporting superordinate theme of “Navigating Therapy Services: A Game of Survival

10.2 Therapy as a precious commodity guarded by individual services

The superordinate theme of “Understandings and Expectations of [SLT](#)” (see Chapter 8) captured how participants perceived therapy as the “*external help*” (Helen) that they needed to help their children. Therapies across all disciplines were depicted by all participants as a scarce but valuable resource in high demand. All participants depicted publicly-funded therapy services as “*overstretched*” with “*huge waiting list[s]*” (Mila), with caps on the amount and type of therapy available. Marian likened therapy to “*gold dust, or like hen's teeth ...*” conveying an interpretation of therapy as a precious commodity of high value that required protection. Indeed, the accounts of all participants suggest interpretations of therapy as a resource often carefully protected by services. However, analysis suggests that participants understood some measures taken by services to guard therapy resources as functioning more as barriers to keep children out, rather than efforts to ensure that therapy resources were carefully used. Participants’ data suggested they perceived many different aspects of services’ operations and organisational structure as barriers. Three of the most frequently discussed categories of “barriers” are presented below and are illustrated in Figure 10.2. Participants appeared to make sense of these service “barriers” as signals that services sometimes prioritised the need to protect resources over the need to help children.

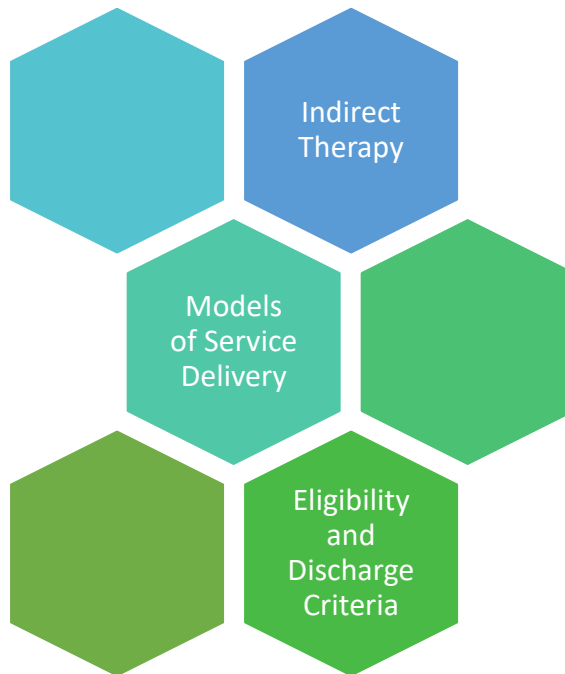


Figure 10.2 Theme of "Therapy as a Precious Commodity Guarded by Individual Services"

10.2.1 Eligibility and Discharge Criteria

Discussions by some participants, relating to eligibility and discharge criteria suggested a perception that services sometimes adopted uncaring positions designed to protect resources above all else. For example, in the extract below Helen depicted her efforts to access behavioural intervention for her son.

*"And then when we tried to get help for the oppositional stuff ... [CAMHS](#) wouldn't do it. And the ... community haven't got the ... resources. They weren't happy to do it either, really." **Extract C1- Helen (AL1644 – 1646)***

This extract conveys Helen and her family as relatively powerless, moving from service to service seeking "*help*" but being declined repeatedly. The extract conveys a perception of both the [CAMHS](#) and "*community*" or Primary Care services as unwilling and

reluctant to provide intervention. Helen appeared to interpret the Primary Care service to be partly influenced by limitations in the availability of resources. However, she understood [CAMHS](#) as having the resources to help her son, but as unwilling to share these resources. A similar sense of “uncaring” service providers was evident in Marian, Gayle and Gloria’s accounts. Participants described their children’s discharge from services using the terms “*thrown out*,” “*dropped*” (Marian) and “*fobbed off*” (Gloria). These verbs conjure imagery of the children involved as unwanted and disposable. Gayle stated “*discharge was the end goal really, rather than the progress*,” suggesting a view that services were uninterested in helping children to progress, and were instead motivated by moving children out of services. The [EIT](#) supporting Gloria’s son only allowed children to access services for 12 months before they were discharged regardless of ongoing clinical needs. For Marian, policies regarding onward referral and age criteria resulted in her son being discharged from two different services. For Marian’s 8-year-old son these policies contributed to him spending approximately three years on waiting lists for different services despite having significant needs.

10.2.2 Models of Service Delivery

Services were also perceived as attempting to protect resources through their models of service delivery. Many participants interpreted services’ reliance on group therapy as an effort to protect resources rather than address clinical needs. Mila explained the use of groups as, “*And there wasn't enough of, of the speech and language so that's why they did the group thing and that's why they got 6 kids together, just to emm, emm sort of ... share the, the services within a, a more kids.*” Mila’s use of “*share*” suggests an empathetic interpretation that this was the service’s attempt to offer some form of “diluted” therapy to a greater number of children. In her interview, Mila described both positive and negative experiences of group therapy indicating an understanding that groups can sometimes

deliver effective intervention. However, Mila, as well as other participants recounted experiences of therapy groups that were “*absolute disaster[s]*” (Mila). Participants described experiences of therapy groups that weren’t “*individualised*” (Helen) and didn’t deal with their children’s “*biggest issue[s]*” (Helen). Groups were sometimes reported to be used when it was “*obvious*” (Mila) that they were not effective or suitable for the children involved. For example, Mila discussed her daughter’s early inclusion in a large group that took place in a small, cluttered room despite her daughter’s significant attention difficulties. Mila reported spending much of these sessions trying to keep her daughter safe and preventing her from climbing and running.

Evidence of a perception that services were delivered with more focus on resource management than on clinical need is also found in extracts describing transdisciplinary models of service delivery. Gayle, Gloria and Marian’s accounts include discussions of experiences that appear to relate to transdisciplinary working. Analysis suggests that these participants interpreted this model of service provision as diluting the quality of the service received, by redistributing the [SLT](#)’s work to other professionals with greater capacity. In the extract below Marian discussed her requests for the [SLT](#) to visit her son’s school and liaise with his teachers.

“I mean, I, I ... You know, they used to say, “Oh, I don’t have time, so I’m sending in say the physiotherapist instead.” You know, well what’s a physiotherapist going to see? ... You know. Don’t shove somebody in because you need to shove somebody in, you know ... Do the right job. You know ...” **Extract C2- Marian (L1510 – 1513)**

Marian appeared to perceive the [EIT](#)’s use of transdisciplinary care as designed to address limitations in [SLT](#) staffing and resources, rather than as a means to provide holistic care. The use of the verb “*shove*” carries connotations of force, suggesting a perception that the physiotherapist is not compatible with the “*job*” required but is being

made to fit. Her final utterance suggests an interpretation that this approach to service delivery promotes a poor form of therapy in which therapists do the “wrong” rather than the “right” job.

10.2.3 Indirect therapy

Two participants (Gloria and Gayle) discussed their interpretation that services discontinued direct therapy, and replaced it with parent-mediated intervention programmes because limitations with “funding” meant that it was “*the only thing*” (Gloria) that services could afford to offer. While Gloria discussed some benefits associated with this approach, she was critical of its generic nature as she perceived it. Both participants interpreted these approaches as an effort by the service to transfer all responsibility for therapy to parents. A more detailed discussion of this interpretation of indirect intervention is provided in the theme “*It’s mainly me*” (see Chapter 9).

Analysis suggests that there was consensus among participants that service organisations held and exerted the power to provide and limit children’s access to therapy. Participants appeared to understand services as motivated by a desire to protect resources, either by offering therapy sparingly and sometimes in “diluted” forms, or by refusing to share resources at all through the application of rigid eligibility and discharge criteria. All participants questioned the priorities of services, sometimes interpreting services to be uncaring and most interested in protecting resources above all else.

10.3 “*No pushing us out. No looking at watches. They were there to help.*”

Therapists can act as Supports or Barriers to Therapy.

When asked about experiences of [SLT](#), participants responded with descriptions of their experiences with services as a whole, as well as with individual professionals across a range of disciplines. While participants’ descriptions of services were largely negative, their

depictions of professionals were varied and multifaceted. Participants appeared to construe therapists to be highly influential to the therapy received. Analysis suggests that participants interpreted therapists' clinical, and relational skills, as well as their interest, availability and reliability to function as supports to accessing effective intervention. However, when participants perceived professionals to have difficulties in these areas, it was interpreted as lessening the quality of therapy received and in some cases as impeding participants' access to and participation in therapy. Figure 10.3 provides an overview of this theme.

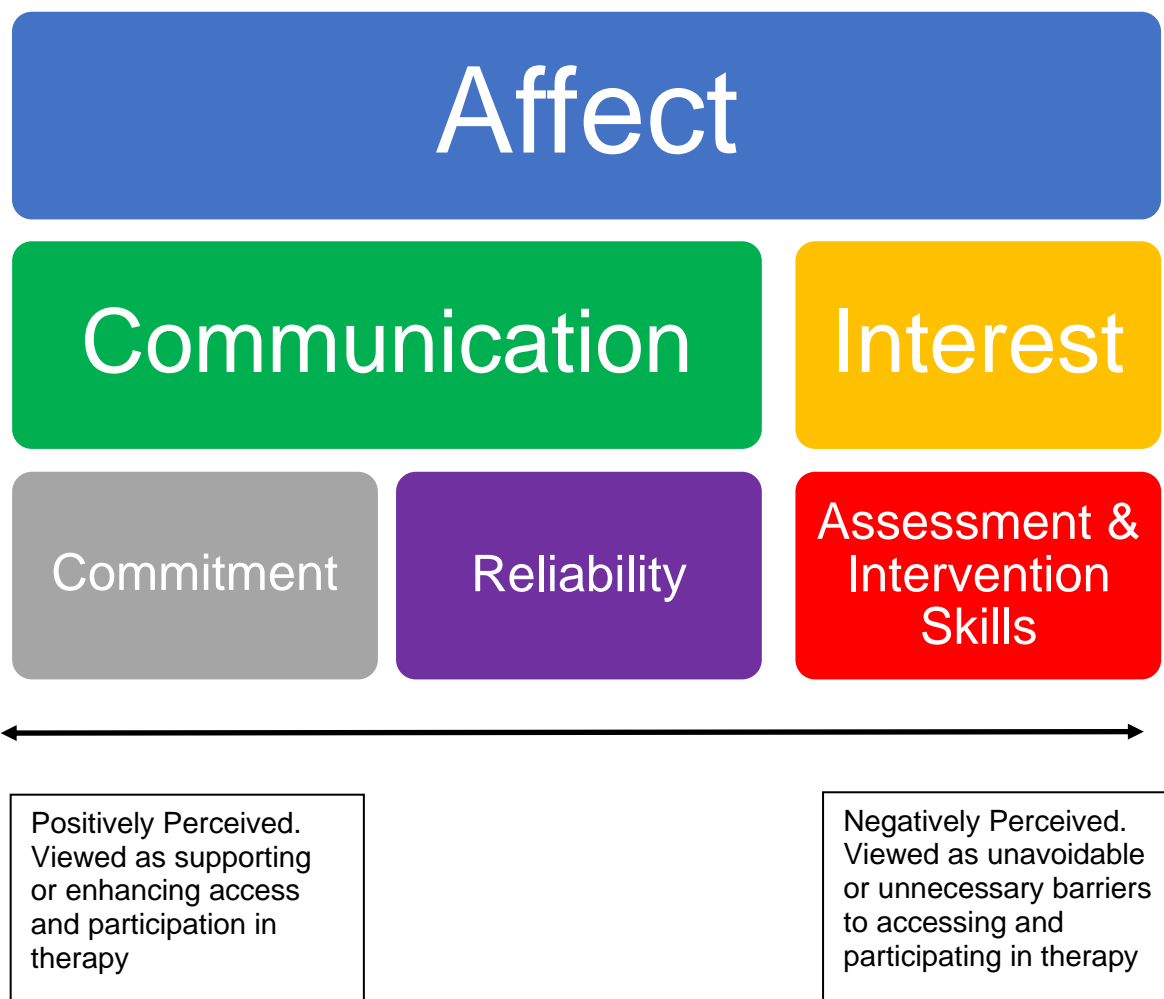


Figure 10.3 Theme of "No pushing us out. No looking at watches. They were there to help." Therapists can act as Supports or Barriers to Therapy.

10.3.1 Affective Dimension: 'Feeling' Supported by Therapists

Descriptions of positive experiences of therapy universally included discussions about how the therapist related to participants and their children and how they made participants feel. Indeed, Marian, Mila and Gayle specifically named the importance of having a positive “*relationship*” with particular professionals. Gayle and Marian described how certain professionals made them “*feel very positive*” (Marian) and feel hopeful about the future. Mila described how she and her daughter had a “*great*” “*relationship*” with their current [SLT](#). When discussing how this [SLT](#) was leaving her post, Mila stated, “*I'm really sad, we are going to lose her.*” The sadness connected to the “loss” of this therapist is suggestive of the affective dimension of this relationship.

10.3.2 Positive communications with therapists

R: I get on very well with all his therapist now.

I: Mmm

R: Because I know what they're doing and I think emm you know they get Cormac and they're working with him that- It's a great relationship you can have. In fact, it's a great hour to go to.

Extract C3- Marian (L1819 – 1823)

A number of participants discussed the importance of therapists' communication skills. For example, Gayle and Marian described certain professionals as communicating openly, and responding in such a way that parents felt listened to and believed. They connected communication skills with how positively they valued these relationships. In extract C3, Marian discussed why she viewed a particular therapist so highly. Marian first offered the explanation, “*I know what they're doing.*” This utterance captured both the therapist's communication skills, and Marian's skills as a listener. Marian's account

conveyed to me an interpretation that she understood the therapist's efforts to communicate the rationale for therapy activities as important, but also recognised that her efforts in listening and making sense of the therapist's communications were influential. Further evidence suggesting an understanding of the reciprocal nature of communication in this relationship may be found in other data extracts in Marian's interview in which she discussed how highly she regarded therapists who were open to receiving "*feedback*" or advice from her about how best to approach working with her son.

10.3.3 Therapists' Interest, Commitment, and Reliability

Extract C3 above also points to the perceived importance of therapist's relationships with the children involved, as well as the therapist's commitment for parents. In extract C3, Marian hinted that she appraised both the therapist's general attitude to her son, as well as her ability to work "*with him*." I interpreted the utterance "*they're working with him*," to convey multiple meanings. It suggests that the therapist had the skills to work with her son. However, the use of the present progressive verb form also conveyed the importance of time. It implied to me that Marian evaluated what the therapist had previously done, as well her ongoing availability, when determining the therapist's commitment and reliability going forward. The temporal aspect of Marian's understanding of therapeutic relationships is also illustrated in how she viewed the relationship to influence the overall experience of therapy in both the present and future. Having a "*great relationship*" was understood as significant to both enjoying the present moment and feeling more hopeful about the future and confident that positive therapy outcomes will be achieved. This was echoed in Gloria's account of her recent experience of assessment with the Primary Care [OT](#) service.

"So then when they got the one to one, I went back and they were, they were great- There was no - We had to leave eventually because Noah had a class. There was no pushing us

out, no looking at watches. They were there to help. I said, "God!" So when - I feel that when you're in the service, it's probably going to be ok." **Extract C4-Gloria (L808 – 812)**

Here Gloria connected her positive appraisal of the [OTs](#) and how they related to her and her son as signals of a more positive future and a reason to be hopeful. Gloria's account is striking in its simplicity. The extract suggests that Gloria perceived a sense of being "wanted" by therapists as a basic but significant component of the therapy process. She interpreted the [OTs](#) to communicate their interest in "helping" her by remaining present and attentive during the appointment, and allocating enough time so that Gloria didn't feel rushed.

10.3.4 Therapists' Intervention Skills

In extract C4, Gloria abstained from making any reference to the therapists' clinical skills. This absence drew my attention. While all positive descriptions of therapy across all participants included depictions of participants' relationships with therapists, the clinical skills of therapists were discussed with less frequency and less depth. The perceived significance of therapist's clinical skills appeared most prominently in Helen's interview. Helen understood autism as "a very, very specialised area." She depicted the high value she placed on her son's current, private [SLT](#) by explaining that "she has it nailed," and "she understands it from the inside out." When prompted to explain what this therapist did to demonstrate such clinical competency, Helen responded:

"She's very good at pegging the child ... and, emm ... exposing them in a very kind, even for me, a very kind way and empowering you to do something about it ... You know, she's a bit of a gem really." **Extract C5-Helen (AL582 – 583)**

This extract suggests a perception of the therapist's clinical skills being overlaid with their relational and communication skills. While the question related to what the

therapist did, Helen also described the manner in which the therapist delivered these skills. The phrases “*pegging the child*” and “*exposing them*” are suggestive of the therapist’s skills in assessment and differential diagnosis. However, the references to “*a very kind way*” and “*empowering*” are more indicative of the therapist’s relational and communication skills. Helen’s use of the phrase “*exposing them*” suggests that involvement in assessment and therapy may be experienced as a process of revealing one’s vulnerabilities, and as such requires both a skilled and caring therapist. The comparison of this therapist to “*a gem*” conveys the value Helen placed on her, as well as hinting that she perceived therapists who hold both high levels of clinical and relational skills as rarities.

10.3.5 Some Therapist-Related Difficulties are Unalterable

Although participants’ accounts all included descriptions of helpful encounters with professionals, negative experiences were also recounted, typically at considerable length and in significant detail. Similar to positive depictions, negative portrayals involved descriptions of therapists’ interest and commitment, as well as clinical and relational skills. Some of the difficulties depicted by participants appeared to be accepted as unalterable and were met with a sense of frustrated resignation. For instance, participants (Mila, Marian, Gloria and Helen) considered some therapists to convey an attitude of “*I’m too busy*” (Gloria). Analysis suggests that this was often accepted by participants as an accurate but disappointing frustration that they were powerless to change. It appeared to contribute to evaluations of the therapy experience as “*it sort of wasn’t a reliable thing*” (Helen). Participants felt compelled to monitor therapists to ensure that agreed actions, such as phone calls to schools or sending reports were completed. At other times, some participants queried if the excuse of, “*I’m too busy*” was used by those therapists who, “*couldn’t or they wouldn’t or they ... whatever. That they weren’t bothered,*” (Helen). Rather than understanding therapists’ perceived inactions in terms of individual professional’s

interest and effort, Mel's data implied a suspicion that publicly funded therapists collectively embodied a culture of inactivity, as conveyed in multiple statements about how her son's therapists "*don't do anything during the summer holidays.*" These concerns about therapists' interest, effort and workload were conveyed with a sense of frustration, but also resignation.

Mila conveyed a similar sense of resignation when depicting feeling "*disappointed*" about therapists' communication skills. When recounting the experience of the "*absolute disaster*" [SLT](#) group, Mila connected feelings of disappointment to her perception that the therapists involved didn't "*say it,*" or openly discuss the difficulties being experienced. She hypothesised that "*Probably why they didn't say it, was they didn't have capacity to offer her anything else at that time.*"

10.3.6 Avoidable, Unnecessary Communication Short-Comings

All participants' accounts, with the exception of Helen's, detailed experiences of therapists not being "*straight*" or "*up front*" (Gloria). Mel and Mila responded to the therapists' perceived communication shortcomings with annoyance and disappointed resignation. However, Gayle, Marian and Gloria appeared to interpret these shortcomings as unacceptable and unnecessary. The communication shortcomings encountered by Gloria and Gayle were interpreted as deliberate acts of "*dishonest[y]*" (Gayle). Gloria and Gayle both described how they understood professionals in their children's [EITs](#) to deliberately refrain from explaining to parents that the majority of intervention provided would involve parent-mediated rather than direct intervention. They both described how when their children's cases were opened by the [EIT](#), they began attending parent-mediated interventions. Both participants conveyed not understanding for several months that the groups they were attending constituted therapy as the therapists "*weren't up front at the beginning.*" (Gloria)

"I just felt emm just very ... You know it just crept up, you know, week, by week, by week until I realised "Oh my gosh, where is the therapy for Jake? You- You're not doing anything for my child!" You know and then it just dawned on me, "Oh my God! This is all for me!"

Extract C6- Gloria (L593 – 596)

Gloria used the term, “*crept up*,” in extract C6 above, and separately referred to a “*drip feed*” of information from professionals, conveying an image of a slow leaking of information that could be easily hidden from view. Gloria appeared to interpret this as a strategy to avoid being “*up front*” with parents. She reported that the professionals involved only explained about the intervention being parent focused when Gloria specifically questioned it and they rationalised this approach with reference to it being evidence based. Separate interview extracts suggested that Gloria interpreted this rationale as a partial truth, as the professionals omitted any reference to the influence of funding on decision-making. Gloria depicted how professionals being “*straight*” would have involved the [EIT](#) therapists saying, “*we're, we're confined to work within the restraints that we have, you know and funding.*”

Gayle depicted a similar interpretation of professionals’ attempting to conceal information regarding the parent focus of most interventions in the [EIT](#). However, Gayle interpreted professionals as engaging in deliberate misrepresentation of information. Gayle described professionals in the [EIT](#) as “*dishonest*” and “*not painting the full picture*,” and “*packaging up what they were suggesting for Liam, as the best thing for him, where all along, I knew and I still know it was all they were resourced to provide him.*” Analysis suggests that both Gloria and Gayle viewed the communication shortcomings they experienced as unnecessary and easily avoided if professionals made more efforts to be “*up front*” (Gloria). Both participants appeared to view professionals’ avoidance of being “*up front*” (Gloria) as partially motivated by a desire to protect themselves from litigation.

Gloria noted that professionals “*would never send anything by email. They would always- They didn't want anything in writing. They always wanted it- wanted you to call them.*”

Gayle appeared to understand many therapists and services to have a “*fear of being sued*” and to be more concerned with “*ticking boxes*” than getting “*any real result.*” For example, she recalled her frustration about the [EIT](#)'s lack of a feeding service; when she initiated a complaint about this, the [SLT](#) responded by referring Gayle's son to a paediatrician to review his weight. Gayle viewed this as “*just a way to stall us, because by doing that we were waiting, oh nearly a year, to see this Consultant,*” so that “*bought the Early Intervention Team about a year, where they didn't have to do anything particularly.*”

10.3.7 Therapists Asserting Power

Marian similarly depicted therapists' communication skills as challenging, but appeared to interpret the therapists' communications as efforts to demonstrate their power. Marian described multiple occasions of feeling that professionals did not listen to her, particularly prior to her son's diagnosis.

I: What was your worst experience of SLT?

R: Emm ... I've had a couple. Emm, I think I've probably mentioned them. Emm ... was the first speech therapist, who, ok he was two, but she didn't believe there was an issue at all ... And she wouldn't assess him. She didn't think it was necessary ... And I ... didn't agree with her ... Emm and I tried to say it to her ... emm a couple of times and she was like, 'Well no. I'm not doing it ... I'm not assessing him .. And I don't see there's any point ... Emm, I'll give him a little bit of speech therapy.' But she- I felt she sort of pushed us away a lot. And I was ... very upset about her. And she's somebody I would never like to go and see again ... She's very

knowledgeable but emm ... Ah [exhales loudly] I didn't get on with her ... And she was very cold, I felt as a therapist ...

Extract C7- Marian (L850 – 860)

In the extract above, Marian discussed an experience from six years prior to the interview, yet used “quotations,” and the present tense. This conveyed to me a sense that consequences of this experience felt current to Marian. The language used to “quote” the therapist is direct and definitive, signalling a perception that Marian viewed the therapist as having all decision-making power in therapy. Marian perceived her concerns to have been heard but not believed or attended to as important. Her utterance, “*I tried to say it to her ... emm a couple of times,*” suggests a sense of powerlessness, as Marian repeatedly tried to voice her preferences but felt dismissed as making requests that didn’t have “*any point.*” Marian distinguished between this therapist’s clinical knowledge and her interpersonal skills and intimated that the therapist’s high level of clinical knowledge was of limited value in the context of her being “*very cold.*” Marian used this phrase “*pushed us away*” three times in connection with different therapists in her interview. I interpreted the phrase to convey an understanding of the therapists’ actions as deliberate, forceful and hurtful. The phrase is suggestive of forcefully placing immediate distance between the parties involved. It suggested an interpretation by Marian, that she and her son were unwanted. The sense of distance evoked by the phrase indicates that Marian understood these therapists to be so removed from her that it made it challenging to both receive help, and have her voice heard.

In multiple other separate extracts Marian repeatedly stated, “*I wasn’t listened to*” in relation to “*speech therapists, and by, by every therapist. I wasn’t listened to.*” She also repeatedly referred to feeling that professionals didn’t believe her. For example, she continually requested a diagnostic assessment from the [EIT](#) but was refused as the

professionals did not agree with her appraisal that her son might have autism. Marian then depicted how she organised an MDT assessment through a paediatric hospital who completed an extensive assessment and concluded that her son had autism. When Marian shared the diagnostic report with the [EIT](#), she described the [EIT](#) team members as telling her, "*We don't believe you. We don't believe [name of hospital] that there's an issue.*" Marian's repeated experiences of perceiving herself to be disbelieved appeared to have had a lasting impact. Approximately half way through the interview, she paused and stressed to me, "*And I'm not alone,*" adding, "*I sound like I'm making all this up, but I, I could- I mean there are other parents out there with similar experiences.*" Marian's language appeared almost pleading, imploring me to listen and trust what she was saying as credible and signalled an ongoing fear of not being believed.

All participants described both positive and negative experiences with professionals. Analysis suggests that professionals' skills, interest, reliability and availability were perceived to support or diminish the quality of intervention received. In some cases, difficulties in these areas were understood as obstacles to accessing therapy. Positive experiences with therapists were often described in terms of the therapy relationship and associated with hope for the future. Negative experiences appeared to be interpreted as either unalterable, leading to a sense of resignation, or avoidable and unnecessary, contributing to strong emotional reactions among participants.

10.4 "*It has coloured my view of the [HSE](#) generally and of the service that Liam will get.*" Mistrust as a Reaction to Feeling "*let down.*"

All participants reported feeling "*let down,*" (Helen, Marian, Mila), "*cheated*" (Mila) frustrated and disappointed by services and sometimes professionals. Participants differed in how they interpreted and reacted to these experiences. Figure 10.4 below shows an overview of this theme. Mila, Mel and Helen appeared to interpret their experiences as

symptomatic of life as a generally unfair construct. Gayle and Marian perceived their experiences as unjust, contributing to significant feelings of anger and fear for the future and a desire to be involved in activism. Gloria demonstrated a complex interpretation of service provision as unacceptable, rather than unjust, but held hope that she could sometimes influence it. These differing experiences are discussed in further depth below. All participants discussed wider experiences of unfairness, sometimes relating to autism and general parenting experiences, and other times relating to “*the system*” (Mila) and society as a whole. This wider context of “unfairness” may have contributed to the experience of being “*let down*” by services and professionals being felt more acutely. Participants’ experiences of being “*let down*” contributed to significant mistrust of current and future publicly-funded therapy services, as well as professionals employed by these services.

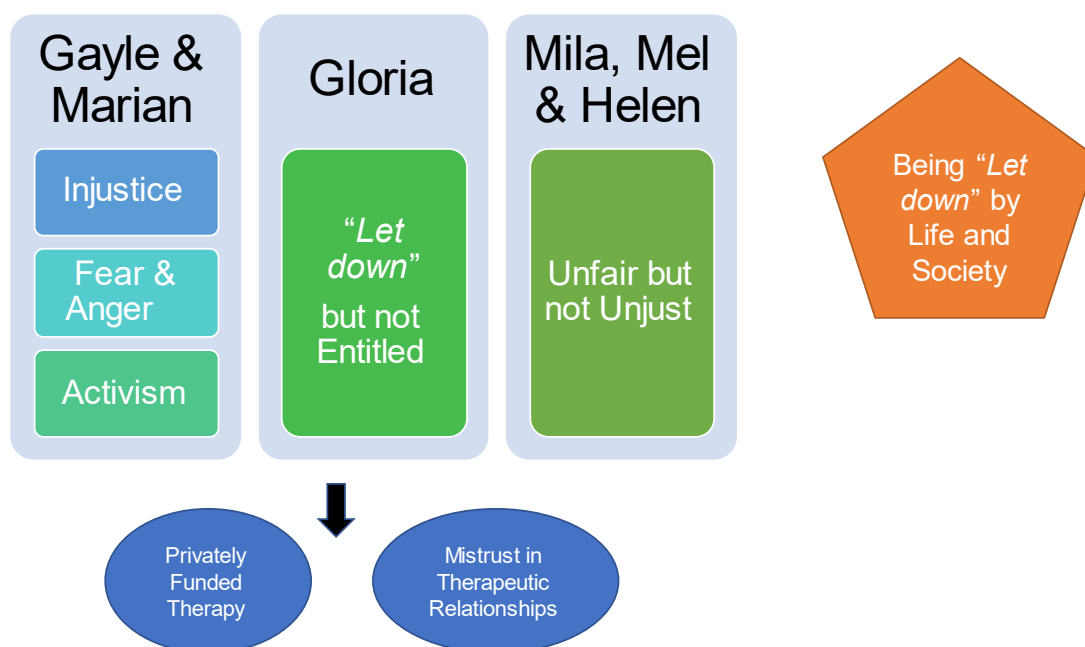


Figure 10.4 Theme of "It has coloured my view of the HSE generally and of the service that Liam will get." Mistrust as a Reaction to Feeling "let down."

10.4.1 Being “*let down*” as an Injustice for Marian and Gayle

All participants made sense of many of the accumulated challenges experienced with services and some professionals by interpreting themselves to have been “*let down*” (Marian, Helen, Mila). Marian and Gayle’s data suggest that they employed both ethical and rights-based lenses to make sense of these experiences. Gayle perceived therapy as a fundamental right that her son was “*entitled to.*” She perceived the type and amount of therapy her son received from publicly funded services as an “*injustice.*” Gayle referred to herself as “*a mammy and a taxpayer,*” and stated that “*needs equal need.*” This language is suggestive of an understanding that therapy should be readily and freely available automatically and its provision should be protected by law and the state. Therapy as a right also points to a conception that therapy is owed to her son, and as such it is not something Gayle should feel grateful about or in debt to service providers or the state about. Gayle’s use of the word “*injustice*” intimated an interpretation that the entire community of children with additional needs were being discriminated against. The language used also evoked a sense of therapy having a moral dimension, suggesting an interpretation that providing services is indicative of ethical behaviour, while limiting or ‘denying’ access to therapy signals unethical behaviour.

10.4.2 Marian and Gayle’s Anger and Fear of Being “*let down*”

The ethical and rights-based lenses Gayle employed, may help to explain the significant anger depicted by Gayle about services and sometimes professionals. She described herself as having “*trouble controlling my anger*” and becoming “*hostile*” and engaging in “*heated discussions*” with the professionals and services who she perceived to have let her and her son down. Marian similarly depicted feeling “*angry.*” She described initially feeling so angry that she would “*seethe at home.*” However, Marian also identified these experiences of being “*let down*” to contribute to an ongoing sense of fear about the future.

I: And where ... does that fear come from?

R: I think it's from initially whenever I was ignored ... and I was emm left and, and emm he was- I felt he was ignored and there was- They told me there was nothing wrong and then was- left me on these huge, big waiting lists ... Emm I'm, I'm just afraid that he's just going to be ... neglected ...again.

Extract C8- Marian (L734 – 738)

In the example above Marian directly connected therapists' perceived communication short-comings and gaps in service provision in the past to her ongoing fear of the future. The term "neglected" carries legal and moral connotations of injustice and unethical behaviour and may be interpreted as a perception of services and professionals failing to do their duty. Marian's utterance "*left me on these huge, big waiting lists,*" is suggestive of Marian's abandonment, rather than her son's, further intimating the impact that these experiences had on Marian. These events occurred a number of years before the time of the interview, yet Marian cited them as the reason for her ongoing fear for her son's future.

10.4.3 Injustice Inspiring Activism for Gayle and Marian

Further tentative evidence of Marian and Gayle's rights-based and moral perspective may be found in the data detailing their involvement in disability activism. Both participants described becoming more involved in parent support groups for families with children on the autism spectrum in response to their experiences of being "*let down*" (Marian). In these groups, both participants outlined how they "*fight for other parents*" (Marian), and how they "*rally*" and "*lobby*" (Marian) politicians for improved services for autism. Sometimes this involved letter writing campaigns, and involvement in organised protests.

"I, I think I'm quite principled and I think when I see somebody- Like I'm going to go marching with Vera Twomey tomorrow. Emm and there's another march on the 3rd of March- emm 3rd of April emm to the Dail, parents of children who aren't getting the services they need from the [HSE](#)." **Extract C9- Gayle (L942 – 946)**

In extract C9, Gayle connected her planned involvement in this march to her personal experience of being part of a community whose children aren't getting what "*they need*." She also appeared to interpret her involvement as relating to her sense of identity. Her reference to being "*quite principled*" contrasts to her perception that the state and publicly funded services behaved in an "unprincipled" manner in relation to her son. It is possible that Gayle's experience of being let down contributed to her valuing and emphasising this aspect of her identity to a greater degree.

10.4.4 Gloria as "*let down*" but not Entitled.

Identity also appeared influential to how Gloria made sense of being "*let down*."

R: I don't know- I don't have ... I don't have this sense of entitlement ... that people think that "Oh because my child has special needs you should be helping me." And I know that most- I'm in the minority that ... Most people think you should be helping. You are the state ... Why should the state help? You know this is my child? This is my child. So, I have no sense of entitlement-

I: Mmm

R: At all. But ... at the, at the end of the day I just wanted- If you're going to work with me- When you say you're going to work with me, well just give me the right intervention that I need to do.

Extract C10- Gloria (L760 – 768)

Similar to Marian and Gayle, Gloria appeared to hold the belief that the therapy services her son received were inadequate. However, she appeared to overtly reject the idea that she and her family should be entitled to therapy. She described feeling “so *grateful to get in*” to services, implying a perception of therapy being “gifted” rather than owed to her. Gloria’s rejection of therapy as an “*entitlement*,” appears to be underscored by a belief in the importance of individuals accepting personal responsibility. Gloria appeared to view herself as ultimately responsible for her child, and as such adopted the stance that she, not the state, had responsibility to help her child. She seemed to take a more localised view of therapy and what it meant in relation to her son and her family, with her repetitive use of “*this is my child*.” I questioned if some of Gloria’s fervour on the topic of entitlement may have been at least partially motivated by a desire to demonstrate that she was an individual and not related to the stereotypes of parents of children with additional needs. She described herself as in a “*minority*” and distinct to those “*people*” who “*give out*” and appear demanding and entitled. While it is unclear who exactly Gloria is referring to here, analysis suggests that she framed her understanding of her experiences through an individual, rather than collective/ autism community perspective. Gloria’s data suggests an interpretation of her experience as unfair rather than unjust. While emphasizing that she did not feel entitled to services, she appeared to suggest that her rationale for feeling let down stemmed from a form of costs-benefits analysis. She referred to the work and time involved in partaking in therapy and the sense of disappointment associated with perceiving the intervention provided as costly and not “*the right intervention*.”

10.4.5 Being “*let down*” is Unfair Rather than Unjust for Helen, Mila and Mel

Other participants’ accounts (Helen, Mila and Mel) suggest an understanding of disappointing encounters as unfair “facts of life.” While these participants understood their

children to have been “*let down*” (Helen and Mila) by services and reported feeling frustrated and fearful (all), angry and sad (Mila) in response to this, their responses were not indicative of perceiving their children’s rights to have been breached. No evidence of an interpretation of their experiences as unjust was found in the descriptive or linguistic content of their interviews. These three participants appeared to react with a sense of resignation, perhaps stemming from an interpretation that, as with many unfair aspects of life, no recourse was possible. None of the three participants reported voicing their disappointment to services or professionals or taking actions to change the way their children’s services were delivered from publicly funded providers.

R: Mmm but we just have to go with it because emm- I have to go with it. We can't just stop like ...

I: And why do you feel you have to go with it?

R ... Well see that's just our opinion that it's no good but the - Like until I can afford the- Well see I was told to go on, on the private speech or the private OT now.

I Ok

R Because this OT carry on with them. Same. It's brutal. So we're- It's €100 so we can only afford every second week-

Extract C10- Mel (L43 – 51)

Extract C10 conveys Mel’s sense that because she did not pay for the publicly-funded therapy, she has no power to influence what and how much therapy was accessed. It is unclear if this is because Mel perceived therapy as a discretionary service provided by the state, rather than a right, or because she viewed public institutions universally as powerful bodies not open to influence by individual citizens. Mel appeared to understand

private interventions as offering the only opportunity for her to influence the amount and quality of intervention provided.

10.4.6 Seeking Privately Funded Interventions

While Mel's account contained no references to any actions taken to change how publicly funded services delivered therapy, she depicted herself as having taken arguably risky actions to access private therapy. Mel detailed how she borrowed money from her father on multiple occasions and sometimes didn't pay her mortgage in order to afford private assessments and [OT](#) intervention. Mel was not unique in accessing privately funded interventions. All participants reported engaging in privately funded interventions to varying degrees, with a number describing the financial impact of this on their families' lives. All participants explained their involvement in private interventions as stemming from their experiences of perceiving publicly-funded services to have let them down. This contributed to the development of "a trust issue" (Helen) with all participants suggesting that they "cannot rely ... on the [HSE](#)," (Marian) to provide the quantity or quality of therapy they perceived their children to need. For example, Mila discussed how the public [SLT](#) was leaving her post and she didn't know if or when the [SLT](#) would be replaced. Private therapy for Mila, as well as for Marian and Gloria, represented a means of supplementing intervention to achieve an adequate dosage (Marian, Mila, Gloria). For others (Gayle, Helen and Mel) private therapy was perceived as offering a higher quality of intervention. Gayle, in particular, held strong opinions about the perceived need to engage in private intervention. She reflected on her negative encounters with the [EIT](#) and concluded:

"Emm ... I think emm I think what it has proven to me- Outside of feeding, what has proven to me, is as long as you have money your child will be fine ... Emm and if you don't, your child is thrown on the scrap heap effectively, I think. Emm, I think you know, so for people

who have money emm they can tap in to most of the services that their child will need.

Emm but I think that's disgusting.” Extract C11-Gayle (L250 – 255)

The above extract further illustrates the lens of injustice through which Gayle evaluated her experiences with public services. Her repetitive use of the word “*proven*” has connotations of the legal justice system, while also suggesting the strength of Gayle’s evaluation of her experience. I found Gayle’s use of the phrase, “*thrown on the scrap heap*,” particularly evocative, conveying an interpretation of publicly-funded services as uncaring and devoid of any hope for children’s’ futures. The word “*disgusting*” suggests the strength of Gayle’s discord with public services, signalling an understanding of their behaviours as unethical and morally repulsive. It is also possible that Gayle perceived the monetization of health in general as unethical, and thus the term ‘*disgusting*’ may also have signalled her discomfort in being a reluctant participant in this system. Nevertheless, despite potentially holding such a view, Gayle and all other participants viewed private therapy as a necessity, albeit an expensive one, due to their considerable mistrust of public services. Indeed, Helen’s mistrust of and frustration with public services eventually contributed to her decision to “*leave the public system behind*” and only access private interventions, as “*we’d been let down a few times in the public system ... which is fine but now it was a final straw.*” Her account is indicative of a perception that she had reached a threshold of being “*let down*” and perceived any further experiences of being “*let down*” as intolerable.

10.4.7 The Impact of Being “let down” on Therapeutic Relationships

Participants all depicted their experiences of being “*let down*” to have impacted their present and future relationships with health professionals. Marian reported feeling “*wary*” and “*distrustful ... of anybody from the [HSE](#).*” This was similarly echoed by Gayle who noted that her experiences with the [EIT](#) “*has coloured my view of the [HSE](#) generally and of*

the service that Liam [Gayle's son] will get." Both these utterances suggest that participants' mistrust may have extended beyond the specific services and professionals who initially triggered it, to a more general mistrust of any organisation or professional associated with the state-funded health service. Helen, Gayle and Gloria also appeared to approach new therapeutic relationships from a position of relative mistrust and showed signs of closely analysing all early encounters with new therapists to determine if these therapists could be trusted. For example, Helen explained her close evaluations of therapists, saying, "*Maybe I'm a bit precious of him ... and I really want to make sure ... I don't trust everybody.*" This mistrust conveyed by participants contributed to the adoption of strategic-defensive and 'fighter' roles, and is discussed further below.

10.4.8 Being "*let down*" by Life and Society

Analysis tentatively suggests that the experience of being "*let down*" by services and some professionals may have been felt with greater magnitude, given the broader contexts in which they occurred. The transcripts of all participants intimated interpretations that life and society operated unfairly, with Gloria noting, "*unfortunately life isn't like that. It's just- It's hard like ...*" All participants, with the exception of Helen, reported feeling sad or angry about this. Helen's data suggested that she understood parenting in the context of autism to be challenging, and perceived society and institutional organisations such as the school system to be less tolerant of people on the autism spectrum. However, her data was also indicative of having accepted this as an annoyance that she had limited power to influence. Helen appeared to accept her life as it was. The meaning of the "unfairness of life" appeared greater for other participants whose data contained multiple comparisons between life before and after autism, and comparisons between their lives and those of other parents who had typically developing children. Most participants, particularly Gayle and Gloria, presented evaluations of their experience of parenting as unfairly challenging

compared to the experience of parenting a child without autism. Gayle noted, *“It’s hard enough parenting a child with additional needs, when that’s all you’ve to do.”* Gayle’s extract suggests a perception of her experience as unfair, while also signalling a perception that any further “injustice” is intolerable to Gayle. Gloria noted, *“I hate that it’s my child.” ... Why not somebody else’s?”* Some participants (Gayle, Mel, Mila, Marian) also perceived autism as unfairly disadvantaging their children, requiring them to take on adult-like responsibilities with their therapy workloads, yet despite this “work” their children were not perceived to reach the same abilities as their peers. For example, Mila compared her daughter Nina, who has autism, to her younger daughter, Sophie, who does not.

R: It, it’s breaking my heart seeing Sophie, who is typical developing child, gets everything, and she is effortless in speech and gross motor, and you know ... It’s, it’s effortless.

I: Mmm

R: But Nina struggles. You know, she’s always few, few steps emm behind emm her-

Extract C12- Mila (L684 – 689)

Extract C12 is suggestive of multiple layers of unfairness. One daughter is perceived to progress with no apparent effort, while the other works and “*struggles*” but despite this always remains a “*few steps emm behind.*” I also found evidence of unfairness in how Mila chose to depict events worthy of celebration (Sophie’s development) as “*breaking my heart.*” This suggested to me that Mila may understand her life to be further unfairly affected, as even causes for celebration now trigger feelings of sadness.

Some participants (Gloria, Helen, Mel) also discussed unfairness in the context of society’s treatment of people on the autism spectrum. Participants discussed the additional challenges children with autism faced in finding school placements and in being

misunderstood by class teachers and peers, sometimes experiencing bullying as a perceived result of this. Gloria discussed this in the most depth, summarising, “*there's an awful lot of awareness about autism ... but there's no acceptance.*” She explained how she perceived society to be more “*politically correct*” but still to have an attitude of “*It's all right but just not on my door step.*”

This theme captures how participants interpreted themselves and their children to be “*let down*” by services and some professionals. Some participants made sense of this using the lens of injustice, while others understood it as a “*fact of life.*” All participants discussed how being “*let down*” triggered difficult negative emotions including fear, anger, sadness and frustration and contributed to feelings of mistrust towards current and future service providers. For some participants the experience may have been felt more acutely given their wider perceptions that life and society treated both them and their children unfairly.

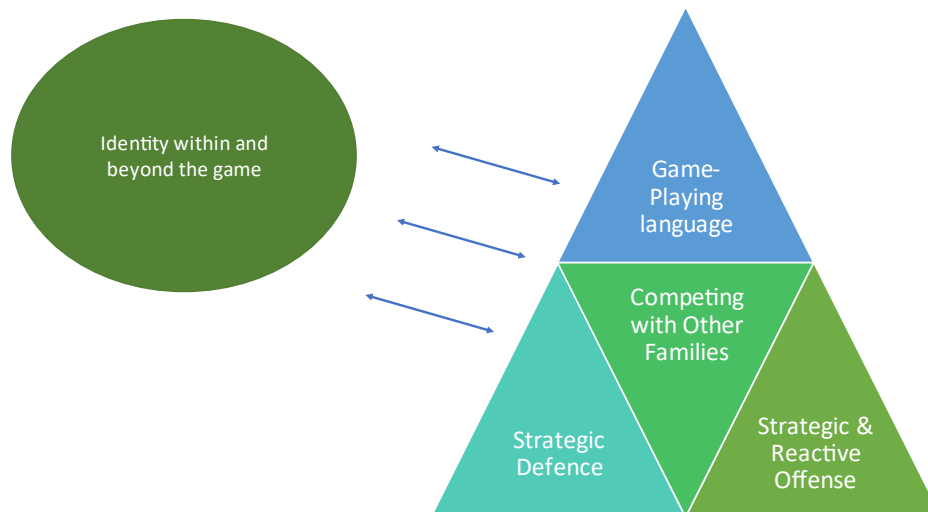


Figure 10.5 Theme of ‘Surviving the Game: “*Staying in the wings*” to protect existing service levels, “*Fighting tooth and nail,*” for your child, or deciding to ‘*cut our losses.*”

10.5 Surviving the Game: “*Staying in the wings*” to protect existing service levels, “*Fighting tooth and nail,*” for your child, or deciding to “*cut our losses.*”

Linguistic and descriptive analyses of all participants’ interviews point to a sense-making of their experiences with services and professionals as akin to a high stakes game. Some participants discussed feeling in competition with other families for therapy resources. Participants responded to the barriers they perceived at service and professional level by adopting defensive and offensive roles akin to advocacy roles. Most participants discussed taking preventative measures and acting strategically to secure therapy. Some participants discussed adopting a “fighter” role designed to “*push*” (Marian) services and professionals to provide additional therapy. Other participants depicted the toll involved in game-playing as costly, and described leaving services in order to “*cut our losses*” (Gloria). Some participants showed pride in the roles they took to “compete” and advocate for their children and appeared to view this role as demonstrative of their identities as “good” mothers. However, for others, I interpreted the experience of game-playing as triggering an internal conflict, as they felt compelled to adopt roles which did not feel compatible with their overall identity. An overview of this theme is found in Figure 10.5 above.

10.5.1 Game-Playing Language

Language associated with game-playing and competition was found in all participants’ accounts, with the exception of Mel. This game-playing language was used to depict participants’ interactions with services and professionals. As discussed in the superordinate theme of ‘*Therapy Mother,*’ Gayle used the sporting metaphor of “*bat the ball back into the parents’ court*” to depict her interpretation of indirect therapy approaches. Participants described the experience of waiting lists as being “*back to square one,*” (Marian), while referring to feeling “*cheated*” (Mila) by the amount of therapy available. Gloria used the term “*cut our losses*” to explain her family’s decision not to “*fight*” being

discharged by the Early Intervention Team, while Helen likened her approach to working with professionals to “*staying in the wings*.” Mila’s account, in particular, was interspersed with subtle but frequent terms that carried connotations of game-playing. Twice, Mila referred to “*chasing*” professionals, while also discussing her desire for more “*back-up*” four times and for professionals to “*touch base*” twice.

10.5.2 Propelled into a Competition with Other Families

The use of this language in the context of the descriptive content of participants’ accounts suggests that participants interpreted their interactions with services and professionals using the metaphor of a game. Three participants (Gayle, Marian and Gloria) appeared to have understood themselves as in competition with other families for services at times. When discussing her son’s transfer to Primary Care services, Gayle stated, “*we’re competing with people who are stroke victims and brain injury victims and all this kind of stuff*” Marian described feeling “*jealousy*” and “*frustration*” when she heard that other children who she perceived as having less severe needs were attending [SLT](#), noting “*And I’m there thinking, ‘Why can’t he be seen?’*” and “*And emm ... Stuff you and your lisp! [both laugh]. You can get that some other time. [laughs] You know, and it sounds terrible! And I wouldn’t- I don’t feel now- God no! But at the time, I felt like you know.*” Marian attributed a temporal dimension to this experience, suggesting that because she now perceived her son’s services to be more consistent and reliable and his needs less severe, this sense of competition had waned. For Gloria, the perception of other families as competitors appears to have been reinforced by her interactions with services. At her son’s “*exit interview*” from [EIT](#), Gloria reported that the professionals justified their model of service delivery and the amount of intervention provided by suggesting that Gloria was “*coping*” better and required less support than other parents in the service.

“So I don't know- Maybe they thought, ‘She's going to do ok. You know she can- she can- And she's a background in training, she'll be alright. She'll manage, you know. And let's go to the parent who is absolutely falling apart.’ But the whole thing is, you know, I was falling apart. I was falling apart at home ...” **Extract C13- Gloria (L656 – 660)**

This extract highlights Gloria's perception of therapy services as a finite resource which is distributed among families. Analysis suggests a tentative understanding that if other families receive more therapy, it is at the expense of Gloria and her son. Allocation of therapy resources was understood to be influenced by professionals' evaluations of families' needs. Gloria highlighted the flaws in such a system noting that professionals' judgements were based on her appearance at appointments, while at home Gloria perceived herself to be “*falling apart*.”

10.5.3 Defending Children by “*staying in the wings*” and Strategizing

Participants described closely monitoring services and professionals by “*staying in the wings*,” (Helen) at all times, remaining vigilant to when preventative or defensive action might be necessary. Some participants indicated that they took a strategic approach to information sharing with professionals in order to protect existing levels of service provision. For example, Mel described choosing not to disclose to the [EIT](#) that her son was attending privately funded [OT](#). She reported that this decision was taken to prevent the [EIT](#) viewing her son as less of a priority as he was receiving intervention elsewhere. The most commonly depicted defensive strategy involved the “*chase*” (Mila) of professionals. Mila used this game-like term to capture her experience of feeling compelled to frequently make contact with professionals to ensure that requested or promised actions were completed. Gloria, Helen and Marian also reported doing this. Marian extended this strategy further, emphasizing that “*you have to get cute*.” She described using these frequent contacts with professionals to ask therapists to pass on messages or questions to

other therapists in the service. Marian explained, "*Your name has to be mentioned. You have to be in there all the time. You know, if you're not mentioned ... you fall off the list.*" Marian's stress of the word "have," is suggestive of an interpretation of this strategizing as a necessity. She appeared to understand her actions as measures designed to protect her son's current level of service provision. Most participants appeared not to enjoy this role and indicated that they did it to fulfil their parental responsibilities of protecting their children by doing "*what you have to do as a parent*," (Marian).

10.5.4 Feeling Compelled to "*fight*" to Protect Children

This parental desire to protect one's children was also presented as the motivation behind adopting a 'fighter' role with services and professionals. Three of the six participants depicted sometimes adopting such a role (Gayle, Marian and Gloria). "*Fighting*" (Marian) was portrayed as being involved in conflict with services and professionals, typically to access additional or different services. It involved writing to service managers and politicians, as well as scheduled or spontaneous verbal exchanges with professionals regarding accessing more, different or earlier therapy. Involvement in this role was described using terms such as "*fight*" (Marian and Gayle) "*heated discussions*," (Gayle) "*personality clashes*," (Gayle), "*run-ins*," (Marian), "*arguing*" (Gloria) and "*being vocal*" (Gloria). All three participants reported initiating this role in reaction to being let down by services and professionals. Marian described herself as "*fight[ing] tooth and nail to see somebody to beg them ... I literally was on the phone begging for- to get therapy.*" This animalistic metaphor captures how participants understood themselves to adopt this role out of their sense of dedication to their children, and their desperation about their circumstances. Marian and Gayle identified that their involvement in "*fighting*" was fuelled by the anger they felt about being "let down" (Marian). They attempted to "*funnel*" that anger "*into ... into doing something*," (Marian). Both Marian and Gayle shared a sense of

pride about their role as “fighters,” while Gloria appeared to be a reluctant “fighter.” Their differing experiences are discussed below.

10.5.5 “*Fighting*” to be a “*Good*” Mother

The role of “fighter” appears to have triggered tension in the personal identities of some participants. Although Marian appeared to understand her adoption of this role as motivated by her identity as a protective mother, she appeared to perceive performing the role as unpleasant and easily misunderstood. Extract C14 outlines Marian’s interpretation of how therapists perceived her.

“You know and that’s why you ring up and you, you’re thinking, ‘Oh that bloody woman again!’ You know ... You know but that’s me. And I know because I, I- You’ll be a pest! ... You have to be a pest! ...” **Extract C14- Marian (L1560 – 1562)**

This extract points to Marian understanding therapists to view her as a nuisance and “*a pest.*” Her phrase, “*but that’s me*” coupled with “*you have to be a pest!*” suggests that Marian also viewed herself this way but perceived this role as a necessity. “*Pest*” is indicative of a negative self-image. It also intimates a perception of a power imbalance. It suggests a comparison between Marian and other small, undesirable creatures who can only impact on those more powerful than them by remaining a persistent and irritating presence. Marian’s overall account suggests that while she did not “enjoy” “*fighting*,” she viewed herself as ultimately successful in helping to protect her son’s future by taking this role. She stated, “*I think I got a lot more than a lot of parents ... I’ve been one of the most successful parents because I think that I pushed a little bit more.*” This extract illustrates Marian’s pride in her sense of achievement. She appeared to consider these achievements as measures of her success as a “parent.” Gayle similarly appeared to make sense of the “fighter” role as intertwined with her identity as a parent. When explaining her involvement in ‘fighting’ for services, Gayle said, “*Parents will go to the ends*

of the Earth for their kids,” suggesting that the lengthy and difficult conflicts that Gayle endured were understood as part of her parental responsibilities. However, Gayle’s data suggested that she perceived this responsibility as greater for mothers. She stated, *“I think mummies are hard wired in a particular way to fight for their children in a way maybe that daddies aren’t.”* Gayle perceived mothers as particularly motivated to protect their children by any means. Engaging in fighting acts as a signal of being a “good” mother for Gayle. This may partly help to explain the pride that Gayle depicted when speaking about her conflicts with services and professionals. It may also illuminate why some of the conflicts described by Gayle and Marian appeared personal rather than professional.

Analysis found evidence of a personal dimension to how Gayle and Marian understood difficulties with services and professionals. When discussing difficult encounters with certain therapists, Marian appeared to make sense of these as the therapists having a personal dislike of both her and her son. Gayle expressed the belief that her conflicts with professionals were *“never personal,”* yet numerous data extracts suggested otherwise. For example, when depicting her involvement in a block of indirect therapy which Gayle had objected to, Gayle recounted the story by adopting a high pitch, squeaky voice for the therapist that appeared mocking. Gayle displayed clear pride in her role as a “fighter,” yet appeared keen for me to perceive her actions as both necessary and as core to her identity as a mother protecting her son, and not as the disproportionate outbursts of an emotional parent. She stressed to me it was *“never my intention”* to *“hurt people’s feelings.”*

10.5.6 Gloria’s Experience of “*Fighting*”

Gloria also sometimes adopted a role in *“fighting”* for services, however her experience appears to have differed significantly to both Marian and Gayle’s. Gloria’s depictions of *“fighting”* were never suggestive of any personal dimensions. Gloria depicted the

professionals involved as “*lovely*” and “*so nice*,” and frequently emphasised an understanding that “*resources*” rather than qualities relating to particular therapists more frequently underpinned most of the perceived limitations in service provision. Gloria described only a small number of events that involved “fighting,” and the related data extracts involved many pauses, unfinished sentences and a vocal quality that suggested sadness rather than pride on reflecting on these periods. Gloria noted evaluating her experience with the [EIT](#) as signalling, “*Ok when we give out, that ok they come out afterwards with ‘You’ll have a block of this. Then you’ll have this and this.’ But that should have all been done.*” Gloria’s conveyed a sadness and frustration about her understanding that she was required to fight to access a basic, rather than enhanced, level of care. Gloria depicted eventually becoming disillusioned with the [EIT](#) therapists’ perceived reliance on manualised rather than individualised therapy approaches. She appeared to lose hope in the [EIT](#), and consequently perceived the energy involved in “fighting” as wasteful. She described how “*you’re only allowed in Early Intervention for a certain amount of time, but you could fight that,*” however Gloria decided to “*cut our losses now,*” and agreed to onward referral to another service. Analysis tentatively suggested that Gloria was uncomfortable with the role of fighting, as she carried a strong sense of the importance of individual responsibility and rejected the idea that her son was “*entitled*” to services from the state (as discussed above). This may also have contributed to Gloria’s choice to “*cut our losses.*”

10.5.7 “*Fed-up-ness with the system*” led Helen to Access only Privately Funded Interventions.

Helen also experienced a desire to “*cut our losses*” (Gloria). Helen identified as “*being John’s advocate,*” but appeared somewhat uncomfortable in this role. At one point, when describing advocating for her son, Helen noted, “*I sound like an awful parent,*” and later

keenly emphasised, "*I wasn't a pushy parent.*" Helen appeared to take some pride in her role as her son's advocate, while simultaneously interpreting this role to carry connotations of being forceful and demanding. It appeared important to Helen during the interview that I didn't consider her as "*pushy*," and instead perceive her simply as a mother trying to protect her son. While Helen's data is not indicative of any history of adopting a 'fighter' role, like Gloria, she also became "*tired*" and disillusioned with publicly funded services and the work she felt compelled to do in strategizing and working defensively for her son. This fatigue, coupled with the mistrust of services, eventually led Helen to discontinue all publicly funded therapies. She noted, "*So I probably let my ... fed-up-ness with the system ... emm, sort of carry us to the private route ...*" Later in this extract, Helen added, "*So it was my emotional issue that probably ... Emm ... Affected my thinking a bit ...*" I interpreted this extract to convey a perception that Helen was involved in a "game" that required considerable work and cost, in terms of time, energy and sense of identity, to play and yet was difficult, if not impossible to "win." While Helen continued to perceive her adoption of the role of "*advocate*" as necessary when she moved to exclusively privately funded therapies, her defensive and strategic work appeared to lessen. She continued to monitor the work of therapists but reported no occasions of "chasing" professionals or taking actions that could be perceived as "*pushy*" by others. By the time of the interview, Helen expressed some regret about leaving the public system. She queried if her son had lost support in terms of transitioning to secondary school or understanding his diagnosis. However, overall, Helen appeared to evaluate her decision to leave the public system as largely the right decision for her family and her well-being at the time.

10.6 Deductive Analysis Results

Evidence was found to support the relevance the superordinate theme of “A Game of Survival” to all participants involved in the deductive analysis. No differences in the number of participants involved in each theme was found between the two studies (see Table 10.2). Sample evidence gathered during the deductive analysis for this superordinate theme is shown in Table 10.3.

Superordinate/ Major Theme	Theme	Core IPA Study -Number of Participants Involved (n=6)	Deductive Analysis – Number of Participants Involved (n=6)
Navigating Therapy Services: A Game of Survival	Therapy is a precious commodity guarded by individual services	6	6
	“ <i>No pushing us out. No looking at watches. They were there to help.</i> ” Therapists can act as supports or barriers to therapy.	6	6
	“ <i>It has coloured my view of the HSE generally and of the service that Liam will get.</i> ” Mistrust as a reaction to feeling “ <i>let down.</i> ”	6	6
	Surviving the Game: “ <i>Staying in the wings</i> ” to protect existing service levels, “ <i>Fighting tooth and nail</i> ” for your child, or deciding to “ <i>cut our losses.</i> ”	6	6

Table 10.2 Numbers of participants in the IPA study and deductive analysis who showed evidence of “Navigating Therapy Services: A Game of Survival.”

Sample Quotes

	Mary	Sarah	Sinead	Susan	Robyn	Trish	
<p>Therapy as a precious commodity guarded by individual services</p>	√	√	√	√	√	√	<p><i>“But then, like if he's lucky ... he'll get a few sessions and then when he's six he'll be discharged from Early Intervention to another team, called the School Aged Team. So it's very annoying because we'll actually have spent most of our time on the list probably getting very little ... services.” (Sinead)</i></p> <p><i>“I think it's that they're trying to cut costs by sending so many parents on these courses.” (Sarah)</i></p>
<p>“No pushing us out. No looking at watches. They were there to help.” Therapists can act as supports or barriers to therapy.</p>	√	√	√	√	√	√	<p><i>“Because every time they give me an appointment, they're cancelling the appointment and changing the appointment ... I'm not going to say anything to them about appointments because they change it around for them own selves and if we did that we get the appointment back at all.” (Mary)</i></p> <p><i>“When she saw him and assessed him she went “ Oh he's definitely a candidate for [name of service] and she went to the board and she fought for him to be accepted into [name of service]” (Robyn)</i></p>

<p>“It has coloured my view of the HSE generally and of the service that Liam will get:” Mistrust as a reaction to feeling “let down.”</p>	√	√	√	√	√	√	<p><i>“He needed intensive OT and SLT which we had to pay for because he wasn’t going to get it in any kind of system. If we waited for the HSE, if we waited for [name of ID service] he wouldn’t have got that one to one every day, three hours intense that he needed.” (Robyn)</i></p> <p><i>“We’re expected to go to these courses so that we’ll get services, because it’s nearly like if you feel if you don’t go to the course you’ll get an X against your name because you didn’t attend and then you won’t get it- You won’t get services again, so when the speech therapy comes and looks she’ll go, ‘Oh she didn’t go to that course.’” (Sarah)</i></p>
<p>Surviving the Game: “Staying in the wings” to protect existing service levels, “Fighting tooth and nail” for your child, or deciding to “cut our losses.”</p>	√	√	√	√	√	√	<p><i>“Absolutely. It’s discriminatory, you know ... You’re constantly fighting. You’re fighting at every level, for everything they ever need ...” (Susan)</i></p> <p><i>“He’s going private for speech therapy but I haven’t told the Early Intervention Team because I don’t want them to know because I feel like if I told them they wouldn’t want to give him more speech therapy before he leaves.” (Mary)</i></p>

Table 10.3 Sample evidence from deductive analysis for “Navigating Therapy Services: A Game of Survival.”

10.7 Reflexive and Reflective Commentary

I found this superordinate theme the most challenging of all themes to analyse. My initial difficulties probably stemmed from my dual identities as both a researcher and a therapist. Hearing participants' accounts of feeling let down by services and professionals triggered memories of difficult encounters I had had as a therapist. This was most evident in Gayle's case, in which I sometimes felt uncomfortable during the interview and at certain moments silently questioned the "veracity" of her appraisal of events. I felt empathy for the therapists whom Gayle described working with and was sometimes tempted during the interview to try and justify their actions. It was challenging to notice and "catch" these thoughts and biases in the moment and I acknowledge that I was not completely successful in doing so. As revealed in my discussion of researcher reflexivity in Chapter 4, I grappled with Gayle's individual case analysis and benefited from both reflexive journaling and supervision to approach analysis from a more empathetic stance.

The more data I collected and analysed relating to this superordinate theme, the more I began to consider challenges with services and professionals as almost "universal" to parents' experiences of services. This grew into a feeling of considerable guilt. As a therapist working in the public health service, I felt responsible for some of the stress, frustration, and anger that participants depicted when describing encounters with services and professionals. This guilt gradually manifested as perhaps an over-identification with participants. I often found the transcription and analytical process emotionally charged. I sometimes became tearful when considering participants' emotional distress, which I considered myself to be partly responsible for. I remained uncomfortable with my preliminary finding that these challenges depicted by participants were best understood as "conflict." I drew from my clinical experience and considered how few of my encounters with families, I would characterise as involving "conflict." I wondered if I was being influenced by "louder" voices among the sample.

While, I was not aware of it at the time, my analysis of Mila case represented the beginning of a slow shift in my thinking. I had noted in Mila's analysis her repeated inclusion of game-like language. I was drawn to this and even at the end of her case write up, felt that this required further interrogation. While I had observed sporting metaphors and language in other participants' accounts and discussed these in the case write up, the louder participant voices who spoke of "fighting" had in a way distracted me. I had interpreted these sports analogies and language as peripheral evidence of "battling" and being on opposing sides. During the cross-case analysis, Mila's case, in particular, helped me to recognise that many of participants did not view themselves as "fighting." I came to the realisation that the construct of "conflict" didn't capture the essence of the phenomenon being studied. Flipping this on the head, and interrogating how the "non-fighters" had depicted their challenges with services and professionals, eventually brought me back to the metaphor of game-playing. I felt that the metaphor of game-playing was more representative of the entire sample. I also felt relief. I had started to become nervous about how my work might be received by other therapists. The lens of "conflict" appeared triggering. Often when I discussed my preliminary findings in terms of "conflict" with my colleagues, it either wasn't received well or was misunderstood. "Conflict" appeared to carry emotional connotations that I feared would contribute to readers becoming entrenched in their position. Game-playing felt both more representative of the data and more helpful, potentially prompting reflection on what changes can be made to make "the game" easier to play.

10.8 Summary

This chapter discussed the superordinate theme of "Navigating Therapy Services: A Game of Survival." This theme attempts to speak to the question of how participants made sense of their role in therapy and also depicted the advocacy role taken by participants. Participants understood themselves to be "let down" by services, which

they perceived to be primarily interested in protecting resources. Participants' experiences with professionals were mixed, with some discussing the role of supportive therapeutic relationships in facilitating their access to positive therapy experiences. All participants, however also depicted challenging encounters with professionals. These encounters, coupled with perceived barriers at service-level contributed to participants' developing a lasting and ongoing mistrust of services and professionals. This manifested in the adoption of "defender" and "fighter" roles when engaging with services and professionals. While some participants reported considerable pride associated with these roles, all participants reported that the responsibilities involved in performing these roles were challenging. Some participants appeared conflicted about their adoption of such roles and what the role signalled about their identity. The next chapter discusses the meaning of my collective findings in relation to theory and practice.

Chapter 11: Discussion

11.1 Introduction

This chapter aims to interpret the significance of the findings of the study. It is presented as three parts. Part one provides a brief summary of the overall research findings in relation to the research questions. Part two discusses the significance of the findings to theory. Finally, part three discusses the implications of the findings to practice.

PART ONE- OVERVIEW OF FINDINGS

11.2 Summary of Findings relating to Maternal Perceptions of their Role

Both the parent survey and [IPA](#) study suggest that many parents enter therapy with loosely defined expectations of a therapy role that encompasses broad domains rather than specific behaviours and attitudes. Parents appear aware of the loose nature of their early expectations and anticipate some degree of role learning in their early experiences. Their initial expectations are largely based on their expected involvement in therapy implementation rather than other domains, such as decision-making. These early expectations of the parent role in implementation are primarily based on a therapist-led, direct intervention context. Two broad categories of the implementer role were depicted in the [IPA](#) study. The first, the “Apprentice Builder” (p214 – 230) captured participants’ experiences as implementers in the context of feeling supported by professionals. This role most often related to the experience of the child and/ or parent being seen for therapy sessions. The role was understood to involve hard work, involvement during and between therapy sessions and an openness to learning how to “build” their child’s communication at home with direction and guidance from therapists. The accounts of participants in this study pointed to a perception of this implementer role as one involving shared

responsibility with clinicians. The behaviours associated with the “Apprentice Builder” role are similar to those described in Parent as Therapist Aide models and have been depicted in a number of other studies investigating the parent role in therapies (e.g., Skeat & Roddam, 2019). Participants in this study also understood their involvement in this role to include a responsibility for engaging their child in the therapy process through a variety of means. These included adopting an excited and interested attitude about their child’s performance, managing their child’s attention and behaviour and sometimes giving feedback to clinicians about how best to engage their child. This aspect of the role has seldom been discussed in parent studies in the literature, but is similar to a parent role described by therapists in a study by Melvin et al. (2020) which was attributed to the maintenance of motivation in therapy.

The second implementer role was depicted in the theme of “Manager-Therapist-Mother” (p231 – 253). While the available literature suggests that parents are sometimes referred to as co-therapists (e.g., Maclean & Chesson, 1991) or therapists (Burrell & Borrego, 2012) in research studies, these terms are distinct to the “Manager-Therapist-Mother” role. Smith and Samuels (2021) equate the co-therapist and therapist roles with the “Adaptor” role described by Davies et al. (2017), and depict it as parents taking a lead role in the implementation of therapy, including the design of how to implement therapy at home. It is typically described in the context of access to professional support, and alludes to parents choosing this role and feeling confident about their choice. In contrast, a key characteristic of the “Manager-Therapist-Mother” role depicted by the [IPA](#) participants was that it was a role they felt compelled to take with limited or no professional support. The [SLT](#)-survey results suggest that many parents in Ireland may experience times of no access, loss of access or limited access to services. This is keeping with the findings by Roddy and O’Neil (2020) that a high number of families of children on the autism spectrum

report unmet therapy needs. In this context of perceived limited support, most mothers in the [IPA](#) study described feeling compelled to enact a hyper-active, professional-type implementation role.

This “Manager-Therapist-Mother” role was understood by parents to encompass attempting to act as case-managers and multiple “*therapists*” without the support or necessary resources and skills. A number of other studies involving parents of children with autism have found that parents depict themselves as case-managers (e.g., Nicholas et al., 2016) and therapists (e.g., Stošić et al., 2020). Lin (2019) conducted an ethnographic study based in China and contended that many clinicians encourage parents to act as “therapists” for their children, with little consideration of the feasibility and consequences of such professionalisation of the parent role for the parents and families involved. Indeed, the “Manager-Therapist-Mother” role in this study was depicted as an isolating experience, involving high personal costs, particularly in relation to how individuals identified as mothers. A qualitative study by Stošić et al (2020), involving parents of children on the autism spectrum, described how acting as their child’s “therapist” was understood by parents to impact on family life and parent roles. Stošić et al. (2020, p. 212), quoted one father as saying, “We have to make time to be parents as well. We need to be parents as well. But I have a feeling, if I am more a parent to him, if I don’t educate him, I am losing time. And that means always forcing something.” This intimates that the motivation to adopt professional roles may be influenced to some degree by a perception of time pressure or a belief that there is a “*window of learning*” (Gloria) that must be maximised and as such waiting for services to commence or recommence is not perceived as an option. Other studies (Hoogsteen & Woodgate, 2013; Nicholas et al., 2020; Safe et al., 2012) discuss the challenges of enacting the therapist role in the context of the multiple other roles and demands placed on parents’ time and resources. In line with

the findings of these studies, the current study concludes that parents' perceptions of the importance and volume of work involved in the therapist role were such that they gave rise to continued attempts to fulfil the therapist role, despite feelings of stress, guilt and inadequacy. These challenges are discussed in greater detail below in the sections relating to role overload and role conflict.

The final role depicted in this study relates to advocacy. Boshoff et al. (2016, p. 42) argue that advocacy is a broad, multi-faceted construct that involves a parent "being a voice for the child" and promoting the child and family's "welfare, well-being and rights," in a variety of different ways. In keeping with this conceptualisation, two different forms of advocacy were identified in this study- "offensive" (p297 – 300) and "defensive" (p296-297) game-playing with services and professionals. "Offensive" game-playing involved parents incorporating behaviours and attitudes when interacting with services and professionals, designed to seek new or enhanced services for their child. It included formal and informal efforts to seek services, as well as efforts to raise their concerns about existing services with a view to accessing a change in service delivery. This "offensive" form of advocacy is similar to much of the advocacy described in the available [SLT](#) and autism literature. Parental involvement in advocacy is largely depicted as recognising and acting on concerns about a child's development by seeking advice, support and services (e.g., Glogowska & Campbell, 2004). To my knowledge, no other studies in [SLT](#) or autism have reported on the second form of advocacy found in this study. This "defensive" strand of advocacy involved incorporating "defensive" game-playing type behaviours and attitudes into interactions with professionals and services. While Davies et al. (2017) presented advocacy as involving parents making judgements about advice received, the defensive advocacy in this study involved monitoring and evaluating services provided to ensure that promised actions had been completed, as well as being strategic with

information sharing and how and why parents communicated with professionals and services. This defensive advocacy was motivated by a desire to protect existing service levels and quality and a perception by participants of having being “*let down*” (Helen, Marian, Mila) by services and professionals in the past.

11.3 Summary of Maternal Sense-Making of their Role

This study’s findings align with the limited available research on parent involvement in interventions, and indicate that mothers’ constructs of their role in [SLT](#) are complex, shaped by intrinsic and extrinsic factors. The study found that parents’ understandings of [SLT](#) (p192 – 205) were influential to their role constructions. A small number of other studies have drawn similar conclusions. For example, parents’ explanatory models of communication disorders and therapy (Marshall et al., 2007), as well as their expectations of therapy and roles (Levickis et al., 2020) are argued to influence parental engagement and participation in therapy. However, the study also found that understandings and expectations of autism (p179 – 192) impacted on maternal role constructions. In the context of autism, parents enter into therapy relationships with a weight of concerns which extend far beyond their child’s communication development alone. The mothers studied held fears about the meaning of autism for their child, themselves, other family members and their family as a unit. These fears related to current and future contexts (social, emotional, academic, financial, family dynamics, and pragmatic concerns such as the child’s school placement, ability to live as an independent adult). This finding aligns with the consensus in the literature that parents’ emotional adjustment to autism can influence how they engage with services (e.g., Gentles et al., 2019). The current study also concluded that parents’ perceptions of the support provided by services and professionals may mediate parental role constructions. A number of studies have found that parents cite therapists’ and the therapeutic relationships as influential to their involvement in therapy.

For example, a qualitative evidence synthesis by O'Toole et al. (2021) concluded that there was evidence that parents understand therapists' interpersonal skills and the therapeutic relationship to influence their engagement in parent-mediated interventions. The impact of services on parental roles in therapy has received less attention. Service factors are more commonly discussed in relation to parental satisfaction with intervention (Corcoran et al., 2015). However, Klatte et al. (2020) argue that service factors may influence parents' involvement in collaborating with therapists to design and implement intervention. Additionally, parental frustrations with services are often depicted as the motivation for parental involvement in advocacy (Boshoff et al., 2016). Todd and Jones (2003) also found that experiences of parent-professional conflict may contribute to parents' anticipating conflict in future relationships involving different professionals. Indeed, the findings of the current study highlight how parents' prior experiences and interactions with professionals and services may influence role construction and contribute to the inclusion of defensive and offensive behaviours and attitudes within their role.

PART TWO- LOCATING THE THESIS IN THEORY

This thesis was born out of my curiosity about roles. It is perhaps therefore unsurprising that its findings offer insights that potentially illuminate theories of role construction. My second research question related to how parents made sense of their role in [SLT](#). The findings that addressed this question led to the development of four conclusions that shifted how I understood and interpreted Role Theory and in turn clinical practices that support role construction.

- 1) The [IPA](#) analysis suggested that mothers' role constructions developed out of their interactions with professionals, but were also influenced by the organization and delivery of services, supporting a blended Role Theory approach to role construction.

- 2) In keeping with Role Theory, expectations influenced mothers' role constructions, however these expectations were encapsulated into more general understandings and contained both cognitive and emotional dimensions.
- 3) Prior experiences, particularly negative experiences, impacted on both the roles constructed and the process of future role constructions for the mothers involved, yet prior experience is not presented as a significant factor in existing theories of role construction.
- 4) Mothers constructed and enacted roles within the context of other roles in their lives. While the interaction of roles is acknowledged in discussions of role strain (e.g., Goode, 1960), individuals' broader repertoires of roles are seldom included as contributory factors in existing theories of role construction.

These conclusions contributed to the development of a model of the role construction process as it related to the particular [IPA](#) participants in this study. The model draws on Katz and Kahn's (1978) Role Episode Model (discussed in Chapter 3) and is presented visually below (see Figure 11.1). An overview of how the study's findings relate to the existing model is first discussed, before presenting an in-depth discussion of three factors that significantly differ from the original model.

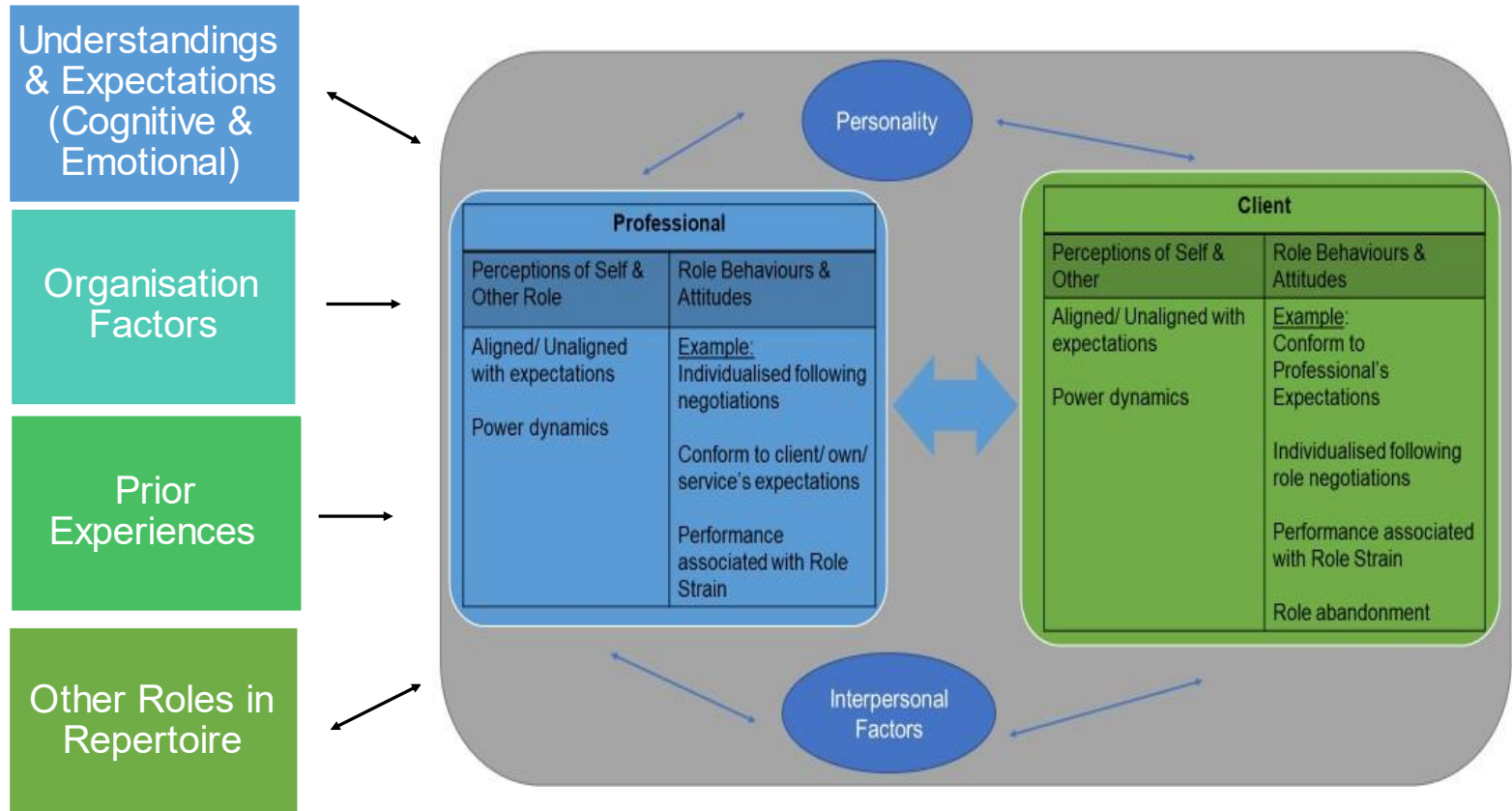


Figure 11.1 Model of Role Construction Process for IPA Participants, based on Katz and Kahn's (1978) Role Episode Model.

11.4 An Overview of the Model

The model shown above represents a blended situation-specific Role Theory model. It is situation specific in that it refers to the role construction process of the [IPA](#) participants in this study. My epistemological position cautions against claims of generalisation to other populations, but allows consideration of the potential for “theoretical transferability” (Smith et al., 2009, p51) when the findings of an in-depth, high-quality study are considered in the wider context of the extant literature.” My model represents a blended model as it includes aspects of both Structural and Interactional Role Theory approaches. It is based on Katz and Kahn’s (1978) Role Episode Model (discussed in Chapter 3), which appeared compatible with my findings as it recognises the service organisation, the interaction within the individuals in the role pair, as well as the relationship between these individuals, as important factors in role construction. This position aligns with Klatte et al. (2020), who contend that parental involvement is mediated by factors intrinsic to the parent, as well as factors relating to the therapist and service. Katz and Kahn’s original model is shown in Figure 11.2 below.

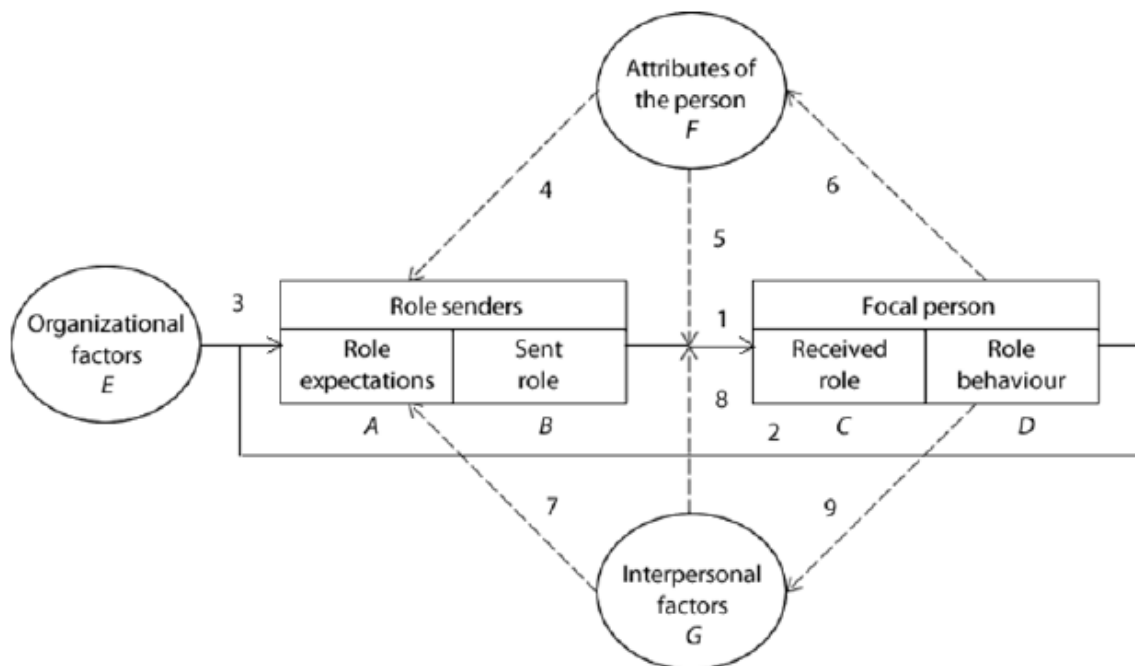


Figure 11.2 Katz and Kahn's Role Episode Model (1978, p 196).

Similar to Katz and Kahn's (1978) model, my model positions role construction as occurring through the interactions of a role pair. This interaction part of the process is surrounded in grey in my model. Katz and Kahn suggested that roles are learned through reinforcement rather than negotiation. Their model proposes that role learning is directed by the figure with more power in the role pair (role sender). The behaviours of the role sender act to reinforce role conformity in their role counterpart (focal person). In a successful role learning experience, the focal person will continually make shifts in their role conception and enactment until they interpret the role sender to be satisfied with their role enactment. Katz and Kahn signal this by using a one-way arrow between the parties. They acknowledge that the focal person will influence the role sender's role conceptions and enactments too, but consider the focal person's influence as minor and occurring indirectly via personality attributes and how they relate to the role sender, rather than through negotiations about the content of their role.

I have adopted the stance of Interactional Role Theory that both parties involved react to one another, shaping each other's role constructions directly, and with each party holding the potential to trigger shifts in the other's role conceptions and enactments. The accounts of participants in this study suggest that initially they expected to have a role in therapy without any firm definitions of what that role would involve (p196 – 197). Their interactions with therapists helped to shape both their understanding and enactments of their roles. Other authors (Reeder & Morris, 2020; Watts-Pappas et al., 2016) have similarly concluded that professionals shape, to varying degrees, the roles enacted by parents. While this study focused only on parents, their accounts intimate that at least on occasion, they may have influenced the role taken by therapists. For example, Helen discussed negotiating with therapists that she should sit outside therapy sessions, reportedly resulting in a shift, with therapists then incorporating the provision of feedback about both the content of sessions, as well as her son's performance in the session into their role. Indeed, my own clinical experience suggests that how I enact my role is informed to varying degrees by how I perceive parents to act towards me and respond to my interactions, as well as my interpretations of their understandings of our mutual roles.

Katz and Kahn's (1978) discussion of their model emphasised that when interacting, each party in the role pair appraises how well the roles being presented align with their expectations. My study found evidence of the importance of expectations (discussed in greater detail below) and that parents evaluated their experiences partly in terms of how well their expectations were met (p197). However, the findings also suggest that perceptions of power, may be influential. In their discussion of their model, Katz and Kahn emphasise that power is significant and that hierarchies exist within organisations that impact on role learning. Their graphical representation of their model does not however include any reference to power. I also propose that power may influence role constructions in the context of many

professions, including but not limited to [SLT](#). I interpret the significance of power to stem from how the individuals involved perceive the power balance, rather than how the organisation depicts the power hierarchy. The participants in this study demonstrated a willingness to be flexible at times and to adopt roles disparate to their initial, albeit loose, expectations, for example by taking part in parent-mediated interventions. Some of this flexibility appeared to stem from perceptions of power. All of the [IPA](#) participants perceived therapists as “*experts*” who held power via access to their skill-set and ability to offer specialised, novel “*external help*” (Helen) that parents could not provide independently. This appeared to be a factor in parents’ attempts to enact unexpected roles. When discussing such roles, participants evaluated them in terms of their acceptability and feasibility, however many participants continued to attempt to enact roles that they were dissatisfied with or felt they could not enact well. Some participants reported that they had no choice but “*to go with it*” (publicly-funded therapy) until they could “*afford*” (Mel) to access private interventions, which they perceived themselves to have greater power over.

While not apparent in the findings of this study, I have chosen to retain Katz and Kahn’s (1978) inclusion of personality (labelled “attributes” by Katz and Kahn) as a factor influential to the interaction process. It appears reasonable to assume that different individuals have different personalities, some of which are more compatible with working with one another than others and thus this may influence the interaction which underpins the role construction process. Another important factor proposed by Katz and Kahn relates to interpersonal factors. This encapsulates the interpersonal dynamics of the relationship between the parties involved. The available literature intimates that a supportive therapeutic relationship may impact on the roles enacted by clients, with studies suggesting an association between the therapeutic relationship and behavioural indicators of parental empowerment in intervention (Reeder & Morris, 2020) and client engagement (Melvin et al., 2019). Evidence of the influence of

interpersonal factors on role constructions was also found in this study. As discussed in the theme of “A Game of Survival,” participants’ accounts suggested that they evaluated their interactions with therapists and made judgments about therapists’ affect, communication, interest, commitment, and reliability (p272 – 282). These different domains were perceived to act as supports or barriers to their participation in therapy.

Finally, owing to its Structural Role Theory roots, Katz and Kahn’s (1978) original model emphasises the influence of the organisation on role constructions. While I do not agree that organisations dictate parent’s role constructions in their entirety, the findings of this study suggest that service organisations can be highly influential to the roles enacted by parents. Other authors (e.g., Klatte et al., 2020) have concluded that services can influence how parents are involved in intervention. The Manager-Therapist-Mother theme in this study depicts how participants perceived themselves as compelled to adopt certain roles partly because of factors relating to the service organisation (p241). Participants’ relationships with services were found to impact on their relationships and interactions with therapists, and contributed to the incorporation of defensive and offensive behaviours and attitudes into participants’ role constructs (p296 – 300). The [SLT](#) survey study (p160 – 165) also indicates that service’s policies and pathways of care can sometimes restrict the role taken by parents, for example in relation to decision-making regarding discharge. Also of note, the survey results suggest that organisations can impact on the [SLT](#) role. For example, the survey found that one third of the therapists sampled report that their autonomy to make decisions about implementing care pathways flexibly was constrained to some degree by service factors. Thus, the findings support conceptualising the service organisation as an influential factor for role constructions for both parties.

The study also points to the significance of three other factors in role construction, two of which are not included in Katz and Kahn’s original model (“Prior

Experiences” and “Other Roles”) and one which represents an expansion and reconfiguration on the original model (“Understandings and Expectations – Both Cognitive and Emotional). These factors are discussed below.

11.5 Understandings and Expectations- Both Cognitive and Emotional

The study’s findings match the general consensus common across Role Theories that expectations are influential to role construction (Stryker, 2001). Biddle (1979) argues that expectations may take many different forms, including norms, beliefs and preferences. Framing expectations in this manner captures their cognitive dimension only. This is the approach adopted in Katz and Kahn’s (1978) Role Episode Model. This cognitive based conceptualisation suggests that norms, beliefs and preferences regarding the role alone are important. I have chosen to broaden the terminology used to also include understandings. Broadening this construct captures the wider context from which expectations may arise. For example, how the [IPA](#) participants understood autism both informed their hopes and expectations of therapy and their roles in it, and also their ability to participate. Additionally, including the term understandings expands the construct to recognise the role of both emotion and cognition in informing role constructions. The traditional conceptualisation (e.g., Biddle, 1979) of expectations is typically limited to cognitive processes.

The theme of “Understandings and Expectations of Autism” (p179 – 192) suggests that fear can characterize parental understandings of autism. The fears depicted included concerns about the current impact of autism on the child’s overall development, on other family members and on the family as a whole, as well as the future potential impact of autism. Shifting perspectives of the meaning of autism in this study appeared connected to shifting levels of fear. Many participants viewed autism as something to be greatly feared at the time of their child’s diagnosis. Some participants indicated a lessening of their fear of autism in the context of their specific child over time. This lessening of fear was most apparent in those parents who appeared to co-

exist with, rather than work “*against the autism*” (Marian). However, lessening or managing fear required much work and effort on the part of the parents involved. Levels of fear appeared to connect with parents’ motivation to access and be involved in therapy. High levels of fear were associated with high levels of motivation to access therapy in this study. The potential relationship between fear and levels of motivation for participation in therapy or performing a role in therapy was similarly connected, but had a threshold. Some participants’ accounts suggested current or historical understandings of autism as a severely frightening entity. This fear overwhelmed and “*consume[d]*” (Mel) some participants to such a degree that they reported limiting rather than increasing their participation in therapy during these times. Thus, parents may engage in SLT carrying fears which can act to either mobilise or impede their capacity to partake in therapy. Whether present as a mobilizing force or an impediment, parents expend time and energy managing or responding to this fear. This potentially impacts their available resources when engaging in therapy. Understandings and expectations of [SLT](#) (p192 – 205) also involved an emotional dimension. While understandings and expectations of [SLT](#) were loosely defined, participants held more concrete conceptions of therapists as experts with the knowledge to oversee the provision of specialist intervention different to anything implemented by parents alone. These more concrete thoughts and beliefs about therapy involved a hopeful stance that therapy and therapists represented an opportunity for a “better” future. Thus, in the context of this study, the significance of understandings and expectations to parental role construction related to both the cognitive and emotional dimensions of these understandings and expectations.

While the significance I place on the emotional dimension of understanding and expectations may be unusual in the context of the Role Theory literature, emotions are commonly discussed in the Health Behaviour literature with its associated interest in the behaviours enacted by clients. Kiviniemia et al. (2018) note that early core work

and theories relating to the field of Health Behaviour focused largely on cognition, rather than emotion, but shifts began to occur in the last two decades. Contemporary theories of health behaviours (e.g., Fishbein et al., 2001) recognise the potential role of emotion in performing health behaviours, albeit often framed in terms of the emotional reactions to the behaviour rather than the diagnosis or disorder. Indeed, in relation to autism, there is evidence of a relationship between parental emotional adjustment to autism and parental engagement in therapy (e.g., Gentles et al., 2019). If one takes the stance that theories of Health Behaviour may offer insight into how the client role is performed, then the growing body of researchers (e.g., Ferrer & Mendes, 2018) in this area who argue and present evidence for the role of emotion in the performance of health behaviours provide further encouragement for Role Theorists to re-examine how they perceive and represent understandings and expectations going forward.

11.6 Prior Experiences

Interactional Role Theory recognises the dynamic nature of roles and proposes that role constructions are continually shaped through the interactions of the individuals in the role pair (Stryker, 2001). While positive interactions are assumed to contribute to role constructions that are mutually respected by each individual in the role pair, negative interactions may also impact on how individuals construct roles (Sluss et al., 2011). The current study also points to the dynamic nature of role constructions and the influence of interactions on role construction and performance. However, the study suggests that both historical and contemporary interactions may be influential to role construction.

It seems logical that if an individual has prior experience of performing a role this will inform his or her understandings and expectations of this role and thus influence future performances of the role. Indeed, Klatte et al. (2020) cite parents' prior experiences of intervention as a likely factor in how parents engage in collaboration with therapists. The IPA participants drew from their experiences with a range of allied

health professionals to respond to questions specifically about SLT, suggesting that prior experiences with other therapists and psychologists etc., may influence how parents make sense of their role in [SLT](#) and vice versa. The theme of “A Game of Survival” (p263 – 301) illustrates how parental role construction may evolve in response to prior experiences with services and prior experiences of role enactment involving other professionals. This theme also points to the potential superior potency of negative prior experiences, a conclusion indirectly supported by the literature regarding the negativity bias. It seems unlikely that prior negative experiences impact uniquely on role construction in relation to SLT, but instead may have more general impact.

Negativity Bias

The negativity bias proposes that humankind is predisposed to recognise negative events or information and evaluate these events or information as more powerful than positive ones (Lazarus, 2021). Baumeister et al.'s (2001, p. 325) seminal paper relating to the negativity bias summarises its impact as “bad things will produce larger, more consistent, more multifaceted, or more lasting effects than good things.” A plethora of studies dating from the 1970's to the current date provide evidence for the influence of negativity bias on attention, behaviour, memory and decision-making among other areas (Norris, 2021). Studies (e.g. Brickman et al., 1978; Kahneman & Tversky, 2000) suggest that negatively perceived events are associated with reactions of greater intensity and duration than positively perceived events. Furthermore, there is some evidence that how individuals perceive collective groups is more susceptible to influence from negative, rather than positive, encounters with individual members of these groups (e.g., Li, Ren, and Luo, 2016). While more recent research suggests that the negativity bias represents a tendency rather than a consistent rule (Unkelbach et al., 2020), the general consensus of the available literature accepts the presence of the negativity bias in human psychology.

Indeed, the negativity bias may help to explain the finding of the current study that prior negative experiences appeared particularly powerful and meaningful to participants' role constructions. All participants reported both positive and negative experiences, yet negative experiences were discussed at greater length and were typically discussed spontaneously. Some of the negative encounters recounted had occurred many years ago, yet were sometimes depicted with great detail. Participants typically appeared less aware and to have reflected less on the role they adopted in the context of positive experiences. It is plausible that positive experiences more closely aligned with parental expectations of therapy and therapy roles and thus triggered less reflection.

Prior Negative Experiences Contribute to Ongoing Mistrust

The findings of this study suggest that historical negative experiences, even those involving different individuals from different professional backgrounds, can sometimes contribute to a persistent mistrust that impacts on contemporary interactions with professionals. The theme "A Game of Survival" (p282 – 294) illustrates that rather than approaching subsequent relationships from a neutral or trusting position, parents' perceptions of future therapists and therapies were "coloured" (Gayle) by their difficult, past experiences. Participants incorporated offensive and defensive attitudes and behaviours into their subsequent role constructions and entered into new relationships with varying levels of suspicion and mistrust.

This experience of mistrust is in keeping with the available literature. In relation to developmental disabilities, Todd and Jones (2003) found that experiences of parent-professional conflict can lead some parents to predict that future relationships with unrelated professionals will also be challenging. More generally, there is some evidence (e.g., Williamson et al., 2019) that prior personal and/ or vicarious negative experiences, including those depicted in the media, with healthcare workers and services can contribute to a phenomenon referred to as medical mistrust. Medical

mistrust is defined as a position of generalised suspicion of healthcare systems, services and professionals (Jaiswal, 2019). It is associated with lower utilisation and satisfaction with healthcare (e.g., LaVeist et al., 2009), and lower levels of engagement in preventative interventions, such as vaccines (e.g., Yu et al., 2021), as well as in medical treatments (D'Avanzo et al., 2019).

Heightened Sensitivity to Multiple Roles of the Role Counterpart

Existing theories of role theory posit that role construction involves two parties relating to one another in a single capacity, or a single, simple role pair, for example parent to [SLT](#) (Stryker, 2001). In this study, participants perceived the actions and attitudes of services, as well as professionals in general, as informative to their understandings and expectations of other therapists going forward. This may suggest that negative experiences can heighten parents' sensitivity to the other roles held by therapists, such as employee or colleague to other team members. This heightened sensitivity may add to the complexity of parents' role construction efforts when entering into new therapeutic relationships.

Turner (1978) proposes a number of principles which direct how an individual perceives the other person in their role pair. One of these principles appears particularly relevant in the context of this research. The "appearance principle" states that "in the absence of contradictory cues, people tend to accept others as they appear," (Turner, 1978, p. 6). This suggests that in straight forward circumstances, individuals tend to accept the other person in the assigned role. However, when the term "contradictory cues" is considered further, it indicates that in more complex circumstances, an individual may not automatically accept the other person to be performing the role designated in the role pair. Contradictory cues may signal that a person is present in a different capacity or not capable of adopting the designated role for different reasons. I hypothesise that following prior negative experiences, some parents may enter into new therapeutic relationships, even those involving different

fields of practice, with an increased awareness of the multiple, potentially conflicting, roles held by therapists. This heightened sensitivity may amplify parents' observations of potential "contradictory cues" challenging their ability to simply accept the next therapist in the capacity of therapist. Rather than relating to the therapist in a single role capacity, the parent may perceive the therapist to represent multiple roles simultaneously.

Indeed, therapists do hold multiple roles simultaneously. For example, an [SLT](#) may hold the roles of therapist to an individual client, therapist to a particular caseload, an employee of a service and a member of a regulated profession. While, it appears reasonable to assume that common to all of these roles is the motivation to help clients and their families, the roles also entail conflicting responsibilities. For instance, an [SLT](#) has a responsibility to all of the clients on their caseload and will often have to engage in difficult decision-making regarding who to prioritise and how to allocate their time most efficiently. The [IPA](#) participants' accounts point to an awareness of this conflict (p277 – 278). They depicted the multiple pulls on therapists' time and focus, with their references to therapists' communicating an attitude of "*I'm too busy*" (Gloria) in their interactions with families.

I hypothesise that following prior negative experiences, parents may enter new therapeutic relationships from a position of suspicion about what role is most influential to the therapist's decision-making and interactions with them. Parents may approach new relationships by attempting to decipher which role is dominant in informing how the therapist will engage with them, and what this means for their own role construction (see Figure 11.3 above).

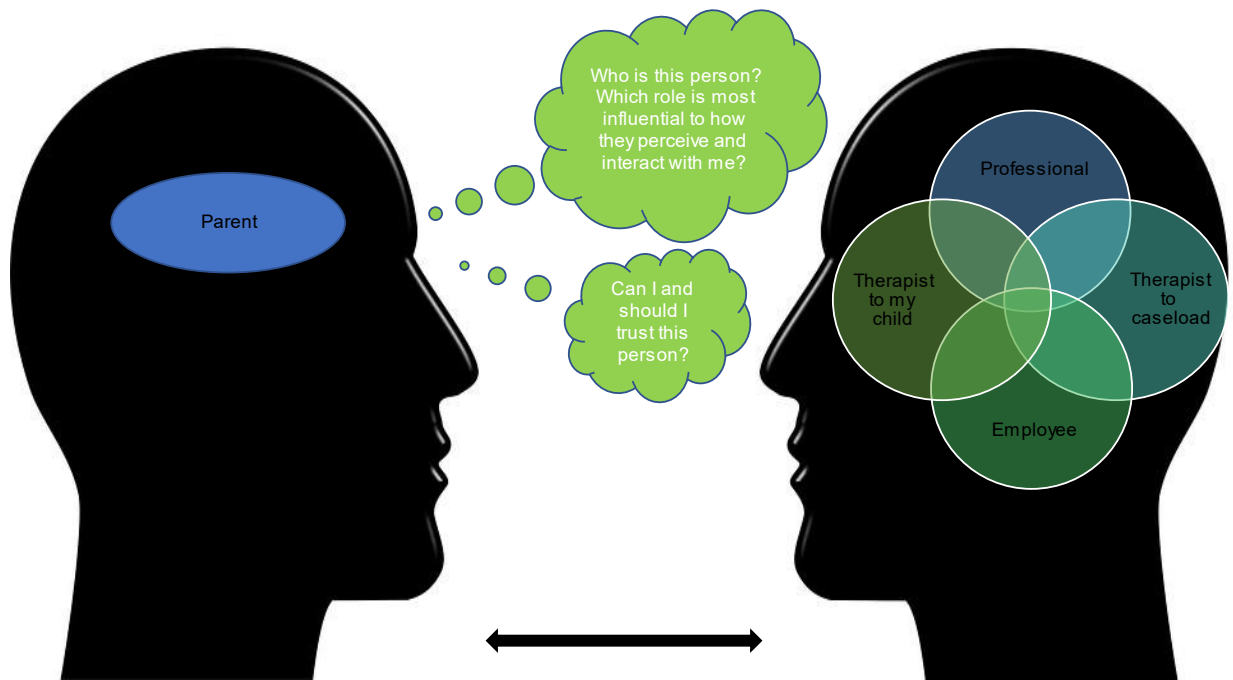


Figure 11.3 Graphic representing my hypothesised process of role construction when challenged by prior negative experiences with others.

Forgiveness and Role Construction with ‘Indirect’ Transgressors

The hypothesis that following prior negative experiences, clients may have heightened sensitivity of the multiple roles held by professionals, may offer an enriched understandings of medical mistrust by examining it from a different perspective; forgiveness. If we accept that following difficult encounters with services and other professionals, clients may relate to future professionals as both a therapist and an employee or representative of the “offending” service, then it appears reasonable that the client may hold the therapist to account, to varying degrees, for perceived unresolved grievances connected to the service. Sullivan (2020) notes that professionals tend to rely on demonstrations of caring and competence to gain trust, but that this may not be sufficient to facilitate a transition from mistrust to trust in patients. Theory and research relating to forgiveness may offer some insight into how to manage the experiences of mistrust depicted in this study.

Worthington (2003) describes two related categories of forgiveness. Decisional forgiveness involves a positive change in the thoughts and intentions underpinning one's behaviours towards their transgressor (Worthington, 2003). Emotional forgiveness involves the process of replacing negative emotions relating to the unforgiveness with neutral feelings, and eventually positive emotions (Worthington, 2003). Forgiveness is relevant to situations where an individual perceives a wrongdoing to have occurred towards them but understands there to be an injustice gap, relating to "the degree to which victims of an offense perceive that the aftermath of that offense is falling short of ideal justice," (Davis et al., 2016, p. 175). While forgiveness is commonly discussed in the literature in relation to individuals in relationships or between communities, Carroll (2004) notes that forgiveness can also apply to organisations.

Forgiveness can involve to a multitude of different situations, including those in which the wrongdoing is perceived to be intentional or unintentional (Hill et al., 2005), and situations in which any wrongdoing in question can be justified by the transgressor (e.g., Schröder et al., 2017). For example, Schröder et al. studied the application of forgiveness in relation to midwives and obstetricians involved in child-birth experiences in which lives were lost or permanent disability caused, but where the actions involved were medically justified. Forgiveness in the context of arguably justifiable actions may be particularly relevant to healthcare organisations. Healthcare organisations can adopt policies and procedures designed to make services more equitable across families and more accountable to taxpayers by delivering services that are cost-effective. However, as demonstrated by the findings of this study, such policies and procedures can sometimes be perceived as uncaring and harmful to some of the individuals involved. The sub-theme of "Therapy is a Precious Commodity Guarded by Individual Services" (p268 – 272), in particular, illustrated this. For example, this sub-theme involved participants' perceptions that services employed certain models, such as group

therapy, to protect resources by providing a “diluted” form of therapy to a greater number of children. Some participants viewed their experiences of group therapy as ineffective, and understood it as harmful as it redirected energy and time away from other more helpful therapies or activities. However, group therapy could be presented as a justifiable effort by a service to serve the common good. Group interventions can act as a cost-effective means to provide intervention to more clients and many are supported by research. This suggests that a service’s use of groups could be considered justifiable at times, particularly if applied with flexibility. However, determining suitability for groups can involve a process of trial and error, in which some clients may understand themselves to incur costs and thus hold services to account. Forgiveness may thus be applicable in such a context.

Vogus et al. (2020) note that healthcare organisations may be hesitant to seek forgiveness due to fears of litigation and admissions of liability. However, there is some evidence (e.g., Lambert et al., 2016) that open communication and efforts to actively seek resolution, rather than adopting a defensive stance, are associated with reduced legal costs, better patient outcomes and experiences and greater learning from error. Some of the resistance to seeking forgiveness in healthcare organisations may stem from factors relating to healthcare workers’ self-image and self-concept (Robbennolt, 2009). In her discussion of physicians and apologies, Robbennolt suggests that physicians inherently identify as “healers” and “helpers.” Apologizing may trigger cognitive dissonance, as these same “healers” and “helpers” must accept that they have, or are part of an organisation which has, caused harm. Nonetheless, while perhaps particularly challenging in the context of organisations, Carroll argues that meaningful efforts to seek forgiveness can be beneficial to both the individual involved and the organisation.

Fostering Forgiveness

Despite forgiveness being studied for many decades, I found no empirical studies exploring forgiveness in a context in of “indirect” transgressors, such as an associated member or employee of the offending organisation. However, it appears reasonable that some of the findings in the existing body of research may be extrapolated to the context of “indirect” transgressors. There is emerging evidence (e.g., Witvliet, Root Luna, et al., 2020) supporting the influence of sincere apologies on forgiveness. Two meta-analyses (Fehr et al., 2010; Riek & Mania, 2012) found that receiving a sincere apology was strongly correlated with forgiveness. Witvliet et al. (2020) depict sincere apologies as including acknowledgments of the wrongdoing, accepting responsibility, communicating remorse and providing reassurance that the wrongdoing will not be repeated. Meeting all such criteria may be both impossible and inappropriate in the context of “indirect” transgressors and healthcare provision in Ireland at present. For example, an apology regarding long waiting times is likely to be insincere if it contains promises that this will not happen again. However, the definition signals the potential benefit of an apology such as, “I’m sorry you’ve had to wait so long to see me. It’s not a good enough excuse but we are understaffed. Other parents tell me the long waits for appointments can feel very lonely and scary. How has it been for you? Is there anything you found helpful while you were waiting that we could signpost other parents to?”

Victims’ feelings of empathy towards their transgressors have also been found to correlate with forgiveness (Fehr et al., 2010; Riek & Mania, 2012). Sullivan (2020, p. 23) presented an approach to managing medical mistrust which she called “comprehension” as a means to promote empathy. Comprehension involves efforts centred on perspective taking aimed at developing an appreciation of how the patient perceives their illness and management, and what experiences and motivations might underpin this. Openly acknowledging mistrust and listening with compassion to

patients' recounts of prior perceived wrong-doings may also aid comprehension. Sullivan notes that how the physician communicates with the patient, for example, using active listening may also facilitate comprehension.

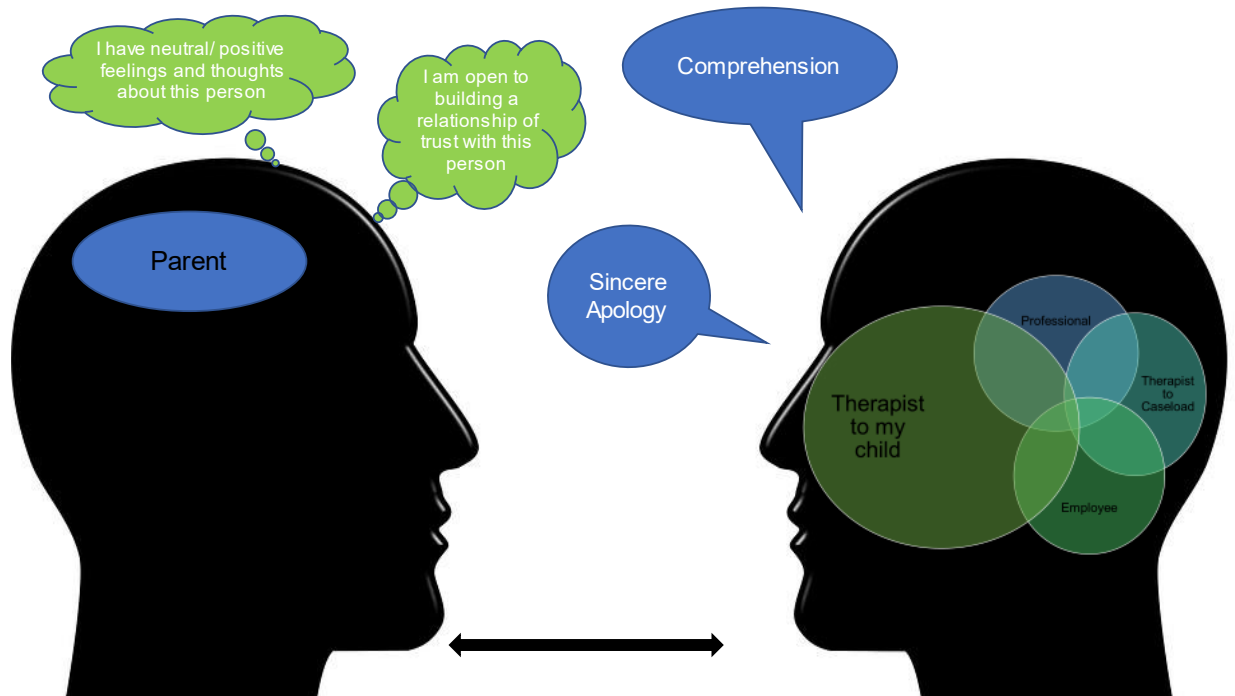


Figure 11.4 Hypothesised impact on role construction process following successful efforts to foster forgiveness.

Theory and research regarding forgiveness has been applied previously to role construction (e.g., Sluss et al., 2011) in the context of role violations occurring within the role pair. I hypothesise that it may also be applied to role constructions that occur in the context of prior negative experiences with different individuals. While untested in the current study, I cautiously hypothesise that in the case of “indirect” transgressors, successful efforts to foster forgiveness may help to establish a neutral or perhaps positive platform on which to build the therapeutic relationship. “Contradictory cues” (Turner, 1978, p. 6) may reduce in significance or be discarded, as efforts made to seek forgiveness in an empathic manner may present the therapist in a manner consistent with the parent’s expectations of the therapist role (for example, a caring,

trustworthy person.) In forgiving the “indirect” transgressor, the roles that connected this individual to the wrongdoing, such as that of employee, may appear less salient to the role construction process (see Figure 11.4 above). Depending on the magnitude and personal significance of the wrongdoing involved, and the level of forgiveness achieved the victim may continue to relate to the “indirect” transgressor in a multiple role capacity, albeit one in which the other roles are less dominant. Forgiveness may thus simplify the role construction process and allow the parent involved to primarily, if not solely, relate to the therapist in the capacity designated by the role pair.

11.7 Other Roles in One’s Repertoire

The final factor which I include in my model of role construction relates to the repertoire of other roles held by the individual. My findings, as detailed in the themes of “Manager-Therapist-Mother” (p231 – 255) and “A Game of Survival” (p263 – 301), indicate that the other roles held by parents can impact on how they conceive and experience their roles in therapy. With the exception of Mel, all participants’ accounts pointed to experiences of role overload and inter-role conflict, highlighting that their role constructions occurred within a wider, interconnected web of the other roles held by parents.

Role Overload

Role overload is a type of role strain that occurs when an individual has too many demands given the time, energy and resources available to them (Turner, 2001). A number of studies (e.g., Safe et al., 2012) of parents of children with autism have found that parents perceive themselves to hold multiple roles and associate this with feelings of stress and guilt. Role overload was evident in the accounts of the [IPA](#) participants in this study. Participants discussed the strain they experienced in attempting to enact the roles associated with their children’s different therapies in addition to the other life roles they held (p231 – 255). All of the participants in this study depicted engaging in therapies while carrying a weight of concerns regarding the present and the future,

their child and the family as a whole. It appears reasonable that these wider concerns may have depleted the time, energy and resources available to them at a time when additional demands were placed on them through their involvement with therapies. The role overload experienced appeared to relate to both an increase in the demands on the parent, coupled with a reduction in their capacity to enact additional and new roles. Gayle referred to feeling required to be “*not just one therapist. You've to be four rolled into one,*” “*on top of everything else.*” Participants appraised what was being asked of them as sometimes impossible, as “*there is only as much you can fit in a day,*” (Mila). The presence of role overload among participants points to the work involved in therapy and is in keeping with the literature relating to burden of treatment (Shippee et al., 2012).

Safe et al. (2012) describe a number of strategies employed by parents to manage multiple roles. These include time management and organisation strategies, as well as reducing the number of demands on time. Participants in the [IPA](#) study demonstrated a number of different strategies. Gayle and Gloria attempted to reduce their therapy workload by renegotiating their role with the professionals involved, albeit unsuccessfully. Many participants attempted to manage role overload by reducing the number of roles held or time spent on other roles. Some participants attempted to reduce the amount of time dedicated to the role of mother, and increase the time spent implementing therapy. Some, like Marian and Helen, chose to leave paid employment. Nicholas et al. (2020) cautions that such strategies may risk isolating parents by reducing their social circles. Safe et al. (2012) concluded that accessing additional formal and informal support may offer a helpful strategy for managing multiple roles. Indeed, all [IPA](#) participants perceived accessing greater frequency of therapy as a means to share their workload with professionals. While the ability to dramatically improve resourcing enough to offer more regular intervention appears unlikely in the near future, the experiences of parents in this study points to the importance of

professionals discussing with parents what they can do outside of offering more appointments to support parents in managing their workloads. For example, better communication between disciplines about scheduling of appointments and the workload that parents are already carrying may help to reduce role overload. While all participants depicted a desire to share their workload more evenly with the professionals involved, only half referenced efforts to share their therapy workload with their spouses. This raises questions about why many of the mothers involved did not appear to perceive increased involvement of their spouses as a solution to reducing their role strain. Participants' accounts suggest that they often rationalised their spouses' level of involvement pragmatically as a consequence of their husband being in full-time employment and the primary source of income for the family. Nonetheless, given the levels of role strain depicted, services may benefit from overtly exploring with families if and how the therapy workload could be shared more between both parents or extended family members, as well as how services could better support families to do so. Furthermore, as the role strain depicted related to perceived increases in demands on parents during a period when their time, energy and resources were lessened by their efforts to adjust to their child's autism diagnosis, role strain may also be managed by addressing parental well-being. This underscores the importance of professionals routinely asking parents about their well-being, signposting parents to existing community supports and education groups, as well as facilitating timely access to counselling and mental health supports as needed.

Role Conflict

Some of these efforts to manage role overload contributed to an experience of inter-role conflict. This occurs when an individual holds two or more roles whose values are incongruent and the enactment of one causes strain in the enactment of another (Turner, 2001). For example, some participants appeared to question their abilities as mothers, discussing how by prioritising time spent doing therapy tasks at home or

advocating for more services, they had less time to dedicate to their mother-child relationships. Other incidences of role conflict appeared to arise simply through the enactment rather than prioritisation of the therapy-mother role. For example, Helen and Mila depicted how their experience of having to do “*formal sit down[s]*” with their children as part of their therapy roles caused tension at times with how they identified as mothers, with Mila describing herself as the “*bad cop*” parent because of this. Gloria also vividly depicted how in enacting her therapy roles, her role as a mother changed, shifting her perception of her parenting role to one in which “*there’s always an agenda,*” and she “*can’t just sit down and play with*” her son. These findings relating to role conflict are in keeping with a small number of other studies (e.g., Brady et al., 2006) which suggests that involvement in interventions for children with developmental disabilities can sometimes be experienced as threatening to parental identities. As discussed previously (p9 - 10), the social communication challenges associated with autism may contribute to heightened parental sensitivities about one’s ability to parent and relate to one’s child on the autism spectrum (Del Bianco et al., 2018; Taylor et al., 2021). Thus, it seems reasonable to assume that mothers may enter SLT already questioning or feeling sensitive about their maternal identities and hoping that SLT will help them to communicate and relate more easily with their child. However, in enacting their role as implementers, rather than gaining confidence and security in one’s identity, some mothers may experience additional threats to their maternal identities and further question their ability to relate with their children.

Participants attempted to reconcile these role conflicts in different ways. Some participants appeared to conduct a costs-benefit analysis, judging the prioritisation of their therapy role as more important to their child’s future, and therefore any associated role strain, necessary for the greater good. Others, like Marian, reframed roles, linking performance in one role as evidence of performance in another. While Marian expressed some guilt about her roles in therapy and advocacy, she also perceived her

“*success*” in these roles as providing evidence of her being “*one of the most successful parents.*” Helen adopted a different approach and referred to “*compartmentalising*” her roles. Indeed, compartmentalization has long been suggested as an adaptive strategy to manage role strain by restricting roles to specific locations, situations or contexts (Goode, 1960). However, some participants’ perceptions of their therapy role were not conducive to compartmentalisation. Gloria understood therapists to expect her to build her son’s communication and cognitive and motor skills “*all the time,*” by incorporating naturalistic strategies across all daily activities. This conception hindered her ability to reduce role strain through compartmentalisation, and also perpetuated role strain, as *any* missed opportunity to build her son’s skills represented a failure in her role. Gloria’s case highlights the need for professionals to review with parents the perceived costs and benefits of the therapy. Such a discussion may have facilitated clinicians to encourage Gloria to adopt a more compartmentalised approach to her role by, for example, agreeing that Gloria would attempt to use strategies only in specific activities.

Empirical studies of the impact of role strain commonly relate to roles associated with work and home life and suggest that role strain can impact on well-being and mental health, as well as on role satisfaction (e.g., Glynn et al., 2009). The findings of this study serve as a reminder that therapy may cause harm through role strain, and that when agreeing therapy roles, both the costs and the benefits for the family and the child should be considered and reviewed in discussions between all stakeholders. They point to the importance of services and professionals interrogating the appropriacy and feasibility of the role being asked or taken by parents. As Demain et al. (2015) argue, if a treatment acts in a similar manner to a disease or disorder, causing problems that curtail people from living their life and being who they want to be, then the treatment can become as burdensome as the disorder. I found the participant accounts depicting role conflict and its impact on their self-conceptualisations as mothers particularly troubling. Communication is about

connection. If therapy is damaging rather than helping people build connections, then the costs may be too high and the overall purpose of therapy lost.

Sousa (2008) found that contemporary discourse of mothers of children with disabilities presents these mothers as warriors and heroes. Nicholas et al. (2020) cautions that such discourse encourages parents and society to understand mothers of children with disabilities as capable of doing the impossible through the love of their children. Indeed, the theme of “Trying to do the Impossible” in Chapter 9 indicates that parents may perceive themselves to be striving to do the impossible and failing with their therapy roles. Given the evidence for role overload and role conflict in this study, there is an onus on services and professionals to follow the advice of Nicholas et al. and carefully reflect on the ethics underpinning the roles that services and professionals ask, expect or allow parents to adopt.

Role “Spillover”

Both role overload and role conflict are widely accepted in the Role Theory literature, yet are typically discussed in isolation of role construction. Stephens and Franks (1999) represent one exception to this. They argue that bidirectional “spillover” (1999, p. 150) can occur between roles and this “spillover” can be experienced as negative or positive and may be particularly apparent between roles with less defined boundaries. Their research is focused on the experience of women caring for parents in the context of multiple other roles, including employee and wife. Stephens and Franks contend that the quality of the roles in an individual’s role set or repertoire is of greater importance to the lived experience of role enactment than the number of roles a person holds. They suggest that high quality roles may bolster the resources available to an individual via increases in self-esteem, enhanced social network and sometimes increased finances. These additional resources may support an individual in learning or maintaining other more challenging roles. Indeed, this was Gayle’s assessment of the importance of maintaining her career, which she appraised as providing her with “*respite*.” Stephens

and Franks also hypothesise that other roles may be associated with more costs than benefits and act as additional stressors on an individual's available resources. Thus, the strain associated with enacting a particularly challenging role may be felt as amplified, if it occurs in a context of holding other strained roles. This stance points to the worth of existing services such as respite services, and financial supports that facilitate parents to leave paid employment if desired. However, it also suggests the potential value of service development aimed at facilitating parents to remain in roles of personal value to them, including the role of employee. Offering greater flexibility of service provision may support some parents to remain in employment if they wish or need to and may facilitate more sharing of the therapy workload across parents. The risk of role strain associated with parental involvement in therapy, underscores the importance of services and professionals adopting a holistic perspective of the lives of both clients and their families and building an awareness of the multitude of different roles being played by parents.

11.8 Relevance of the Model to other Parent-Professional Relationships

The data from which this model of role construction was derived stemmed from interview questions that asked specifically about participants' experiences of [SLT](#). Yet the responses generated by participants depicting their experiences with a range of allied health professionals ([SLTs](#), psychologists, OTs, and physiotherapists). Parents understood each profession to be distinct and not "*all mis-mashed into one profession*" (Gayle), while also understanding these professions to be related. They considered encounters with other professionals as offering an insight into their experiences with [SLT](#) and vice versa. All of the professions described by participants have a focus on child development and well-being, and are traditionally associated with a power imbalance between an "expert" professional and a "layperson" parent. It seems reasonable that if parents consider all these professions to be similar, then they may engage in a similar sense-making process when navigating their role with these other

professions. It appears logical, for example, that if prior negative experiences with a service are influential to future role construction in the context of [SLT](#), then relationships with other professionals who work for the same service may be similarly affected. Equally, if understandings and expectations of [SLT](#) can influence how mothers approach therapy and relationships in it, then understandings and expectations of psychology, for example, may be influential to how mothers engage with a psychologist. Indeed, the data from the study provides evidence for the relevance of the factor “Other Roles” to mothers’ role constructions in the context of involvement with a range of professionals. This factor stemmed from the theme of “Manager-Therapist-Mother” which depicted the challenges experienced by mothers as they attempted to be “*four [therapists] rolled into one.*” The role strain described did not relate only to SLT, but to the accumulated work involved in enacting their various therapy roles. Thus, I argue that the model of role construction proposed above has applications to maternal role constructions in the context of a variety of professional relationships including other allied health professionals.

PART THREE- LOCATING THE THESIS IN PRACTICE

Central to this study was the question of how mothers perceive their role in therapy in Ireland. Capturing mothers’ role perceptions included exploring what mothers’ perceptions meant for their expectations of what they should do, and how they should engage with services and with professionals. Thus, the study’s findings regarding the question of how mothers perceive their role have implications for clinical practice, as well as knowledge. These implications relate to three core conclusions, each of which are discussed in detail below. As discussed above, the data generated in this study related to participants’ experiences with a range of health professionals, including [SLTs](#), but all participants used experiences with a variety of professionals to respond to

questions As such, some of the conclusions drawn from the data may apply to a range of professions, rather than [SLT](#) exclusively.

1. Parents' initial expectations of therapy are loosely defined and based on presumptions that therapy will be directed by a therapist and involve direct therapist-child interactions. Routine discussions of expectations in therapy may be beneficial in calibrating expectations and laying the foundation for positive, collaborative interactions between parents and therapists.
2. Capturing contextualized parental behaviours and attitudes, as well as the reported motivations that underpin these behaviours and attitudes, may offer better understandings of parent roles in therapy and facilitate greater acknowledgement of the work, commitment and sacrifice involved for parents, than role conceptualisations based on behaviour alone.
3. Mothers may experience a sense of holding high levels of responsibility for implementing their child's therapy, without an accompanying high level of power in decision-making. Reflecting on how and why services encourage parental involvement in therapy may facilitate services to support parental involvement more constructively.

11.9 Loose Expectations of Therapist Led Models

Both the [IPA](#) (p196 – 197) and parent-survey (p157 – 160) study found that parents hold loosely defined expectations of [SLT](#). The term “loose expectations” is designed to capture how 1) parents' expectations were based on an understanding that they appreciated some of the broad domains of their role, (although these predominantly related to implementation) while accepting that they had more to learn about the role, and 2) parents' expectations of these domains did not appear to include a detailed repertoire of the behaviours and attitudes associated with these domains. This finding regarding loosely defined expectations is in keeping with the limited available literature (e.g., Sugden et al., 2019) and may suggest a relatively low level of understanding of

[SLT](#) among the general public. Parents' expectations in this study, while loose, were mostly grounded in "expert – layperson" type relationships. The survey data suggest that many parents hold traditional expectations of therapy roles based on an understanding of [SLT](#) that appears to be influenced by both medical and educational contexts. The [IPA](#) study similarly intimated an understanding of therapists as teachers who assigned homework to parents. Other studies (Davies et al., 2017; Skeat & Roddam, 2019) have comparably found that parents understand therapists to act as teachers. Yet the available literature suggests that therapists hold a more nuanced understanding of their role as a coach (Davies et al., 2019), and are hesitant to identify as teachers (Davies, 2014). Similar potential for discrepancies between the expectations and understandings of parents and therapists may be found in relation to models of service delivery. Both the parent survey and [IPA](#) study findings suggest that many parents understand therapy as characterised by direct therapist-child interventions. This echoes the findings of other [SLT](#)-based studies (e.g., Watts-Pappas et al., 2016). However, a large scale [SLT](#) survey study found that therapists spend approximately equal amounts of time engaged in indirect and direct therapy (Pring et al., 2012), pointing to the likelihood of parents encountering occasions in which their original expectations will differ to the intervention approach taken.

The findings signal the importance of healthcare professionals' routinely discussing expectations of what therapy involves and what roles are implied in therapy. Coyne et al. (2013) found that role expectations are not routinely discussed in healthcare and discussions often only occur following conflict. If, as this study suggests, many parents arrive to therapies with an expectation that their role will be similar to their role in medical interventions, or in an educational context, discussions about expectations may be particularly necessary when professionals or services anticipate using indirect approaches, where emphasis is placed on the roles of other key stakeholders. Routine, planned discussions about expectations may help to identify

mismatches in expectations before conflict arises and may help to improve engagement in therapy as families may feel more listened to and respected. Additionally, Thornton and Nardi (1975) predict that, as parents' experience with therapy grows, their expectations of their role will change. This hypothesis is supported by the work of Davies et al. (2017) who found that parents' role conceptions in therapy are dynamic, further supporting the need for healthcare professionals to routinely discuss and re-visit expectations when working with families.

11.10 Reframing the Parent Role

Parents' roles in healthcare are often described using labels such as passive and active. (e.g., Smith & Samuels, 2021). Indeed, Smith and Samuels recently presented different parent "roles" in intervention, involving a range of professions, as occurring on a continuum of passive to active responsibility in interventions. Often decisions regarding how active or passive a particular role is, are based only on researchers' evaluations of parental behaviours. The findings of this study suggest that evaluating parent roles in such a way may miss some of the richer picture regarding the parent role in therapy, and inadvertently contribute to misleading representations of parental involvement.

As discussed above in relation to role strain, the [IPA](#) study findings (p231 – 253) indicate that parents can understand their role to involve hard work, personal costs and sacrifice. In all cases studied, the mothers partook in therapies while also carrying a significant weight of other concerns regarding their child's autism. Participants described feelings of guilt about the impact their therapy role had on family life, including the time available for other children in the family, and the impact on the mother-child relationship with the child with autism. Given this context, it seems likely that none of the [IPA](#) participants would be likely to classify their involvement in therapy as anything other than active. Yet if, for example, their behaviour was considered using Smith and Samuels' (2021) continuum of parental involvement, some of their roles

would be categorised as either passive or at best at a midpoint on the continuum. For example, on Smith and Samuels' (2021, p. 9) continuum, Helen would be classified as engaging in a passive role as a "bringer" for some therapy episodes. Yet Helen's account suggests that her transition from "observer" to "bringer" (Smith & Samuels, 2021, p. 9) reflected her desire to encourage her son to become more independent, and did not appear connected to any reduction in parental engagement as evidenced by her reported continued involvement in doing "homework" in between sessions and keenness to receive both feedback and guidance from therapists. This points to the potential value in understanding parents' rationale for exhibiting certain behaviours. The [IPA](#) data (p 218 – 222) indicates that parents who primarily observed during sessions adopted this role out of a "respect" for the expertise of clinicians. They interpreted keenly observing "expert" clinicians at work in order to "*copy*" (Mel) the therapist when at home, as beneficial for their children. Given that there is some evidence (Coyne et al., 2013) to suggest that roles are not regularly discussed in healthcare, it is plausible that some observed parental behaviours may reflect parents' attempts to act in the manner they assume therapists expect and desire. Understanding parents' rationales for their behaviour appears important for understanding and describing roles.

Parental attitudes also appear significant when attempting to capture parental role conceptualisations. For example, participants' accounts suggested that their behaviour of observing therapists was accompanied by an attitude of openness to learning and responsibility for their child's development. It appears reasonable that such a role is distinct from a role in which a parent primarily observes with an attitude of curiosity but no shared responsibility. Yet existing research tends to focus on behaviour alone, risking inadvertent misrepresentation of the parental role enacted. Furthermore, the findings of this study point to the need to consider the wider context of the role taken. For example, Smith and Samuels (2021) contend that involvement in

shared decision-making is a signal of active parental involvement. The [IPA](#) data suggests that few participants were involved in decision-making in therapy and thus might be categorised as occupying a passive role on Smith and Samuels' continuum. Yet the [SLT](#) survey (p164 – 165) results indicate that parents may be afforded few opportunities to engage in shared decision-making beyond goal-setting. Some of the parents, such as Gayle, expressed their desire to have more decision-making power in their child's interventions but presented professionals and services as restricting their involvement. Thus, conveying Gayle as “passively” involved in decision-making appears an inaccurate appraisal of her role.

When attempting to capture parents' roles in healthcare, relying on behaviours in isolation from accompanying parental attitudes and motivations and the wider context appears problematic. Further complicating this issue is the use of continuums of passive to active. These terms “active” and “passive” appear value-laden, and may suggest that certain types of parental involvement are universally better than others. Evaluations of what constitutes a passive or active role in the literature are determined by researchers. Perhaps unsurprisingly given the few studies on this topic, I found no research which involved parents' categorisations of their role in therapy. Framing roles as occurring along a continuum may be helpful for researchers seeking to compare parents to one another. Yet doing so may inadvertently encourage practitioners to also do this. Professional and regulatory bodies (e.g., CORU, 2019b; Royal College of Speech and Language Therapists, 2009) recommend practices that are both family centred and evidence based. Both family-centred practice and evidence-based practice emphasise the importance of including client preferences and values in intervention planning (Hanna & Rodger, 2002; Strauss et al., 2012). Thus, rather than framing parent roles on a predetermined continuum, perhaps there is greater benefit in clinicians engaging in discussions about roles with parents, negotiating what roles both

therapists and parents will aspire to and then comparing the roles enacted by both parties to the roles agreed.

11.11 Being Cognisant of the Rationale for Parental Involvement in Therapy

Parent involvement in allied health therapies is cited as beneficial for a number of different reasons. The benefits yielded appear to relate to how parents are involved. Engaging parents in treatment implementation at home is proposed as an economical means for services to increase treatment dosage, thus benefiting services and children (Steiner et al., 2012). Parental involvement in therapy is also often promoted as a means of empowering parents (Dodd et al., 2009). Empowerment is a psychological construct which relates to the development of a sense of control over one's own life and ability to meet one's needs as defined by that person (Dempsey & Foreman, 1997). Providing parents with information and including them in the implementation of therapy has been shown to offer some degree of parental empowerment (e.g., O'Toole et al., 2021). However, the reference in the definition of empowerment to having some control, strongly points to the significance of parents choosing to be involved in implementation, if the rationale for their involvement is empowerment. This is further supported by the experience of the "Manager-Therapist-Mother" role depicted by the [IPA](#) participants in this study. These parents perceived themselves as compelled to take a role in implementation (p241) and described it in terms of isolation rather than empowerment (p234 – 241). Dempsey and Foreman's definition of empowerment points to the potential value of including parents in decision-making. Inclusion in decision-making affords parents some degree of control over their child's intervention. Parental involvement in decision-making is also argued to contribute to more meaningful therapy outcomes, via involvement in goal-setting (Espe-Sherwindt, 2008). Furthermore, including parents in the decision-making process facilitates evidence-based practice as it affords clinicians the opportunity to understand client preferences

and values, and to integrate this with the research evidence and clinical expertise (Straus et al., 2019). Thus, involvement in decision-making across all stages of intervention may yield benefits for children, parents and therapists alike.

There was a strong consensus among the [IPA](#) participants that the role expected of them by health professionals and services was motivated by resource shortages (e.g., p271), rather than clinical best practice. Band et al. (2002) similarly found that parents understood cost-saving to be highly influential in decisions regarding service delivery in [SLT](#). Accounts relating to the Apprentice Builder role (p214 – 230) pointed to a perception of a shared workload with therapists, but did not suggest accompanying shared decision-making powers. The data pertaining to the Manager-Therapist-Mother role (p231 – 253) indicated a perception by participants that they were obliged to carry the responsibility for all the work involved, to work in a capacity for which they felt unqualified and with limited power to refuse or renegotiate this role. Their experience of limited perceived power is complimented by the findings of the [SLT](#) survey (p164 – 165). This found that therapists do not routinely involve parents in shared decision-making beyond goal-setting. The available literature regarding [SLTs](#)' reports of parental involvement in decision-making conveys a mixed picture. A number of studies suggest that [SLTs](#) involve parents in goal-setting (e.g., Watts-Pappas et al., 2008). Some studies suggest that therapists want parents to be more involved in decision-making (e.g., Melvin et al., 2020). Yet research (McCurtin & Carter, 2015; McCurtin & Clifford, 2015) also indicates that in practice, [SLTs](#)' decision-making is not heavily informed by client preferences and values, and the client factors more frequently considered relate to the individual client's pathology, rather than the client's perspective. Studies with other allied health professionals (e.g., Topp et al., 2018) have similarly found that therapists' reported practices are more often aligned with paternalistic decision-making approaches.

This study's findings are suggestive of a parent role in intervention as an implementer rather than a decision-maker. As discussed above, this involvement may be argued to yield economic benefits to services while also helping children. Hypothetically, when parents engage in therapy in this way, their children will directly benefit, while parents should benefit indirectly, through the progress made by the child. However, the findings of this study caution that the success of such a role may be dependent on the time frames involved and level of support provided. Participants' depictions of the "Apprentice Builder" role (p218 – 222) suggest that they viewed implementation at home favourably when they had access to support and further guidance from therapists. However, participants did not view working independently for long periods as sustainable, as depicted in the "Manager-Therapist-Mother" role (p244). Participants appeared to define therapy in terms of "*external help*" (Helen), suggesting that they expected and valued the support of therapists in order to fulfil their roles as parents. This desire or need for support is perhaps unsurprising given the weight of concerns and responsibilities often carried by parents of children on the autism spectrum. Other studies have found that parents report the need for continued support to aid them in their role as implementers at home, even after extensive training in parent-mediated interventions (O'Toole et al., 2021). When possible, the [IPA](#) participants accessed privately funded interventions, rather than working at home independently for long periods. While it appears reasonable that many parents may continue to work effectively at home for several weeks or even months, expecting parents to work without professional "*back-up*" (Mila) for periods approaching a year or longer, was perceived as unrealistic and unfair by participants. Given trends in resourcing, it seems naive to assume that therapy services in Ireland will soon be in a position to see families dramatically more frequently for intervention. Mila's discussion of the importance of "*back-up*" intimates that for some families, therapist-initiated phone contact during periods while they are waiting for further therapy, may sometimes offer enough support to continue implementation at home, with perhaps less emotional costs

incurred, as parents may feel less alone. Furthermore, Gayle's experience points to the importance of services and professionals being open about the rationale for parents taking such a role. If parents are being asked to act as implementers for extended periods, presenting this as a consequence of inadequate resources rather than best practice or parental empowerment, may be beneficial to maintaining trust in the therapeutic relationship.

Finally, the study signals that parents' involvement in decision-making may be underutilised in [SLT](#) in Ireland at present. The available literature (e.g., Topp et al., 2018) suggests that this finding is likely not unique to SLT and may apply across allied health professions. Current resourcing translates into limitations in the amount, frequency, range and type of therapies that services can offer. Nonetheless, greater inclusion in decision-making without substantial increases in resources appears achievable. Some authors (e.g., Entwistle, 2009) contend that the experience of feeling involved in the decision-making process is more important than who has the final say in intervention decisions. Even within current resourcing, individual clinicians can foster more collaboration with parents by, for example, offering choices regarding treatment approaches and engaging parents in discussions about the advantages and disadvantages of different approaches. As greater parental inclusion in decision-making may yield benefits for parents, children and therapists alike, efforts to do so appear worthwhile for all involved.

11.12 Reflexive and Reflective Commentary

I found this chapter incredibly difficult to write. There are a multitude of ways that I interpreted the findings of the study to have relevance to clinical practice. In writing this chapter I was faced with an ethical challenge of determining what conclusions deserved discussion given the constraints of the word count. Somewhat strategically I largely chose to write about the conclusions I felt I had the most evidence to support, although this process also confronted me with the realisation that some of the

conclusions which appeared well-substantiated in my mind were perhaps less scientific than I had previously understood them to be. This further illustrated to me how the writing process represents a continuation of the analytical process for me.

I was much less comfortable writing about theory than practice. I think my work as a clinician gives me some degree of confidence that I have earned the right to commit my clinical practice conclusions to paper. I have less confidence in relation to theory. Perhaps it relates to imposter syndrome, or perhaps it stems from the idiographic nature of the [IPA](#) study and my clear awareness that the [IPA](#) studies can make no claims of generalisability. However, when I consider this in the context of my epistemology, I question how credible any claims of knowledge construction and advancements of theory are, that aren't accompanied by notes of caution. In particular, taking the position that negative experiences may heighten one's sensitivity to the multiple roles held by a person and lend itself to the need for forgiveness within new therapeutic relationships felt scary. While I am committed to this conclusion, I anticipate that for some it may feel like too ambitious a claim. However, having begun to use some of the forgiveness strategies within my clinical practice, and reaped rewards in terms of the forging of therapeutic relationships, I feel confident that this conclusion has some merit.

11.13 Summary

This chapter discusses the significance of the key findings of this study. While the research questions specifically related to [SLT](#), the data generated largely referred to a range of paediatric interventions. Thus, the conclusions drawn have implications beyond [SLT](#), and extend to allied healthcare professionals engaging families in the context of autism. Parents' initial expectations of therapy were found to be loosely defined and based on presumptions that therapy will be led by a therapist and involve a therapist working directly with a child. Parents expect their role to involve implementation and advocacy. They report that the amount and type of involvement in

these domains can exceed their expectations. Indeed, the study found that mothers may experience a sense of high levels of responsibility for the implementation of therapy, without an accompanying high level of power in decision-making. I argue that this represents an opportunity for all stake-holders. Efforts to increase parental involvement in decision-making appear attainable without significant increases in resources, and may benefit all stakeholders.

The study found that parents' role constructions are influenced by a number of factors. I proposed a model to capture these factors. It is based on Katz and Kahn's (1978) Role Episode Model but includes the modified factor of "Understandings and Expectations (Cognitive and Emotional)," as well as the additional factors of "Prior Experiences" and "Other Roles." If accepted as valid, these factors may have implications for practice. They support the available literature that suggests that a parent's emotional well-being may impact on their role and should thus be considered when negotiating roles. Prior experiences, particularly negative one, were found to influence role construction, pointing to the potential benefits of applying learning from the field of forgiveness to therapeutic relationships involving mistrust. Finally, I argue for the importance of clinicians' considering the other roles held by parents. This may facilitate reflection on the feasibility of what is being asked of parents, the potential costs involved for them and how best to mitigate the risk of role overload.

Additionally, I argue that to fully appreciate the role of parents, consideration should be made not just to their observable behaviours, but also to parental attitudes and reported motivations, and the broader context in which roles occurs. This approach may foster better acknowledgement of the work, commitment and sacrifice often involved for parents in therapy. The next chapter brings the thesis to a conclusion with a critical evaluation of the study in its entirety.

Chapter 12: Conclusion

12.1 Introduction

This chapter seeks to bring the dissertation to a close by summarising the study and reviewing how it addressed the research aims. It provides a critical evaluation of the study and recommendations for future research. The chapter concludes with a discussion of the personal impact of the study.

12.2 Overview of Research Project

To my knowledge, this study represents the first in-depth qualitative study to focus on mothers' role constructions in [SLT](#) using a phenomenological approach in an Irish context. This exploratory study represents an IPA study informed by two supplementary research strands – two survey studies and a deductive analysis. The [IPA](#) study involved interview data with six mothers of children with autism. Applying an [IPA](#) approach to this research topic contributed to the knowledge base regarding therapy roles, by offering an idiographic insight into both the shared and unique aspects of how the mothers involved perceived and made sense of their role in [SLT](#). Four superordinate themes were constructed through the [IPA](#) study – 1) Understandings and Expectations of Autism, 2) Understandings and Expectations of [SLT](#), 3) “*Therapy Mother*” and 4) A Game of Survival. The core findings of this project and how they relate to the research aims are reviewed below.

12.3 Reviewing the Research in the Context of the Research Aims

This study sought to increase understandings of the parent role in [SLT](#), with a more specific focus on the role of mothers. While much literature celebrates the importance of parental involvement in therapy, definitions, perceptions and the meaning attached to parental involvement in [SLT](#) have seldom been explored in detail in published studies. Of the few studies which specifically focus on the parent role, nearly all adopt a

narrow definition of a role as a concept involving behaviours alone. This study adds to the knowledge base regarding the parent role in [SLT](#) by providing an in-depth study of mothers' perceptions of roles, which utilises a broader definition of a role as a concept involving both behavioural and attitudinal domains.

The study specifically addressed the questions:

1. How do mothers of children on the autism spectrum perceive their role in [SLT](#) in Ireland?
2. How do mothers of children on the autism spectrum in Ireland make sense of their role in SLT?

12.3.1 Perceptions of Roles

The study found that parents' expectations of their role in therapy are loosely defined. The mothers studied perceived their role to primarily involve advocacy and implementation, rather than decision-making. The [IPA](#) participant accounts pointed to an interpretation of their interactions with services as akin to being thrust into a game of survival in which services sought to protect resources above all else. In this context, mothers constructed their roles as advocates. Some of the advocacy roles depicted have not previously been discussed in the available literature, to my knowledge. In addition to advocating for additional services, mothers' accounts were suggestive of a "defensive" form of advocacy motivated by a desire to protect children's existing service provision. Involvement in defensive advocacy may influence how mothers engage in therapeutic relationships, e.g., impacting on information sharing between parents and clinicians. With regard to their role in therapy implementation, the participants' accounts pointed to two different categories of implementation. The first, the "Apprentice Builder" involved implementation under the direction of an expert-[SLT](#), and broadly aligns with much of the available literature regarding parents' experiences of implementation. The second, the "Manager-Therapist-Mother" involved implementation in the perceived absence of support, and was depicted as a role

participants felt compelled to take due to resource constraints and one associated with costs in terms of the mother-child relationship and maternal identities.

12.3.2 Sense-Making of Roles

The findings support the available literature which suggests that a number of intrinsic and extrinsic factors can impact on role construction. Specifically, this study found that mothers' role constructions were influenced by their understandings and expectations of autism and SLT, as well as factors relating to therapists and the service organisation. The findings indicate that role construction can be a dynamic process situated both in contemporary and historical interactions between parents, services and professionals, as well as in the context of the multiple other roles a parent holds. Prior experiences, particularly negative ones, were depicted as influential to how mothers engaged with subsequent therapists and services. The participants constructed and enacted their roles in therapy in a context of holding additional roles, sometimes manifesting in challenges related to role overload and role conflict.

12.4 Summary of Implications for Practice and Theory

An in-depth discussion of how the findings of this study may apply to practice and theory is provided in Chapter 11. While the research study was focused on [SLT](#), the data generated largely referred to a range of paediatric interventions and as such I argue that the study has implications for allied healthcare in general. Despite utilising a broader definition of a role (i.e., encompassing both behaviours and attitudes) than that employed in most published healthcare studies, I concluded that a full understanding of therapy roles also requires consideration of parental reports of the rationale underpinning their behaviours and attitudes, as well as the wider context in which they occurred. Additionally, given that the study found that parents' expectations of therapy and therapy roles are loosely defined and primarily based on assumptions of therapist-led, direct models of interventions, I hypothesise that health professionals may benefit

from routinely scheduling discussions with parents about their expectations of therapy and roles. Finally, as the mothers studied depicted roles involving advocacy and implementation rather than decision-making, I argue that this may represent an opportunity for all stakeholders. Greater parental inclusion in decision-making should facilitate the provision of care which more closely reflects evidence-based practice and family-centred care, while also empowering parents.

The findings of the study, coupled with my review of the literature, contributed to the development of a model of role construction, based on Katz and Kahn's (1978) "Role Episode Model". This model differs to Katz and Kahn's model in a number of ways. I proposed that while existing role theories emphasise the influence of cognition through expectations, emotions may also be influential. I interpreted the evidence of role overload and role conflict in my study to point to the impact of an individual's overall repertoire of roles on their role constructions. This factor is seldom included in models of role construction. Finally, I added prior experiences as an influential factor. This study found that historical experiences with services and professionals can influence the role enacted by parents in future relationships with unrelated clinicians and services.

12.5 Critique of the Study

Few studies have addressed the topic of the parent role in intervention. This study enriches understandings of the topic by approaching it from a novel methodological perspective. Additionally, this study adopted a broader definition of roles than is found in much of the available literature which arguably facilitated me in capturing a richer portrayal of parent roles in [SLT](#). Nonetheless, as with any research, this study is not without its limitations.

Some of these limitations stem from my status as a novice researcher. This study represented my first attempt to conduct an [IPA](#) study and survey studies. While I attempted to limit the impact of my inexperience by researching [IPA](#), interviews and

surveys, and accessing additional training in [IPA](#), as well as accessing additional support through the online [IPA](#) email forum, my inexperience undoubtedly impacted on this study to some degree. My inexperience in [IPA](#) was evident in the amount of time my analysis took. Partly because of this, I had to limit the number of participant accounts for analysis to six, potentially limiting the impact of the study. I found the interpretative, rather than descriptive, part of the analysis challenging and acknowledge that a more experienced [IPA](#) researcher may have been more confident and competent at constructing more interpretative themes. My inexperience as a researcher was also evident in my survey design. The surveys included a number of closed questions which may have limited participants' responses. Some questions involved selection of photographs, a novel approach but one that is relatively untested. In analysing participants' choices of photographs, I was dependent on assuming that my interpretations aligned with participants,' in terms of the differentiation of actors in the photographs and the meaning of the photographs.

My status as both a clinician and a researcher may have impacted on the study, particularly during the [IPA](#) data collection and analysis. Participants were aware of this status, and as such it is plausible that it impacted on their responses provided. They may have tempered their accounts in an effort to be more "polite" towards my profession. This status also impacted on my analysis of the data, as discussed in Chapter 4 in relation to researcher reflexivity. Some participants reminded me of past clients and this required considerable engagement with researcher reflexivity to determine how this was influencing my interpretations of the data. Indeed, the final "limitation" of this study relates to my alignment with constructionism and choice of [IPA](#) as a methodology. I perceive my findings to be co-constructed, and thus accept that I have influenced them to some degree. My philosophical leanings position me to interpret all investigations of social realities to be co-constructed, and thus I do not perceive any other qualitative methodologies that are geared towards exploring

participant experiences to offer knowledge that is free of researcher-bias. Nonetheless, I understand in choosing a methodology that openly adopts this position I may invite criticism and limit my ability to publish my findings. I also understand that in selecting [IPA](#), because of its qualitative nature, any findings which are published may be considered as weak evidence under hierarchies used to guide evidence-based practice. Thus, the choice of [IPA](#) as a methodology may limit the impact of the study.

My choice of [IPA](#) as a methodology may also have limited the scope of my research, owing to the time involved in conducting a high-quality [IPA](#) analysis. As my research project progressed and I analysed my [IPA](#) data, I became increasingly aware of the potential influence of clinicians and services on the parent role, for example. A different, less time-consuming methodology may have allowed me the time required to do additional strands of research, involving mother-clinician role pairs which would likely have enriched my understandings further. Nonetheless, given that research on the topic of roles in [SLT](#) is at an early stage, [IPA](#) proved to me a helpful methodology. It facilitated me in adopting an exploratory stance and offered a valuable means to add to the knowledge base by bringing a phenomenological and idiographic perspective.

12.6 Recommendations for Future Research

The study highlights the need for further investigation in a number of areas.

12.6.1 Developing Consensus on What to Capture When Investigating the Parent Role

My review of the literature found that parents' roles in [SLT](#) are often portrayed in terms of behaviours alone. Research aiming to establish what components different stakeholders agree are fundamental to understanding the parent role in therapy would be helpful in advancing further studies on the topic and ensuring easier comparisons

between study findings. Given the topic involved, this research may benefit from utilising Public and Patient Involvement (PPI), particularly during data analysis.

12.6.2 Interrogating the Model

A key contribution of my research is the model of role construction which I proposed. This model requires further interrogation both as a whole and of its components to determine its' soundness. Potential directions that this interrogation may take are discussed below.

Capturing Role Construction as a Contextualised Process

My study provided an in-depth insight into mothers' perceptions and sense-making of their roles at a single point in time. However, the model of role construction which I propose illustrates my stance that role construction occurs as a process involving the contextual interactions of a role pair. Further research involving specific mother-therapist pairs and reviews of their corresponding service organisation's documentation is warranted. Such research should seek to understand what expectations mothers, therapists and services hold about roles prior to commencing therapy, as well as how therapists and mothers understand their own role and the role of their counterpart during and after a therapy episode. Collecting this data at different time points should facilitate capturing the process of role construction, if or how role conceptions change within a role pair and how each party's role conceptions impact on one another.

Expectations

The model of role construction which I proposed concurs with Role Theory's stance that expectations can influence role construction. I hypothesise that clinician-initiated discussions of expectations of therapy and therapy roles prior to and during therapy may facilitate role enactment. Further investigations designed to test this hypothesis are required. Such research might involve a control group in which expectations are not discussed and a group in which expectations are discussed. Researchers could

explore how therapists and parents in each group evaluated the success of the roles enacted and their satisfaction with the roles enacted.

Hope and Anxiety

The model proposed in this thesis draws from the findings of this study and the available literature to suggest that parents' emotions, particularly those related to their understandings of autism and therapy, can influence role conceptions. The emotions found to be particularly powerful in this study were hope and anxiety. Further research is required to interrogate what relationship (if any) exists between measures of parental anxiety and hope and the role enacted by parents as perceived by parents and therapists. A longitudinal design involving repeated use of measures and evaluations over the course of a number of episodes of care may be particularly helpful in exploring if these emotions have a relationship with how parents engage in therapy.

Prior Experiences

I found that mothers' prior experiences with services and clinicians can influence role constructs and expectations of future interactions with services and professionals. I welcome further research exploring the relationship between parents' evaluations of services and therapists as negative or positive, their expectations of future experiences, as well as their self-ratings of feelings of trust towards services and professionals in general, their named current therapist and future professionals. This may help to establish if negatively perceived experiences with services contribute to parental mistrust of unrelated professionals going forward.

Role Overload

This study found that mothers' experiences of being involved in therapy were often perceived to contribute to role overload and associated feelings of stress, guilt and anxiety. In keeping with the available literature, the mothers in this study took the lead or exclusive parent role in therapy. This raised questions for me about how or if

mothers would experience similar levels of role overload if their partners were more involved in therapy. Future research might benefit from investigating if clinician-initiated discussions encouraging the involvement of two guardians in therapy may reduce parental reports of role overload.

Role Conflict

One of the findings of my study which troubled me greatly, related to participants' perceptions that their involvement in therapy changed their parent-child relationship and their identities as mothers. While further evidence for this is found in a small number of other studies in the literature, it requires further research involving larger sample sizes to fully interrogate its frequency and nature. Survey-based research may offer a means to explore the question of if and how involvement in therapy impacts on maternal identity and the mother-child relationship using a larger sample size.

12.6.3 Defensive Advocacy

The theme of "A Game of Survival" illustrated how advocacy manifested in both defensive and offensive approaches. To my knowledge, defensive advocacy has not been discussed in the research previously. Further studies to determine the presence and reported impact of this phenomenon in other mothers' experiences are warranted, as it seems logical that if present, defensive advocacy may impact on therapeutic relationships.

12.6.4 Decision-Making

This study found that parents are not routinely invited to participate in decision-making beyond goal-setting in Ireland. An Irish-based study involving all stakeholders which explores barriers and facilitators to parental inclusion in decision-making may be helpful. Situating this study in an Irish context may be particularly helpful in identifying culturally specific or institutionally-based factors of significance.

Based on the experiences of the participants in my study, I hypothesised that parental involvement in implementation offers some potential for empowerment but involvement in decision-making may yield greater gains in this area. A comparative study exploring the impact on measures of parental empowerment of three different conditions a) parental involvement in implementation only, b) parental involvement in decision-making only and c) parental involvement in both implementation and decision-making, may help to test this hypothesis and offer insights into what type of parental involvement will best meet the stated aims of the intervention.

12.6.5 Relevance to Other Populations

The findings of this study relate to mothers of primary-school aged children on the autism spectrum in Ireland. As discussed in Chapter 2, there is evidence to suggest that the experience of mothers may differ to fathers due to socio-political factors. Kingston (2007) and You and McGraw (2011) suggest that mothers, in particular, can experience pressure to act as the “good” mother who puts her children’s needs first. Thus, it could be inferred that mothers, more so than fathers, may be at greater risk of role overload and role conflict. Similar idiographic research exploring father’s perceptions and sense-making of their roles may help to understand what, if any, aspects of fathers’ experiences are different to mothers.

The children of the parents in this study were all of primary school age. It seems reasonable that as children increase in age, a parent’s role in general will change in response to the child’s transition towards greater independence from the parent. Anecdotally, in Ireland, as a client enters into adolescence and adulthood, intervention appears to shift away from impairment-based interventions or interventions which are heavily focused on the immediate family, to instead focus on developing communication supports in environments such as schools, work places or residential care settings. Additionally, in some cases no therapeutic services are available for adults with developmental disabilities. Furthermore, adolescence and adulthood can

often signal that considerable time has passed since a child first received their diagnosis of autism. Thus, it appears likely that parents' perceptions of their role may shift as increases occur both in a child's age and the time since diagnosis. This suggests that further research exploring the role concepts of parents of children of different age-groups may be useful in determining if they understand their role in similar or different ways to the participants in this study.

Also relevant is research involving mothers of children with different diagnoses. There is some evidence that parenting in the context of autism may present different challenges than parenting children with other developmental disabilities. For example, parents of children on the autism spectrum have been found to have higher rates of stress (Hayes & Watson, 2013), anxiety and depression (Dumas et al., 1991; Firat et al., 2002) compared to parents of children with other developmental disabilities. Thus, the experiences of role strain found in my study may arguably be specific to an autism context or may be more pronounced than in the context of parents of children with different diagnoses, suggesting that further research involving parents of children with different disabilities would be beneficial.

12.7 Personal Learning and Development

While I understand that dissertations are examined in relation to their contribution to theory and knowledge, perhaps the biggest gains associated with this PhD have been personal, leading to shifts in how I understand myself and the many different roles I enact in life. Many of my oldest friends tease me about my desire to put everything and everyone "into a box," referring to my tendency to try and make sense of people and things in a way that often assumes they are static, with clearly defined boundaries and features. This tendency was likely exacerbated by an emotional immaturity that found comfort in seeing the world as concrete and certain, and involving rights and wrongs. The philosophical component and process of this PhD has contributed to my acceptance and recognition of the many shades of grey in the world and the subjective

nature of much of our realities. In particular my learning regarding epistemologies and the philosophies that underpin [IPA](#) contributed to a gradual, uncomfortable, but worthwhile shift in how I seek to understand the world. This learning gave me a greater appreciation for the many different forces, internal and external, that shape how I perceive my reality and has caused me to reflect more on my opinions and what biases and socio-political influences may be influencing my perspectives.

Perhaps, unsurprisingly the PhD process has led to changes in how I understand my role as a researcher. Much of this stems from the philosophies relating to [IPA](#). The emphasis in [IPA](#), on our role as interpreters of our own experiences and re-interpreters of the experiences of others, helped me to develop more self-awareness of the what and how of being a student. In reading the work of other researchers, I understand myself to be re-interpreting their interpretations. This underscored the importance of close readings of others' work. It encouraged me to consider what overlays I had imposed on others' work via my own prejudices and bias, and heightened my awareness of the risk of others doing so. This challenged me to critically reflect more on the work of researchers and consider what other interpretations might explain their findings. Furthermore, the principle of the hermeneutic circle central to [IPA](#) opened my eyes to how I approach learning. I have always considered myself to be a slow learner. Approaching data analysis using the hermeneutic circle, offered some insight into my "slowness." When trying to disentangle the meaning of the data, I felt I struggled a lot of the time. Rather than moving from the "woods to the trees" or "the trees to the woods," I felt like I could see all of the woods and the trees in such high definition that it was overwhelming and nothing was clear. I now recognise that when learning new things, I often take this course. The concept of the hermeneutic circle gave me permission to move from part to whole and vice versa, and alleviated my unconscious fears that I should be able to understand it all at once.

The experience of the PhD also illuminated my transition into motherhood. Trying to juggle my studies with my new role as a mother proved challenging. Understanding role strain and role conflict gave me a better insight into my experience. Applying my learning, gave me an insight into the embodied struggle that can be inherent in the experience of role strain and role conflict. It strengthened my perspective that these experiences should not be minimised or dismissed. My understandings of how roles are constructed gave me some comfort when reflecting on the challenges I experienced in transitioning to motherhood. Understanding the influence that society can have on role construction, helped me to decipher my experience and why I felt so much pressure and guilt in the presence of a supportive spouse who felt none of these things. It also helped me to regain some feelings of control as I better appreciated that I had a degree of power to shape this role through how I interacted and interpreted my interactions.

However, the role over which this PhD has had the most pronounced impact is that of clinician. When embarking on this PhD process, I was frustrated with all aspects of my job. Doing this PhD reinvigorated my interest and enjoyment of [SLT](#) and has ultimately kept me in the profession. I have a heightened appreciation of the relationship between continuous professional development and my sense of job satisfaction and commitment to the profession. The opportunities for reflection and reflexivity that this PhD afforded me, have illustrated the power and importance of reflection and reflexivity in improving my practice. I now regularly use reflective and reflexive writing to guide my decision-making in relation to both individual clients and my caseload as a whole. Professionally, this has challenged me to reflect on my practices and how compatible they are with the philosophies of intervention I presume myself to hold. It has also been particularly helpful in relation to incidences of conflict or dissatisfied service users. Using these tools has allowed me to better understand the legitimate anxieties and frustrations of families. Coupled with my learning from Role

Theory, reflexive and reflective writing has led me to consider myself as a highly influential factor in therapy again. I continue to consider if treatment approaches are the best fit for a client, but I am much more cognisant of the potential that how / am using the approach, how / am discussing and presenting it, how / signal to families my expectations of them, and how / listen and respond to families may hugely impact on how families engage in therapy. I am also now much more mindful of the language I use to speak to families. Gloria's case, in particular, pointed to the power of language to give or dash hope. Her repeated references to the therapist's use of the term "*magic wand*," resonated with me, provoking me to consider how easily, well-intentioned words can cause damage unbeknownst to the speaker. This underscored for me the importance of striving to be more careful in how I communicate with parents.

Aligned with this is my amplified appreciation for the importance of the therapeutic relationship to therapy. Prior to my PhD, the resource-constrained nature of the contexts in which I worked had unconsciously impacted on my practice to a point where I perceived time spent getting to know clients, or engaging with them on a personal level as almost discretionary. I now perceive the quality of the therapeutic relationship as foundational for the effectiveness of intervention. I always use family member's names, and endeavour to ask about previously discussed planned personal activities. I routinely ask parents if they have any questions or suggestions for how I could improve future sessions in the hope that parents may understand this as both my recognition of their expertise and an invitation to shape intervention. Understanding the importance of participatory practices in the therapeutic relationship, I include parents in decision-making about goals and offer choices about types of treatment and engage parents in discussions about the costs and benefits of different treatment approaches, within the constraints of the service's resources.

The study's findings, supplemented with the experience of becoming a mother, have contributed to a greater appreciation for the work and sacrifice of parents who

engage in therapy. Prior to this study, I am ashamed to admit that I had thoughts such as, "It's not that big a deal. Why can't/ won't she do it?" as well as wrongly assuming that when parents expressed a preference for direct intervention it was suggestive of a desire to be minimally involved. In the case of autism, where parental involvement may occur over many years, and in an Irish context, may involve gaps and unmet service needs, I now admire parents who engage in therapy in any way. I approach therapy with three questions relating to the parent role- 1) Is the role being asked of this parent feasible? 2) Do the potential gains outweigh the potential benefits for this parent and separately for this child? 3) What role is required of me to help this parent be successful in their role? Additionally, the PhD process and the findings of the study, coupled with becoming a mother have shifted how I understand parents' involvement in advocacy. Prior to the PhD, I interpreted parental advocacy efforts almost personally. I considered dealing with complaints as a futile exercise that ultimately cost families and services, as time was redirected from clinical time to respond to these complaints. I now perceive clients as right when they advocate. I view parents who advocate as admirable figures who are driven by their love for and desire to protect their children, not as the "*pest*" that Marian depicted. In my opinion, current levels of service provision are inadequate. In a wealthy, developed country, it appears astounding that services for children with disabilities are so under-resourced. COVID-19 showed that both government and health services can react swiftly, change dramatically and allocate resources differently. Change is possible. For change to occur parents, clinicians and services need to highlight needs and come together more, change what they can within the constraints of current resources and advocate for more resources to make greater change.

12.8 Concluding Notes

This study contributes insight into the lived experiences of mothers of children on the autism spectrum who have a role in [SLT](#) interventions in Ireland. The findings suggest that mothers' role constructions evolve through an intricate process involving intrinsic and extrinsic factors situated in historical and contemporary interactions with therapists and services and within the wider context of roles held by mothers. The study found that mothers perceive their role to involve implementation and advocacy, rather than inclusion in decision-making. The roles presented by participants in this study are indicative of hard work, sacrifice and much personal costs, most notably in relation to how participants identified as mothers. They serve as a reminder that therapy has the potential to both help and harm, and signal the importance of being mindful of all that parents do and risk in an effort to support the therapists and services working with their children. The findings call for acknowledgement and respect for the work done by parents, as well as heightened sensitivity to the influence that services and professionals can have on parents' roles.

References

- Ajzen, I. (1988). *Attitudes, personality and behavior*. Open University Press.
- Allen, D. A., & Hudd, S. S. (1987). Are we professionalizing parents? Weighing the benefits and pitfalls. *Mental Retardation*, *25*(3), 133-139.
- Alves de Oliveira, J., & Vandenberghe, L. (2009). Upsetting experiences for the therapist in-session: How they can be dealt with and what they are good for. *Journal of Psychotherapy Integration*, *19*(3), 231-245.
<https://doi.org/10.1037/a0017070>
- Ambrose, S. E., Appenzeller, M., Mai, A., & DesJardin, J. L. (2020). Beliefs and self-efficacy of parents of young children with hearing loss. *Journal of Early Hearing Detection and Intervention*, *5*(1), 73-85.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). #SaytheWord: A disability culture commentary on the erasure of 'disability'. *Rehabilitation Psychology*, *64*(2), 111-118.
<https://doi.org/10.1037/rep0000258>
- Andrews, T. (2012). What is social constructionism?. *Grounded Theory Review*, *11*(1), 39-46.
- Ang, K. Q. P., & Loh, P. R. (2019). Mental health and coping in parents of children with Autism Spectrum Disorder (ASD) in Singapore: An examination of gender role in caring. *Journal of Autism & Developmental Disorders*, *49*(5), 2129-2145.
<https://doi.org/10.1007/s10803-019-03900-w>
- Aronson, J. K. (2007). Compliance, concordance, adherence. *British journal of clinical pharmacology*, *63*(4), 383-384. <https://doi.org/10.1111/j.1365-2125.2007.02893.x>
- Ayres, L. (2008). Semi-structured interview. In L. M. Given (Ed.), *The sage encyclopedia of qualitative research methods* (pp. 810-811). Sage.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . Dowling, N. F. (2018). Prevalence of Autism Spectrum Disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 Sites, United States, 2014. *MMWR Surveill Summ*, *67*(6), 1-23.
<https://doi.org/10.15585/mmwr.ss6706a1>
- Band, S., Lindsay, G., Law, J., Soloff, N., Peacey, N., Gascoigne, M., & Radford, J. (2002). Are health and education talking to each other? Perceptions of parents

- of children with speech and language needs. *European Journal of Special Needs Education*, 17(3), 211-227. <https://doi.org/10.1080/08856250210162121>
- Bandura, A. (1986). *Social foundations of thought and action : a social cognitive theory*. Prentice-Hall.
- Barnes, C., & Mercer, G. (2010). *Exploring disability: a sociological introduction* (2nd ed.). Polity.
- Baumeister, R. F., Bratslavsky, E., Finkenauer, C., & Vohs, K. D. (2001). Bad is stronger than good. *Review of General Psychology*, 5(4), 323-370. <https://doi.org/10.1037/1089-2680.5.4.323>
- Baxendale, J., Frankham, J., & Hesketh, A. (2001). The Hanen parent programme: a parent's perspective. *Int J Lang Commun Disord*, 36 Suppl, 511-516.
- Beighton, C., & Wills, J. (2017). Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration. *Journal of Intellectual Disabilities*, 21(4), 325-345.
- Berger, P., & Luckmann, T. (1991). *The social construction of reality - A treatise in the sociology of knowledge*. Penguin Books.
- Bezdek, J., Summers, J. A., & Turnbull, A. (2010). Professionals' attitudes on partnering with families of children and youth with disabilities. *Education & Training in Autism & Developmental Disabilities*, 45(3), 356-365.
- Biddle, B. J. (1979). *Role theory : expectations, identities and behaviors*. Academic Press.
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214.
- Blaikie, N. W. H. (1993). *Approaches to social enquiry*. Polity Press.
- Blum, L. M. (2007). Mother-blame in the prozac nation: raising kids with invisible disabilities. *Gender and Society*, 21(2), 202-226. <https://doi.org/10.1177/0891243206298178>
- Bogataj, Š., Pajek, M., Buturović Ponikvar, J., & Pajek, J. (2020). Outcome expectations for exercise and decisional balance questionnaires predict adherence and efficacy of exercise programs in dialysis patients. *International journal of environmental research and public health*, 17(9), 3175. <https://doi.org/10.3390/ijerph17093175>
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health & Development*, 42(6), 784-797. <https://doi.org/10.1111/cch.12383>

- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0014>
- Brady, N., Skinner, D., Roberts, J., & Hennon, E. (2006). Communication in young children with Fragile X Syndrome: A qualitative study of mothers' perspectives. *American Journal of Speech-Language Pathology*, *15*(4), 353-364. [https://doi.org/10.1044/1058-0360\(2006/033\)](https://doi.org/10.1044/1058-0360(2006/033))
- Brickman, P., Coates, D., & Janoff-Bulman, R. (1978). Lottery winners and accident victims: Is happiness relative? *Journal of Personality and Social Psychology*, *36*(8), 917-927. <https://doi.org/10.1037/0022-3514.36.8.917>
- Bronfenbrenner, U. (1979). *The ecology of human development : experiments by nature and design*. Harvard University Press.
- Brookes, K., Davidson, P. M., Daly, J., & Halcomb, E. J. (2007). Role theory: A framework to investigate the community nurse role in contemporary health care systems. *Contemporary Nurse*, *25*(1-2), 146-155. <https://doi.org/10.5172/conu.2007.25.1-2.146>
- Broom, A., & Willis, E. (2007). Competing paradigms and health research. In M. Saks & J. Allsop (Eds.), *Researching health. Qualitative, quantitative and mixed methods*. (pp. 16-31). Sage.
- Brotherson, M. J., & Goldstein, B. L. (1992). Time as a resource and constraint for parents of young children with disabilities: Implications. *Topics in Early Childhood Special Education*, *12*(4), 508.
- Brown, L. A., Wiley, J. F., Wolitzky-Taylor, K., Roy-Byrne, P., Sherbourne, C., Stein, M. B., . . . Craske, M. G. (2014). Changes in self-efficacy and outcome expectancy as predictors of anxiety outcomes from the CALM study. *Depression and anxiety*, *31*(8), 678-689. <https://doi.org/10.1002/da.22256>
- Brown, M. E. L., & Dueñas, A. N. (2020). A medical science educator's guide to selecting a research paradigm: building a basis for better research. *Medical Science Educator*, *30*(1), 545-553. <https://doi.org/10.1007/s40670-019-00898-9>
- Burrell, T. L., & Borrego, J. (2012). Parents' involvement in ASD treatment: What is their role? *Cognitive and Behavioral Practice*, *19*(3), 423-432. <https://doi.org/https://doi.org/10.1016/j.cbpra.2011.04.003>
- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It defines who I am" or "It's something I have": What language do [autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-020-04425-3>

- Caldwell, G. (2008, October 16). Theory with a capital 'T': Exploring the various roles of theory within the IPA research process. Glasgow group short report. [Online forum post] Yahoo Groups. IPA Qualitative Group.
<https://groups.io/g/ipaqualitative/message/2383?p=%2C%2C%2C20%2C0%2C0%2C0%3A%3Acreated%2C0%2Ctheory+with+a+capital%2C20%2C2%2C0%2C65018942>
- Carpenter, L., & Austin, H. (2007). Silenced, silence, silent. *Qualitative Inquiry*, 13(5), 660.
- Carroll, C. (2010). "It's not everyday that parents get a chance to talk like this": Exploring parents' perceptions and expectations of speech-language pathology services for children with intellectual disability. *International Journal of Speech-Language Pathology*, 12(4), 352.
- Carroll, M. (2004). Organisations and forgiveness: the challenge. In C. Ransley & T. Spy (Eds.), *Forgiveness and the Healing Process* (pp. 86 - 104). Brunner-Routledge.
- Chacko, A., Jensen, S. A., Lowry, L. S., Cornwell, M., Chimklis, A., Chan, E., . . . Pulgarin, B. (2016). Engagement in behavioral parent training: Review of the literature and implications for practice. *Clin Child Fam Psychol Rev*, 19(3), 204-215. <https://doi.org/10.1007/s10567-016-0205-2>
- Charnsil, C., & Bathia, N. (2010). Prevalence of depressive disorders among caregivers of children with autism in Thailand. *ASEAN Journal of Psychiatry*, 11(1), 87-95.
- Charpentier, A., Morgan, S., & Harding, C. (2020). A service evaluation of parent adherence with dysphagia management therapy guidelines: Reports from family carers supporting children with complex needs in Greece. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, 42(3), 426-433. <https://doi.org/10.1080/09638288.2018.1499048>
- Chen, Y.-Y., Shek, D. T. L., & Bu, F.-F. (2011). Applications of interpretive and constructionist research methods in adolescent research: Philosophy, principles and examples. *International Journal of Adolescent Medicine and Health*, 23(2), 129-139. <https://doi.org/10.1515/ijamh.2011.022>
- Chilisa, B. (2012). *Indigenous research methodologies*. Sage.
- Christians, C. G. (2005). Ethics and politics in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The sage handbook of qualitative research*. (3rd ed.). Sage.
- Ciciolla, L., & Luthar, S. S. (2019). Invisible household labor and ramifications for adjustment: Mothers as captains of households. *Sex Roles: A Journal of Research*, 81(7-8), 467-486. <https://doi.org/10.1007/s11199-018-1001-x>

- Conner, M., & Norman, P. (2005). Predicting health behaviour: A social cognition approach. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 1-27). Open University Press.
- Constantino, M. J., Glass, C. R., Arnkoff, D. B., Ametrano, R. M., & Smith, J. Z. (2011). Expectations. In J. C. Norcross (Ed.), *Psychotherapy Relationships That Work. Evidence Based Responsiveness* (2nd ed., pp. 354 - 376). Oxford University Press.
- Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders : A systematic review and meta-synthesis. *Journal of intellectual disabilities*. <https://doi.org/10.1177/1744629515577876>
- CORU. (2019a). *CORU Health and Social Care Professionals Council annual report 2019*. <https://coru.ie/files-publications/annual-reports/coru-annual-report-2019.pdf>
- CORU. (2019b). *Speech and language therapists registration board code of professional conduct and ethics*. <https://www.coru.ie/files-codes-of-conduct/sltrb-code-of-professional-conduct-and-ethics-for-speech-and-language-therapists.pdf>
- Costantino, T. E. (2008). Constructivism. In L. M. Given (Ed.), *The sage encyclopedia of qualitative research methods* (pp. 116-119). Sage.
- Couper, M. P., Tourangeau, R., & Kenyon, K. (2004). Picture this! Exploring visual effects in web surveys. *The Public Opinion Quarterly*, 68(2), 255-266.
- Coyne, I., Murphy, M., Costello, T., O'Neill, C., & Donnellan, C. (2013). A survey of nurses' practices and perceptions of Family-Centered Care in Ireland. *Journal of Family Nursing*, 19(4), 469-488. <https://doi.org/10.1177/1074840713508224>
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice*, 20(2), 153-162.
- Crocker, A. F., & Smith, S. N. (2019). Person-first language: are we practicing what we preach? *J Multidiscip Healthc*, 12, 125-129. <https://doi.org/10.2147/jmdh.s140067>
- Crotty, M. (1998). *The foundations of social research : meaning and perspective in the research process*. SAGE.
- Crowe, N. J.(2020). Axiology. In: Salem Press Encyclopedia. 2020. <https://search-ebscohost-com.elib.tcd.ie/login.aspx?direct=true&db=ers&AN=87321020>
- D'Arrigo, R., Copley, J. A., Poulsen, A. A., & Ziviani, J. (2020). Parent engagement and disengagement in paediatric settings: An occupational therapy perspective.

- Disability and Rehabilitation: An International, Multidisciplinary Journal*, 42(20), 2882-2893. <https://doi.org/10.1080/09638288.2019.1574913>
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with Autism and Down Syndrome. *Journal of Intellectual Disability Research*, 54(3), 266-280.
- Davies, K. E. (2014). *Parents' and speech and language therapists' roles in intervention for pre-school children with speech and language needs*. Unpublished manuscript. Manchester Metropolitan University.
- Davies, K. E., Marshall, J., Brown, L. J. E., & Goldbart, J. (2017). Co-working: parents' conception of roles in supporting their children's speech and language development. *Child Language Teaching and Therapy*, 33(2), 171-185. <https://doi.org/10.1177/0265659016671169>
- Davies, K. E., Marshall, J., Brown, L. J. E., & Goldbart, J. (2019). SLTs' conceptions about their own and parents' roles during intervention with preschool children. *International Journal of Language & Communication Disorders*, 54(4), 596-605. <https://doi.org/10.1111/1460-6984.12462>
- Davis, D. E., Yang, X., DeBlaere, C., McElroy, S. E., Van Tongeren, D. R., Hook, J. N., & Worthington, E. L. (2016). The injustice gap. *Psychology of religion and spirituality*, 8(3), 175-184. <https://doi.org/10.1037/re10000042>
- Davis, R., Campbell, R., Hildon, Z., Hobbs, L., & Michie, S. (2015). Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health psychology review*, 9(3), 323-344. <https://doi.org/10.1080/17437199.2014.941722>
- Deane, P. (2018). *A guide for interdisciplinary researchers: Adding axiology alongside ontology and epistemology*. <https://i2insights.org/2018/05/22/axiology-and-interdisciplinarity/>
- DeGroot, J. M., & Vik, T. A. (2019). "Fake smile. Everything is under control.": The flawless performance of motherhood. *Western Journal of Communication*, 1-19. <https://doi.org/10.1080/10570314.2019.1678763>
- Del Bianco, T., Ozturk, Y., Basadonne, I., Mazzoni, N., & Venuti, P. (2018). The thorn in the dyad: A vision on parent-child relationship in Autism Spectrum Disorder. *Europe's Journal of Psychology*, 14(3), 695-709. <https://doi.org/10.5964/ejop.v14i3.1453>
- Demain, S., Gonçalves, A.-C., Areia, C., Oliveira, R., Marcos, A. J., Marques, A., . . . Hunt, K. (2015). Living with, managing and minimising treatment burden in long term conditions: A systematic review of qualitative research. *PLoS ONE*, 10(5), 1-18. <https://doi.org/10.1371/journal.pone.0125457>

- Dempsey, I., & Foreman, P. (1997). Toward a clarification of empowerment as an outcome of disability service provision. *International Journal of Disability, Development and Education*, 44(4), 287-303.
<https://doi.org/10.1080/0156655970440402>
- Dickerson Mayes, S., Gorman, A., Hillwig-Garcia, J., & Syed, E. (2013). Suicide ideation and attempts in children with autism. *Research in Autism Spectrum Disorders*, 7, 109 - 119.
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed-mode surveys : the tailored design method* (4th ed.). Wiley.
- Dilthey, W., & Rickman, H. P. (1976). *W. Dilthey, selected writings*. Cambridge University Press.
- Dodd, B., & Barker, R. (1990). The efficacy of utilizing parents and teachers as agents of therapy for children with phonological disorders. *Australian Journal of Human Communication Disorders*, 18(1), 29-45.
<https://doi.org/10.3109/asl2.1990.18.issue-1.03>
- Dodd, J., Saggars, S., & Wildy, H. (2009). Constructing the "ideal" family for family-centred practice: Challenges for delivery. *Disability & Society*, 24(2), 173-186.
- Drogomyretska, K., Fox, R., & Colbert, D. (2020). Brief report: stress and perceived social support in parents of children with ASD. *J Autism Dev Disord*.
<https://doi.org/10.1007/s10803-020-04455-x>
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with Autism, Down Syndrome, behavior disorders, and normal development. *Exceptionality*, 2(2), 97.
- Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-oriented program models and professional helping practices. *Family Relations*, 51(3), 221-231.
- Duxbury, L., Stevenson, M., & Higgins, C. (2018). Too much to do, too little time: Role overload and stress in a multi-role environment. *International Journal of Stress Management*, 25(3), 250-266. <https://doi.org/10.1037/str0000062>
- D'Avanzo, P. A., Bass, S. B., Brajuha, J., Gutierrez-Mock, L., Ventriglia, N., Wellington, C., & Sevelius, J. (2019). Medical mistrust and PrEP perceptions among transgender women: A cluster analysis. *Behavioral Medicine*, 45(2), 143-152.
<https://doi.org/10.1080/08964289.2019.1585325>
- Eatough, V., & Smith, J. (2008). Interpretative phenomenological analysis In C. Willig & W. Stainton-Rogers (Eds.), *The sage handbook of qualitative research in psychology* (pp. 179-194). Sage.

- Ebert, K. D., & Kohnert, K. (2010). Common factors in speech-language treatment: an exploratory study of effective clinicians. *J Commun Disord*, *43*(2), 133-147. <https://doi.org/10.1016/j.jcomdis.2009.12.002>
- Eide, P. J. (2008). Recruiting participants. In L. M. Given (Ed.), *The sage encyclopedia of qualitative research methods*. Sage.
- Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, *40*(10), 1274-1284. <https://doi.org/10.1007/s10803-010-0986-y>
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *Br J Clin Psychol*, *38* (Pt 3), 215-229.
- Entwistle, V. (2009). Patient involvement in decision making: the importance of a broad conceptualisation. In A. Edwards & G. Elwyn (Eds.), *Shared decision-making in health care achieving evidence-based patient choice* (2 ed., pp. 37-44). Oxford University Press.
- Espe-Sherwindt, M. (2008). Family-centred practice: collaboration, competency and evidence. *Support for Learning*, *23*(3), 136-143. <https://doi.org/10.1111/j.1467-9604.2008.00384.x>
- Eton, D. T., Elraiyah, T. A., Yost, K. J., Ridgeway, J. L., Johnson, A., Egginton, J. S., . . . Montori, V. M. (2013). A systematic review of patient-reported measures of burden of treatment in three chronic diseases. *Patient Related Outcome Measures*, *5*(4), 7-20.
- Fehr, R., Gelfand, M. J., & Nag, M. (2010). The road to forgiveness: a meta-analytic synthesis of its situational and dispositional correlates. *Psychol Bull*, *136*(5), 894-914. <https://doi.org/10.1037/a0019993>
- Ferrer, R. A., & Mendes, W. B. (2018). Emotion, health decision making, and health behaviour. *Psychology & Health*, *33*(1), 1-16. <https://doi.org/10.1080/08870446.2017.1385787>
- Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology & Practice*, *3*(1), 6.
- Finlay, L. (2012). Five lenses for the reflexive interviewer. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research. The complexity of the craft*. (2nd ed., pp. 317 - 332). Sage.
- Firat, S., Diler, R. S., Avci, A., & Seydaoglu, G. (2002). Comparison of psychopathology in the mothers of autistic and mentally retarded children. *J Korean Med Sci*, *17*(5), 679-685. <https://doi.org/10.3346/jkms.2002.17.5.679>

- Fishbein, M., Triandis, H. C., Kanfer, F. H., Becker, M., Middlestadt, S. E., & Eichler, A. (2001). Factors influencing behaviour and behaviour change. In *Handbook of health psychology* (pp. 3- 18). Lawrence Erlbaum Associates.
- Flowers, P. (2008). Temporal tales: The use of multiple interviews with the same participant. *Qualitative Methods in Psychology Newsletter*, 5, 24-27.
- Foody, C., James, J., & Leader, G. (2015). Parenting stress, salivary biomarkers, and ambulatory blood pressure: A comparison between mothers and fathers of children with Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, 45(4), 1084-1095. <https://doi.org/10.1007/s10803-014-2263-y>
- Fox, N. J. (2008). Induction. In L. M. Given (Ed.), *The sage encyclopedia of qualitative research methods* (pp. 429-430). Sage.
- Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C. R., Montori, V. M., . . . Mair, F. S. (2013). Uncovering treatment burden as a key concept for stroke care: A systematic review of qualitative research. *PLoS medicine*, 10(6), e1001473. <https://doi.org/10.1371/journal.pmed.1001473>
- Gemignani, M. (2017). Toward a critical reflexivity in qualitative inquiry: Relational and posthumanist reflections on realism, researcher's centrality, and representationalism in reflexivity. *Qualitative Psychology*, 4(2), 185-198. <https://doi.org/10.1037/qup0000070>
- Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbin, K. A., & Szatmari, P. (2019). Parent engagement in autism-related care: a qualitative grounded theory study. *Health Psychology and Behavioral Medicine*, 7(1), 1-18. <https://doi.org/10.1080/21642850.2018.1556666>
- Gibbard, D. (1998). *Parent-based intervention programme: a group approach for language-delayed children*. Winslow.
- Giorgi, A. (2000). Concerning the application of phenomenology to caring research. *Scandinavian Journal of Caring Sciences*, 14(1), 11.
- Giorgi, A. (2009). *The descriptive phenomenological method in psychology : a modified Husserlian approach*. Duquesne University Press.
- Glass, M. R. (2015). Teaching critical reflexivity in short-term international field courses: practices and problems. *Journal of Geography in Higher Education*, 39(4), 554-567. <https://doi.org/10.1080/03098265.2015.1084610>
- Glogowska, M., & Campbell, R. (2000). Investigating parental views of involvement in pre-school speech and language therapy. *International Journal Of Language & Communication Disorders*, 35(3), 391-405.
- Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society*, 18, 266 - 277.

- Glogowska, M., Campbell, R., Peters, T. J., Roulstone, S., & Enderby, P. (2002). A multimethod approach to the evaluation of community preschool speech and language therapy provision. *Child Care Health Dev*, 28(6), 513-521.
- Glynn, K., Maclean, H., Forte, T., & Cohen, M. (2009). The association between role overload and women's mental health. *Journal of Women's Health*, 18(2), 217-223. <https://doi.org/10.1089/jwh.2007.0783>
- Goffman, E. (1975). *The presentation of self in everyday life*. Anchor Books.
- Goldbart, J., & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC. *AAC: Augmentative & Alternative Communication*, 20(4), 194-208.
- Golden, S. D., & Earp, J. A. L. (2012). Social ecological approaches to individuals and their contexts: Twenty years of health education & behavior health promotion interventions. *Health Education & Behavior*, 39(3), 364-372. <https://doi.org/10.1177/1090198111418634>
- Goode, W. J. (1960). A Theory of Role Strain. *American Sociological Review*, 25(4), 483-496.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-107). Sage.
- Gubrium, J. F., & Holstein, J. A. (2012). Narrative practice and the transformation of interview subjectivity. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The sage handbook of interview research* (pp. 27 - 44). Sage.
- Gwaltney, C. J., Metrik, J., Kahler, C. W., & Shiffman, S. (2009). Self-efficacy and smoking cessation: a meta-analysis. *Psychology of addictive behaviors : Journal of the Society of Psychologists in Addictive Behaviors*, 23(1), 56-66. <https://doi.org/10.1037/a0013529>
- Haanstra, T. M., van den Berg, T., Ostelo, R. W., Poolman, R. W., Jansma, E. P., Cuijpers, P., & de Vet, H. C. (2012). Systematic review: do patient expectations influence treatment outcomes in total knee and total hip arthroplasty? *Health and quality of life outcomes*, 10, 152-152. <https://doi.org/10.1186/1477-7525-10-152>
- Hage, J., & Powers, C. H. (1992). *Post-industrial lives : roles and relationships in the 21st century*. Sage.
- Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: a review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, 49(1), 14-24.

- Harris, M., & Butterworth, G. (2002). *Developmental psychology : a student's handbook*. Psychology Press.
- Hayes, S. & Watson, S. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 43(3), 629-642. <https://doi.org/10.1007/s10803-012-1604-y>
- Haynes, R. B., McDonald, H., Garg, A. X., & Montague, P. (2002). Interventions for helping patients to follow prescriptions for medications. *Cochrane Database Syst Rev*(2), Cd000011. <https://doi.org/10.1002/14651858.cd000011>
- Health Services Executive (2012). National review of autism services past, present and way forward. <http://www.fedvol.ie/fileupload/Next%20Steps/autismreview2012.pdf>
- Health Services Executive (2018). *Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders*. <https://assets.gov.ie/10708/33f312f0421443bc967f4a5f7554b0dd.pdf>
- Health Services Executive (2020). *Progressing Disability Services for Children and Young People Programme (PDS)*. <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/>
- Hill, P. C., Exline, J. J., & Cohen, A. B. (2005). The social psychology of justice and forgiveness in civil and organizational settings. In E. Worthington & N. G. Wade (Eds.), *The Handbook of Forgiveness* (pp. 477 - 491). Routledge.
- Hindin, M. J. (2007). Role theory. In G. Ritzer (Ed.), *The blackwell encyclopedia of sociology* (pp. 3959 - 3962). Blackwell Publishing Ltd.
- Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. *Social Science & Medicine*, 96, 138-146 139p. <https://doi.org/10.1016/j.socscimed.2013.07.012>
- Hoogsteen, L., & Woodgate, R. L. (2013). Centering Autism within the family: A qualitative approach to Autism and the family. *Journal of Pediatric Nursing*, 28(2), 135-140. <https://doi.org/http://dx.doi.org/10.1016/j.pedn.2012.06.002>
- Howson, A. (2021). Disability and Impairment. In: Salem Press Encyclopedia. 2020. Accessed October 10, 2021. <https://eds-p-ebSCOhost->

com.elib.tcd.ie/eds/detail/detail?vid=0&sid=08606b0f-7ebf-41da-bc55-4d43ec0a9c00%40redis&bdata=#AN=89185429&db=ers

- Hunt, K. J., & May, C. R. (2017). Managing expectations: cognitive authority and experienced control in complex healthcare processes. *BMC Health Services Research, 17*, 1-13. <https://doi.org/10.1186/s12913-017-2366-1>
- Hurtig, T., Kuusikko, S., Mattila, M.-L., Haapsamo, H., Ebeling, H., Jussila, K., . . . Moilanen, I. (2009). Multi-informant reports of psychiatric symptoms among high-functioning adolescents with Asperger syndrome or autism. *Autism: The International Journal of Research & Practice, 13*(6), 583.
- Iles, R. A., Davidson, M., Taylor, N. F., & O'Halloran, P. (2009). Systematic review of the ability of recovery expectations to predict outcomes in non-chronic non-specific low back pain. *Journal of Occupational Rehabilitation, 19*(1), 25-40. <https://doi.org/10.1007/s10926-008-9161-0>
- Jackson, J. (1998). Contemporary criticisms of role theory. *Journal of Occupational Science: Australia, 5*(2), 49-55.
- Jaiswal, J. (2019). Whose responsibility is it to dismantle medical mistrust? Future directions for researchers and health care providers. *Behavioral Medicine, 45*(2), 188-196. <https://doi.org/10.1080/08964289.2019.1630357>
- James, D. M. (2011). The applicability of normalisation process theory to speech and language therapy: a review of qualitative research on a speech and language intervention. *Implementation science : IS, 6*, 95. <https://doi.org/10.1186/1748-5908-6-95>
- Kaba, R., & Sooriakumaran, P. (2007). The evolution of the doctor-patient relationship. *International Journal of Surgery, 5*(1), 57-65. <https://doi.org/https://doi.org/10.1016/j.ijisu.2006.01.005>
- Kahneman, D., & Tversky, A. (2000). *Choices, values, and frames*. Cambridge University Press.
- Katz, D., & Kahn, R. L. (1978). *The social psychology of organizations* (2nd ed.). Wiley.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. <https://doi.org/10.1177/1362361315588200>
- Kim, S. H., Paul, R., Tager-Flusberg, H., & Lord, C. (2014). Language and communication in autism. In F. R. Volkmar, S. J. Rogers, R. Paul, & K. A. Pelphrey (Eds.), *Handbook of autism and pervasive developmental disorders* (4th ed., Vol. 1. Diagnosis, development and brain mechanisms, pp. 230-262). Wiley.

- Kinard, J., & Watson, L. (2021). Parent responsiveness to children at risk of ASD. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders* (2nd ed., pp. 3288-3300). Springer.
- King, G., Chiarello, L. A., Ideishi, R., D'Arrigo, R., Smart, E., Ziviani, J., & Pinto, M. (2020). The nature, value, and experience of engagement in pediatric rehabilitation: Perspectives of youth, caregivers, and service providers. *Dev Neurorehabil*, *23*(1), 18-30. <https://doi.org/10.1080/17518423.2019.1604580>
- King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: a motivational framework. *Child Adolesc Ment Health*, *19*(1), 2-8. <https://doi.org/10.1111/camh.12015>
- Kingston, A. K. (2007). *Mothering special needs : a different maternal journey*. Jessica Kingsley Publishers.
- Kiviniemi, M. T., Ellis, E. M., Hall, M. G., Moss, J. L., Lillie, S. E., Brewer, N. T., & Klein, W. M. P. (2018). Mediation, moderation, and context: Understanding complex relations among cognition, affect, and health behaviour. *Psychology & Health*, *33*(1), 98-116. <https://doi.org/10.1080/08870446.2017.1324973>
- Klatte, I. S., Lyons, R., Davies, K., Harding, S., Marshall, J., McKean, C., & Roulstone, S. (2020). Collaboration between parents and SLTs produces optimal outcomes for children attending speech and language therapy: Gathering the evidence. *International Journal of Language and Communication Disorders*, *55*(4), 618-628. <https://doi.org/10.1111/1460-6984.12538>
- Koro-Ljungberg, M. (2008). A social constructionist framing of the research interview. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 429-444). The Guilford Press.
- Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *8*, 1339-1350. <https://doi.org/10.1016/j.rasd.2014.07.002>
- Lambert, B. L., Centomani, N. M., Smith, K. M., Helmchen, L. A., Bhaumik, D. K., Jalundhwala, Y. J., & McDonald, T. B. (2016). The "seven pillars" response to patient safety incidents: Effects on medical liability processes and outcomes. *Health Serv Res*, *51* Suppl 3(Suppl 3), 2491-2515. <https://doi.org/10.1111/1475-6773.12548>
- Larkin, M., & Griffiths, M. D. (2002). Experiences of addiction and recovery: The case for subjective accounts. *Addiction Research & Theory*, *10*(3), 281-311. <https://doi.org/10.1080/16066350211866>

- Larkin, M., Shaw, R., & Flowers, P. (2018). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology*. <https://doi.org/10.1080/14780887.2018.1540655>
- Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (pp. 101-116). Wiley Blackwell.
- Lau, A. S., Gonzalez, J. C., Barnett, M. L., Kim, J. J., Saifan, D., & Brookman-Fraze, L. (2018). Community therapist reports of client engagement challenges during the implementation of multiple EBPs in children's mental health. *Evidence-Based Practice in Child and Adolescent Mental Health*, 3(3), 197-212. <https://doi.org/10.1080/23794925.2018.1455545>
- LaVeist, T. A., Isaac, L. A., & Williams, K. P. (2009). Mistrust of health care organizations is associated with underutilization of health services. *Health Services Research*, 44(6), 2093-2105. <https://doi.org/10.1111/j.1475-6773.2009.01017.x>
- Lazarus, J. (2021). Negativity bias: An evolutionary hypothesis and an empirical programme. *Learning and Motivation*, 75. <https://doi.org/10.1016/j.lmot.2021.101731>
- Levickis, P., McKean, C., Wiles, A., & Law, J. (2020). Expectations and experiences of parents taking part in parent-child interaction programmes to promote child language: a qualitative interview study. *Int J Lang Commun Disord*, 55(4), 603-617. <https://doi.org/10.1111/1460-6984.12543>
- Li, C., Unger, J. B., Schuster, D., Rohrbach, L. A., Howard-Pitney, B., & Norman, G. (2003). Youths' exposure to environmental tobacco smoke (ETS): Associations with health beliefs and social pressure. *Addictive Behaviors*, 28(1), 39-53. [https://doi.org/10.1016/S0306-4603\(01\)00215-5](https://doi.org/10.1016/S0306-4603(01)00215-5)
- Li, Y., Ren, L., & Luo, F. (2016). Is bad stronger than good? The impact of police-citizen encounters on public satisfaction with police. *Policing: An International Journal of Police Strategies & Management*, 39(1), 109-126. <https://doi.org/10.1108/PIJPSM-05-2015-0058>
- Lillo-Navarro, C., Medina-Mirapeix, F., Escolar-Reina, P., Montilla-Herrador, J., Gomez-Arnaldos, F., & Oliveira-Sousa, S. L. (2015). Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study. *Journal of Physiotherapy*, 61(2), 81-86. <https://doi.org/https://doi.org/10.1016/j.jphys.2015.02.014>

- Lim, K. K., & Chong, W. H. (2017). Moderating effect of child's autism spectrum disorder (ASD) diagnosis on benefit finding and negative affect of parents. *Am J Orthopsychiatry*, *87*(3), 357-364. <https://doi.org/10.1037/ort0000251>
- Lin, E. X. (2019). Moral hierarchies within autism parenting: Making parent-therapists and perpetuating disparities within contemporary China. *BioSocieties* *14*(2), 155–178.
- Love, B., Vetere, A., & Davis, P. (2020). Should interpretative phenomenological analysis (IPA) be used with focus groups? Navigating the bumpy road of “iterative loops,” idiographic journeys, and “phenomenological bridges”. *International Journal of Qualitative Methods*, *19*, 1609406920921600. <https://doi.org/10.1177/1609406920921600>
- Lyons, R., O'Malley, M. P., O'Connor, P., & Monaghan, U. (2010). "It's just so lovely to hear him talking": Exploring the early-intervention expectations and experiences of parents. *Child Language Teaching and Therapy*, *26*(1), 61-76.
- MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations*, *8*(1), 74-85. <https://doi.org/10.1111/j.1369-7625.2005.00319.x>
- Macleon, M. F., & Chesson, R. (1991). Factors affecting parents' role as co-therapists: A pilot study of parents of children with motor-learning difficulties. *The British Journal of Occupational Therapy*, *54*(7), 262-266. <https://doi.org/10.1177/030802269105400708>
- Macleod, C., & Bhatia, S. (2008). Postcolonialism and psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The sage handbook of qualitative research in psychology* (pp. 576 - 589). Sage.
- Marsack-Topolewski, C. N., & Church, H. L. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *124*(2), 145-156. <https://doi.org/10.1352/1944-7558-124.2.145>
- Marshall, J., & Goldbart, J. (2008). Research report: 'communication is everything I think.' Parenting a child who needs Augmentative and Alternative Communication (AAC). *International Journal of Language & Communication Disorders*, *43*(1), 77-98 22p.
- Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language & Communication Disorders*, *42*(5), 533-555.

- Martin, L. R., Williams, S. L., Haskard, K. B., & Dimatteo, M. R. (2005). The challenge of patient adherence. *Therapeutics and clinical risk management*, 1(3), 189-199.
- Matson, J. L., & Burns, C. O. (2019). Comorbidity and the need for interdisciplinary treatments. In R. D. Rieske (Ed.), *Handbook of Interdisciplinary Treatments for Autism Spectrum Disorder* (pp. 29 - 48). Springer.
- Matthews, W. J. (1998). Let's get real: The fallacy of post-modernism. *Journal of Theoretical and Philosophical Psychology*, 18(1), 16-32.
<https://doi.org/10.1037/h0091169>
- May, C. R. (2014). The burden of treatment and the burden of symptoms: the problem of workload and institutional boundaries in chronic disease. *Working Papers in Health Sciences*, 1(9), 1 – 6.
- May, C. R., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., . . . Shippee, N. (2014). Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Serv Res*, 14, 281.
<https://doi.org/10.1186/1472-6963-14-281>
- May, C. R., Montori, V., M., & Mair, F., S. (2009). We need minimally disruptive medicine. *BMJ: British Medical Journal*(7719), 485.
- Mayall, B. (2002). *Towards a sociology for childhood : thinking from children's lives*. Open University Press.
- McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *Int J Speech Lang Pathol*, 13(3), 251-267.
<https://doi.org/10.3109/17549507.2011.535565>
- McCubbin, H. I., & Patterson, J. M. (1983). The Family Stress Process. *Marriage & Family Review*, 6(1-2), 7-37. https://doi.org/10.1300/J002v06n01_02
- McCurtin, A., & Carter, B. (2015). 'We don't have recipes; we just have loads of ingredients': explanations of evidence and clinical decision making by speech and language therapists. *Journal of Evaluation in Clinical Practice*, 21(6), 1142-1150. <https://doi.org/10.1111/jep.12285>
- McCurtin, A., & Clifford, A. M. (2015). What are the primary influences on treatment decisions? How does this reflect on evidence-based practice? Indications from the discipline of speech and language therapy. *Journal of Evaluation in Clinical Practice*, 21(6), 1178-1189. <https://doi.org/10.1111/jep.12385>
- McGarry, K. (2019). Reflexivity as a process for coming into knowing. *LEARNing Landscapes*, 12(1), 155-170.

- McGrew, J. H., & Keyes, M. L. (2014). Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 8(10), 1373-1385. <https://doi.org/10.1016/j.rasd.2014.07.011>
- Mead, G. H. (1934). *Mind, self and society from the standpoint of a social behaviorist*. University of Chicago Press.
- Meleady, J., Clyne, C., Braham, J., & Carr, A. (2020). Positive contributions among parents of children on the autism spectrum: A Systematic review. *Research in Autism Spectrum Disorders*, 78. <https://doi.org/10.1016/j.rasd.2020.101635>
- Meleady, J., Nearchou, F., Bramham, J., & Carr, A. (2020). Family adaptation among parents of children on the autism spectrum without a comorbid intellectual disability: A test of the Double ABCX model. *Research in Autism Spectrum Disorders*, 78. <https://doi.org/10.1016/j.rasd.2020.101637>
- Melvin, K., Meyer, C., & Scarinci, N. (2019). What does "engagement" mean in early speech pathology intervention? A qualitative systematised review. *Disability and rehabilitation*, 1-14. <https://doi.org/10.1080/09638288.2018.1563640>
- Melvin, K., Meyer, C., & Scarinci, N. (2020). What does a family who is "engaged" in early intervention look like? Perspectives of Australian speech-language pathologists. *International Journal of Speech-Language Pathology*, 1-11. <https://doi.org/10.1080/17549507.2020.1784279>
- Moorcroft, A., Scarinci, N., & Meyer, C. (2019). "I've had a love-hate, I mean mostly hate relationship with these PODD books": parent perceptions of how they and their child contributed to AAC rejection and abandonment. *Disability and Rehabilitation: Assistive Technology*, 1-11. <https://doi.org/10.1080/17483107.2019.1632944>
- Moore, T. R., & Symons, F. J. (2009). Adherence to Behavioral and Medical Treatment Recommendations by Parents of Children with Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, 39(8), 1173-1184. <https://doi.org/10.1007/s10803-009-0729-0>
- National Institute for Health and Care Excellence. (2013). *The management and support of children and young people on the autistic spectrum*. NICE. <https://www.nice.org.uk/guidance/cg170>
- Nicholas, D., B., Zwaigenbaum, L., Ing, S., MacCulloch, R., Roberts, W., McKeever, P., & McMorris, C., A. (2016). 'Live it to understand it' : The experiences of mothers of children with Autism Spectrum Disorder. *Qualitative Health Research*, 26(7), 921-934.
- Nicholas, D. B., MacCulloch, R., Roberts, W., Zwaigenbaum, L., & McKeever, P. (2020). Tensions in maternal care for children, youth, and adults With Autism

- Spectrum Disorder. *Global Qualitative Nursing Research*, 7, 2333393620907588. <https://doi.org/10.1177/2333393620907588>
- Norris, C. J. (2021). The negativity bias, revisited: Evidence from neuroscience measures and an individual differences approach. *Social Neuroscience*, 16(1), 68-82. <https://doi.org/10.1080/17470919.2019.1696225>
- Noyan Erbaş, A., Özcebe, E., & Cak Esen, T. (2020). Investigation of the effect of Hanen's "More Than Words" on parental self-efficacy, emotional states, perceived social support, and on communication skills of children with ASD. *Logoped Phoniatr Vocol*, 1-11. <https://doi.org/10.1080/14015439.2020.1717601>
- O'Toole, C., Lyons, R., & Houghton, C. (2021). A qualitative evidence synthesis of parental experiences and perceptions of parent-child interaction therapy for preschool children with communication difficulties. *J Speech Lang Hear Res*, 64(8), 3159-3185. https://doi.org/10.1044/2021_jslhr-20-00732
- Ombudsman for Children (OCO) (2020). *Unmet needs - A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs*. https://www.oco.ie/app/uploads/2020/10/15438_OCO_Assessmnet_of_Need_Report_Interactive.pdf
- Okpara, N., Chauvenet, C., Grich, K., & Turner-McGrievy, G. (2021). "Food doesn't have power over me anymore!" Self-efficacy as a driver for dietary adherence among African American adults participating in plant-based and meat-reduced dietary interventions: A qualitative study. *Journal of the Academy of Nutrition and Dietetics*. <https://doi.org/10.1016/j.jand.2021.10.023>
- Palys, T. (2008). Purposive sampling. In L. M. Given (Ed.), *The sage encyclopedia of qualitative research methods* (pp. 697-698). Sage.
- Parsons, T. (1991). *The social system*. Routledge.
- Patterson, G. R., & Chamberlain, P. (1994). A functional analysis of resistance during parent training therapy *Clinical Psychology: Science and Practice*, 1(1), 53-70. <https://doi.org/https://doi.org/10.1111/j.1468-2850.1994.tb00006.x>
- Petty, N. J., Thomson, O. P., & Stew, G. (2012). Masterclass: ready for a paradigm shift? Part 1: Introducing the philosophy of qualitative research. *Manual Therapy*, 17, 267-274. <https://doi.org/10.1016/j.math.2012.03.006>
- Peytchev, A., & Hill, C. A. (2010). Experiments in mobile web survey design similarities to other modes and unique considerations. *Social Science Computer Review*, 28(3), 319-335. <https://doi.org/10.1177/0894439309353037>
- Phoenix, M., Smart, E., & King, G. (2019). 'I didn't know what to expect': Describing parents' expectations in children's rehabilitation services. *Physical &*

- Occupational Therapy In Pediatrics*, 1-19.
<https://doi.org/10.1080/01942638.2019.1665155>
- Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii [A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology]. *Czasopismo Psychologiczne*, 18(2), 361-369.
- Piggot, J., Hocking, C., & Paterson, J. (2003). Parental adjustment to having a child with cerebral palsy and participation in home therapy programs. *Physical and Occupational Therapy in Pediatrics*, 23(4), 5-29.
- Piven, J., & Rabins, P. (2011). Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of the American Geriatrics Society*, 59(11), 2151-2155. <https://doi.org/10.1111/j.1532-5415.2011.03632.x>
- Portone, C., Johns, I. I. I. M. M., & Hapner, E. R. (2008). A review of patient adherence to the recommendation for voice therapy. *Journal of Voice*, 22(2), 192-196. <https://doi.org/10.1016/j.jvoice.2006.09.009>
- Potter, J., & Hepburn, A. (2005). Qualitative interviews in psychology: problems and possibilities. *Qualitative Research in Psychology*, 2(4), 281-307. <https://doi.org/10.1191/1478088705qp045oa>
- Potter, J., & Hepburn, A. (2012). Eight challenges for interview researchers. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The sage handbook of interview research* (2nd ed., pp. 555-570). Sage.
- Powell, W., Richmond, J., Mohottige, D., Yen, I., Joslyn, A., & Corbie-Smith, G. (2019). Medical mistrust, racism, and delays in preventive health screening among African-American men. *Behavioral Medicine*, 45(2), 102-117. <https://doi.org/10.1080/08964289.2019.1585327>
- Pring, T., Flood, E., Dodd, B., & Joffe, V. (2012). The working practices and clinical experiences of paediatric speech and language therapists: a national UK survey. *Int J Lang Commun Disord*, 47(6), 696-708. <https://doi.org/10.1111/j.1460-6984.2012.00177.x>
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: a discussion and critique. *Nurse Researcher*, 18(3), 20-24.
- Rafferty, D., Tidman, L., & Ekas, N. V. (2020). Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability. *Journal of Intellectual Disability Research*, 64(6), 463-474. <https://doi.org/10.1111/jir.12728>

- Ramig, L. O., Sapir, S., Countryman, S., Pawlas, A. A., O'Brien, C., Hoehn, M., & Thompson, L. L. (2001). Intensive voice treatment (LSVT (R)) for patients with Parkinson's disease: a 2 year follow up. *Journal of Neurology Neurosurgery and Psychiatry*, *71*(4), 493-498.
- Reeder, J., & Morris, J. (2020). Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care? *Journal of Child Health Care*, 1-16.
<https://doi.org/10.1177/1367493520910832>
- Reisi, M., Mostafavi, F., Javadzade, H., Mahaki, B., Tavassoli, E., & Sharifirad, G. (2016). Impact of health literacy, self-efficacy, and outcome expectations on adherence to self-care behaviors in Iranians with type 2 diabetes. *Oman medical journal*, *31*(1), 52-59. <https://doi.org/10.5001/omj.2016.10>
- Riek, B. M., & Mania, E. W. (2012). The antecedents and consequences of interpersonal forgiveness: A meta-analytic review. *Personal Relationships*, *19*(2), 304-325. <https://doi.org/10.1111/j.1475-6811.2011.01363.x>
- Rios, K., Aleman-Tovar, J., & Burke, M. M. (2020). Special education experiences and stress among Latina mothers of children with autism spectrum disorder (ASD). *Research in Autism Spectrum Disorders*, *73*.
<https://doi.org/10.1016/j.rasd.2020.101534>
- Robbennolt, J. K. (2009). Apologies and medical error. *Clinical Orthopaedics and Related Research*, *467*(2), 376-382. <https://doi.org/10.1007/s11999-008-0580-1>
- Roddy, Á., & O'Neill, C. (2019). The economic costs and its predictors for childhood Autism Spectrum Disorders in Ireland: How is the burden distributed? *Autism: The International Journal of Research and Practice*, *23*(5), 1106-1118.
- Roddy, Á., & O'Neill, C. (2020). Predictors of unmet needs and family debt among children and adolescents with an autism spectrum disorder: Evidence from Ireland. *Health Policy*. <https://doi.org/10.1016/j.healthpol.2020.01.005>
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education Quarterly*, *15*(2), 175-183.
- Roulstone, S., Harding, S., & Morgan, L. (2016). *Exploring the involvement of children and young people with speech, language and communication needs and their families in decision making – a research project*.
https://www.thecommunicationtrust.org.uk/media/443274/tct_involvingcyp_research_report_final.pdf
- Royal College of Speech and Language Therapists. (2009). *Resource manual for commissioning and planning services for SLCN: Autistic Spectrum Disorders* . RCSLT.

- Ryan, C., & Quinlan, E. (2018). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31, 203-214. <https://doi.org/10.1111/jar.12354>
- Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53. <https://doi.org/10.1111/j.1468-3148.2008.00438.x>
- Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, 23(3), 199.
- Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability*, 37(4), 294-302. <https://doi.org/10.3109/13668250.2012.736614>
- Saha, S., & Beach, M. C. (2020). Impact of physician race on patient decision-making and ratings of physicians: a randomized experiment using video vignettes. *J Gen Intern Med*, 35(4), 1084-1091. <https://doi.org/10.1007/s11606-020-05646-z>
- Santer, M., Ring, N., Yardley, L., Geraghty, A. W. A., & Wyke, S. (2014). Treatment non-adherence in pediatric long-term medical conditions: systematic review and synthesis of qualitative studies of caregivers' views. *BMC Pediatrics*, 14(1), 63. <https://doi.org/10.1186/1471-2431-14-63>
- Sarrett, J. C. (2015). Custodial homes, therapeutic homes, and parental acceptance: Parental experiences of Autism in Kerala, India and Atlanta, GA USA. *Cult Med Psychiatry*, 39(2), 254-276. <https://doi.org/10.1007/s11013-015-9441-z>
- Sav, A., Salehi, A., Mair, F., S., & McMillan, S., S. (2017). Measuring the burden of treatment for chronic disease: implications of a scoping review of the literature. *BMC Medical Research Methodology*, 17(1), 1-14. <https://doi.org/10.1186/s12874-017-0411-8>
- Schraeder, K. E., & Reid, G. J. (2015). Why wait? The effect of wait-times on subsequent help-seeking among families looking for children's mental health services. *Journal of Abnormal Child Psychology*, 43(3), 553-565. <https://doi.org/10.1007/s10802-014-9928-z>
- Schrøder, K., la Cour, K., Jørgensen, J. S., Lamont, R. F., & Hvidt, N. C. (2017). Guilt without fault: A qualitative study into the ethics of forgiveness after traumatic childbirth. *Social science & medicine (1982)*, 176, 14-20. <https://doi.org/10.1016/j.socscimed.2017.01.017>
- Schuermans, N. (2013). *Towards rigour in qualitative research* [Paper presented at Human Geography PhD Research Seminar, Leuven].

https://www.academia.edu/3068584/Schuermans_2013_Towards_rigour_in_qualitative_research

- Schwandt, T. (2000). Three epistemological stances for qualitative inquiry: interpretivism, hermeneutics and social constructivism. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 189-214). Sage.
- Schwellnus, H., Seko, Y., King, G., Baldwin, P., & Servais, M. (2020). Solution-focused coaching in pediatric rehabilitation: Perceived therapist impact. *Physical & Occupational Therapy In Pediatrics, 40*(3), 263-278.
<https://doi.org/10.1080/01942638.2019.1675846>
- Shippee, N. D., Shah, N. D., May, C. R., Mair, F. S., & Montori, V. M. (2012). Review article: Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology, 65*, 1041-1051. <https://doi.org/10.1016/j.jclinepi.2012.05.005>
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with Autism Spectrum Disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*, 921-929.
<https://doi.org/10.1097/CHI.0b013e318179964f>
- Sinclair, J. (2013). *Why I dislike person first language*. <http://www.larry-arnold.net/Autonomy/index.php/>
- Skeat, J., & Roddam, H. (2019). What do parents think about their involvement in speech-language pathology intervention? A qualitative critically appraised topic. *Evidence-Based Communication Assessment & Intervention, 13*(1/2), 15.
- Sluss, D. M., van Dick, R., & Thompson, B. S. (2011). Role theory in organizations: A relational perspective. In S. Zedeck (Ed.), *APA handbook of industrial and organizational psychology, Vol 1: Building and developing the organization*. (pp. 505-534). American Psychological Association. <https://doi.org/10.1037/12169-016>
- Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition—A concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing, 30*, 143-159.
<https://doi.org/10.1016/j.pedn.2014.10.014>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54.

- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27.
<https://doi.org/10.1080/17437199.2010.510659>
- Smith, J. A., Larkin, M. H., & Flowers, P. (2009). *Interpretative phenomenological analysis : theory, method and research*. SAGE.
- Smith, J. A., & Osborne, M. (2003). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 53-80). Sage.
- Smith, K. A., & Samuels, A. E. (2021). A scoping review of parental roles in rehabilitation interventions for children with developmental delay, disability, or long-term health condition. *Research in Developmental Disabilities*, 111.
<https://doi.org/10.1016/j.ridd.2021.103887>
- Sousa, D. (2008). From Monet's paintings to Margaret's ducks. *Existential Analysis: Journal of the Society for Existential Analysis*, 19(1), 143-155.
- Spiers, J., & Riley, R. (2019). Analysing one dataset with two qualitative methods: The distress of general practitioners, a thematic and interpretative phenomenological analysis. *Qualitative Research in Psychology*, 16(2), 276-290. <https://doi.org/10.1080/14780887.2018.1543099>
- Steiner, A., Koegel, L., Koegel, R., & Ence, W. (2012). Issues and theoretical constructs regarding parent education for Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, 42(6), 1218-1227.
<https://doi.org/10.1007/s10803-011-1194-0>
- Stephens, M. A. P., & Franks, M. M. (1999). Parent Care in the Context of Women's Multiple Roles. *Current Directions in Psychological Science*, 8(5), 149-152.
- Stewart, M., McGillivray, J., Forbes, D., & Austin, D. (2017). Parenting a child with an autism spectrum disorder: a review of parent mental health and its relationship to a trauma-based conceptualisation. *Advances in Mental Health*, 15(1), 4 - 14.
- Stošić, J., Frey Škrinjar, J., & Preece, D. (2020). Families of children on the autism spectrum: experience of daily life and impact of parent education. *Support for Learning*, 35(2), 205-221. <https://doi.org/10.1111/1467-9604.12300>
- Straus, S. E., Glasziou, P., Richardson, W. S., & Haynes, R. B. (2019). *Evidence-based medicine : how to practice and teach EBM* (5th ed.). Elsevier.
- Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities*, 33, 688-703. <https://doi.org/10.1016/j.ridd.2011.11.008>

- Stryker, S. (2001). Traditional symbolic interactionism, role theory, and structural symbolic interactionism. The road to Identity Theory. In J. H. Turner (Ed.), *Handbook of Sociological Theory* (pp. 211 - 232). Springer.
- Sugden, E., Munro, N., Trivette, C. M., Baker, E., & Williams, A. L. (2019). Parents' experiences of completing home practice for speech sound disorders. *Journal of Early Intervention, 41*(2), 159-181.
<https://doi.org/10.1177/1053815119828409>
- Sullivan, L. S. (2020). Trust, risk, and race in American Medicine. *Hastings Center Report, 50*(1), 18-26. <https://doi.org/10.1002/hast.1080>
- Swaine, Z. (2011). Medical Model. In J. S. Kreutzer, J. DeLuca, & B. Caplan (Eds.), *Encyclopedia of Clinical Neuropsychology* (pp. 1542-1543). Springer New York.
https://doi.org/10.1007/978-0-387-79948-3_2131
- Sweeney, M. R., Staines, A., & Boilson, A. (2016). *Autism counts a report on Autism Spectrum Disorder prevalence estimation in the Republic of Ireland. Executive summary report.*
- Sønsterud, H., Kirmess, M., Howells, K., Ward, D., Feragen, K. B., & Halvorsen, M. S. (2019). The working alliance in stuttering treatment: A neglected variable? *International Journal of Language & Communication Disorders, 54*(4), 606-619.
<https://doi.org/10.1111/1460-6984.12465>
- Tabatabai, A. (2020). Mother of a person: neoliberalism and narratives of parenting children with disabilities. *Disability & Society, 35*(1), 111-131.
<https://doi.org/10.1080/09687599.2019.1621739>
- Taylor, L. J., Luk, S. Y. L., Leadbitter, K., Moore, H. L., & Charman, T. (2021). Are child autism symptoms, developmental level and adaptive function associated with caregiver feelings of wellbeing and efficacy in the parenting role? *Research in Autism Spectrum Disorders, 83*. <https://doi.org/10.1016/j.rasd.2021.101738>
- Ten Have, P. (2004). *Understanding Qualitative Research and Ethnomethodology*. Sage.
- Thompson, K. M. (1998). Early intervention services in daily family life: Mothers' perceptions of 'ideal' versus 'actual' service provision. *Occupational Therapy International, 5*(3), 206-221. <https://doi.org/10.1002/oti.76>
- Thornton, R., & Nardi, P. M. (1975). The dynamics of role acquisition. *American Journal of Sociology*(4), 870-885.
- Todd, S., & Jones, S. (2003). 'Mum's the word!': Maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities, 16*(3), 229-244. <https://doi.org/10.1046/j.1468-3148.2003.00163.x>

- Tomkins, L., & Eatough, V. (2010). Reflecting on the use of IPA with focus groups: Pitfalls and potentials. *Qualitative Research in Psychology, 7*(3), 244-262. <https://doi.org/10.1080/14780880903121491>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with Autism: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry, 45*, 561-569. <https://doi.org/10.1097/01.chi.0000205701.48324.26>
- Topp, J., Westenhöfer, J., Scholl, I., & Hahlweg, P. (2018). Shared decision-making in physical therapy: A cross-sectional study on physiotherapists' knowledge, attitudes and self-reported use. *Patient Education and Counseling, 101*(2), 346-351. <https://doi.org/https://doi.org/10.1016/j.pec.2017.07.031>
- Traynor, S. M., Metsch, L. R., Gooden, L., Stitzer, M., Matheson, T., Tross, S., . . . Feaster, D. J. (2021). Self-efficacy as a mediator of patient navigation interventions to engage persons living with HIV and substance use. *Drug and Alcohol Dependence, 221*, 108567. <https://doi.org/https://doi.org/10.1016/j.drugalcdep.2021.108567>
- Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family–professional partnerships: Collective empowerment as the model for the early twenty-first century. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention., 2nd ed.* (pp. 630-650). Cambridge University Press. <https://doi.org/10.1017/CBO9780511529320.029>
- Turner, R. H. (1978). The role and the person. *American Journal of Sociology, 81*(1), 1 - 23.
- Turner, R. H. (2001). Handbook of sociological theory. In J. H. Turner (Ed.), *Handbooks of sociology and social research* (pp. 233 - 254). Springer. <https://doi.org/10.1007/0-387-36274-6>
- Unkelbach, C., Alves, H., & Koch, A. (2020). Negativity bias, positivity bias, and valence asymmetries: Explaining the differential processing of positive and negative information. *Advances in Experimental Social Psychology, 62*, 115-187. <https://doi.org/10.1016/bs.aesp.2020.04.005>
- van Leer, E., & Connor, N. P. (2015). Predicting and influencing voice therapy adherence using social-cognitive factors and mobile video. *American Journal of*

- Speech-Language Pathology*, 24(2), 164-176.
https://doi.org/10.1044/2015_AJSLP-12-0123
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36-49. <https://doi.org/10.1016/j.rasd.2015.11.008>
- Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, 50(2), 691-693. <https://doi.org/10.1007/s10803-019-04280-x>
- Vogus, T. J., Gallan, A., Rathert, C., El-Manstrly, D., & Strong, A. (2020). Whose experience is it anyway? Toward a constructive engagement of tensions in patient-centered health care. *Journal of Service Management*, 31(5), 979-1013. <https://doi.org/10.1108/JOSM-04-2020-0095>
- Wagstaff, C., & Williams, B. (2014). Specific design features of an interpretative phenomenological analysis study. *Nurse Researcher*, 21(3), 8-12.
- Wampold, B. E., & Imel, Z. E. (2015). *The great psychotherapy debate: The evidence for what makes psychotherapy work, 2nd ed.* Routledge/Taylor & Francis Group.
- Watson, L. R. (1998). Following the child's lead: Mothers' interactions with children with autism. *Journal of Autism & Developmental Disorders*, 28(1), 51-59. <https://doi.org/10.1023/A:1026063003289>
- Watts Pappas, N., McAllister, L., & McLeod, S. (2016). Parental beliefs and experiences regarding involvement in intervention for their child with speech sound disorder. *Child Language Teaching and Therapy*, 32(2), 223-239. <https://doi.org/10.1177/0265659015615925>
- Watts Pappas, N., & McLeod, S. (2009). Parents' perceptions of their involvement in pediatric allied health intervention. In N. W. Pappas & S. McLeod (Eds.), *Working with families in speech-language-pathology* (pp. 73 - 110). Plural Publishing.
- Watts-Pappas, N., McAllister, L., & McLeod, S. (2016). Parental beliefs and experiences regarding involvement in intervention for their child with speech sound disorder. *Child Language Teaching and Therapy*, 32(2), 223-239. <https://doi.org/10.1177/0265659015615925>
- Watts-Pappas, N., McLeod, S., & McAllister, L. (2009). Models of practice used in speech-language pathologists' work with families. In N. Watts Pappas & S. McLeod (Eds.), *Working with families in speech-language pathology* (pp. 1 - 38). Plural Publishing.

- Watts-Pappas, N., McLeod, S., McAllister, L., & McKinnon, D. H. (2008). Parental involvement in speech intervention: A national survey. *Clinical Linguistics & Phonetics*, 22(4-5), 335-344. <https://doi.org/10.1080/02699200801919737>
- Westin, A., Barksdale, C., & Stephan, S. (2014). *The effect of waiting time on youth engagement to evidence based treatments*.
<http://elib.tcd.ie/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ssf&AN=94081229&site=eds-live&scope=site>
- Whalley Hammell, K. R. (2013). Client-centred practice in occupational therapy: Critical reflections. *Scandinavian Journal of Occupational Therapy*, 20(3), 174-181. <https://doi.org/10.3109/11038128.2012.752032>
- WHO, W. H. O. (2003). *Adherence to long-term therapies: evidence for action*. W. H. Organisation.
https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1
- Williamson, L. D., Smith, M. A., & Bigman, C. A. (2019). Does discrimination breed mistrust? Examining the role of mediated and non-mediated discrimination experiences in medical mistrust. *Journal of Health Communication*. <https://doi.org/10.1080/10810730.2019.1669742>
- Willig, C. a. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.
- Willis, J. (2007). *Foundations of qualitative research : Interpretive and critical approaches*. SAGE.
- Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010). Opportunities lost--Why some parents of young children are not well-connected to the service systems designed to assist them. *Australian Social Work*, 63(4), 431-444. <https://doi.org/10.1080/0312407X.2010.508170>
- Witvliet, C. v., Root Luna, L., Worthington, E. L., Jr., & Tsang, J. A. (2020). Apology and restitution: The psychophysiology of forgiveness after accountable relational repair responses. *Front Psychol*, 11, 284. <https://doi.org/10.3389/fpsyg.2020.00284>
- Witvliet, C. v., Wade, N. G., Worthington, E. L., Luna, L. R., Van Tongeren, D. R., Berry, J. W., & Tsang, J.-A. C. (2020). Apology and restitution: Offender accountability responses influence victim empathy and forgiveness. *Journal of Psychology & Theology*, 48(2), 88-104. <https://doi.org/10.1177/0091647120915181>
- Wong, V., McGrew, J., & Ruble, L. (2020). Predicting the outcomes of parents of transition-age youth or young adults with ASD. *Journal of Autism &*

Developmental Disorders, 50(8), 2723-2739. <https://doi.org/10.1007/s10803-020-04362-1>

- Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with Autism. *Qualitative Health Research*, 18(8), 1075-1083.
- World Health Organization. (2002). Towards a common language of functioning, health and disability. World Health Organization.
- Worthington, E. L. (2003). *Forgiving and reconciling: Bridges to wholeness and hope*. InterVarsity.
- Wright, C. R. (1967). Changes in the occupational commitment of graduate sociology student: A research note. *Sociological Inquiry*, 37(1), 55.
- Wrong, D. H. (1961). The oversocialized conception of man in modern sociology. *American Sociological Review*, 26(2), 183 - 193.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228.
- You, H.-K., & McGraw, L. A. (2011). The intersection of motherhood and disability: Being a "good" Korean mother to an "imperfect" child. *Journal of Comparative Family Studies*, 42(4), 579-598. <https://doi.org/10.3138/jcfs.42.4.579>
- Ytterhus, B., Wendelborg, C., & Lundebj, H. (2008). Managing turning points and transitions in childhood and parenthood--Insights from families with disabled children in Norway. *Disability & Society*, 23(6), 625-636.
- Yu, V. G., Lasco, G., & David, C. C. (2021). Fear, mistrust, and vaccine hesitancy: Narratives of the dengue vaccine controversy in the Philippines. *Vaccine*, 39(35), 4964-4972. <https://doi.org/10.1016/j.vaccine.2021.07.051>
- Yu, Y., McGrew, J. H., Rand, K. L., & Mosher, C. E. (2018). Using a model of family adaptation to examine outcomes of caregivers of individuals with autism spectrum disorder transitioning into adulthood. *Research in Autism Spectrum Disorders*, 54, 37-50. <https://doi.org/10.1016/j.rasd.2018.06.007>