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The University of Dublin

Mothering Stories

A feminist occupational justice exploration of lived experiences of mothering autistic children attending mainstream schools.

Sarah Quinn
M.Phil., B.Sc. (Curr. Occ.).

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Declaration

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Dedication

In memory of my patient and loving, accepting and ever-present mother,

Mary Quinn née Davis (1936-2018).

Summary

Mothering is a learned and meaningful occupation (Bar & Jarus, 2015; Horne et al., 2005; Larson, 2000), grounded in individual contexts (Maher, 2005; Nurse et al., 2023), and shaped by societal and cultural definitions (Sethi, 2020). Mothering autistic children creates additional complexity to what is already considered a multilayered and nuanced role (Nurse, 2023) and moves the practice into a non-normative occupational experience (Chiaraluce, 2018). In recent years, Ireland has witnessed increases in numbers of autistic children attending mainstream schools and additional pressure on autism supports (Cremin, 2018). Mothers of autistic children are subject to high intensity and frequency of interactions with external bodies (Byrne et al., 2018). Further shaping mothering experiences are neoliberal principles such as self-responsibilisation and prevalent mothering ideologies prescribing what it means to be a *good* mother (Dash et al., 2023; Hays, 1996; Schmidt et al., 2023). Structural and sociocultural factors that compound the challenges of mothering autistic children create an impetus to explore mothers' lived experiences, and their agency in addressing issues, from an occupational justice perspective. Drawing on feminism as a diverse epistemology, this study aimed to contribute to the growing literature on occupational justice theory by exploring its relevance to this population.

Situated within narrative inquiry, this study investigated the lived experiences of mothers of autistic children attending mainstream school. It explored the relevance of occupational justice in these mothers' lives, mothers' micro-macro level supports, and their use of mothering as a mechanism for agency, belonging, becoming, and occupational identity construction. The self-biographising narrative accounts of 17 mothers were elicited using the biographical narrative interpretive method (BNIM) (Wengraf, 2001) which allowed for open consideration of the topic, free from imposed categories (O'Flynn, 2018). Reflexive thematic analysis (Braun & Clarke, 2022) was used to provide an overview of findings while, consistent with the conventions of BNIM, a smaller sample of four cases were chosen for more in-depth BNIM analysis.

Findings revealed that mothers took primary responsibility for understanding their child and services, adapting practices and advocating for needs. This was related to their absorption of societal gender role expectations and influenced by prevalent mothering ideologies. The reliance of society and fathers on mothers to care and cope placed constraints and obligations on their occupational engagement. Career, social, and leisure activities were found to be compromised.

Mothers were over-engaged in care work leading to occupational imbalance. Many mothers were excluded from the routine and expected activities of normative mothering and childhood, due to a lack of societal understanding or appropriate supports, resulting in experiences of occupational marginalisation.

Adapting to alternative mothering practices disrupted and reconstructed mothers' occupational identities (OI) and placed new demands on their mothering competence. Insufficient micro-macro supports restricted choices for subjectivity and increased obligated engagement. However, through the active practice of non-normative mothering, mothers strengthened their OI and claimed their own subjectivities. The mother-advocate forged a new role in society with associated purposeful activities that brought mothers meaning, opportunities to develop a sense of belonging and enabled them to become through mothering.

The study demonstrated that prevalent mothering ideologies and singular normative mothering conceptualisations are problematic for mothers of autistic children. In the context of neoliberal and gender role expectations and a devaluation of caring occupations, in Ireland mothers are expected to take responsibility for care and advocacy without provision of adequate supports, reinforcing perceptions of mothering autistic children as a site of loss and sacrifice, and compounding experiences of occupational injustice. The study bridges a knowledge gap related to mothering autistic children and their experiences of occupational justice interpreted using feminism. Society can better support these mothers to enhance their everyday experiences of mothering by reconceptualising care and mothering, sharing the burden, and valorising alternative forms of intensive-inventive good mothering. The study has implications for occupational science, mother-centred feminist scholarship, and service delivery.

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Chapter One

Introduction

Whatever else is unsure in this stinking dunghill of a world a mother's love is not. Your mother brings you into the world, carries you first in her body. What do we know about how she feels? But whatever she feels, it, at least, must be real (Joyce, 1916).

1.1 Introducing the current study

This study was born out of a commitment to occupational justice and a keen interest in understanding the lives of women in context. Mothering autistic children in Ireland represents a complex occupation (Moran et al., 2023) occurring in the context of the culturally circulating discourses within Irish policy, hegemonic attitudes, and available supports. These mothers' everyday lives are lived under conditions that may restrict or support their occupational engagement; their lived experiences have gone under-researched within the Irish context (Byrne et al., 2018) while their relationship with occupational justice has been little examined internationally.

Mothering, across cultures and time, has resisted generalisation (Nurse et al., 2023), leading Nurse et al. (2023) to call for further research into its nuances particularly related to mothering as situated in economic and social contexts. Policy shifts in Ireland in the 21st century support the inclusion of children with disabilities in mainstream education (Cremin, 2018; Education for Persons with Special Educational Needs (EPSEN) Act, 2004). In the context of increased pressure on services, which many already consider insufficient (Cremin, 2018), mothers of autistic children are subject to greater intensity and frequency of interactions with external services such as education and healthcare (Byrne et al., 2018) than those mothering children without autism. Given the likely additional challenges to their mothering, an exploration of these mothers' experiences of occupational justice, and their agency in addressing issues, is considered valuable scholarship. Research into mothers of autistic children within current neoliberal and biomedical contexts is recommended (Douglas & Klar, 2019) so that mothering work can be understood and best supported. With this in mind, this study set out to explore the lived experiences and present the unique voices of mothers of autistic children in mainstream school.

This chapter serves as an introduction to the research presented in this thesis. It outlines the research purpose and clarifies the position of this study on core concepts: *mothering* (including mothering an autistic child[1]) and *occupational justice*. To provide background information, mothering as understood in an Irish context is explained and the research is situated within relevant Irish structures and policies. An overview of the study design, described in detail in Chapter Four, is presented, and the importance of undertaking the study – its significance and contribution to knowledge – is highlighted. Finally, the chapter summarises the structure of the thesis by previewing the chapters that follow.

The following section outlines the aims of the current study, the study design, and briefly introduces the narrative methodology employed to gather data.

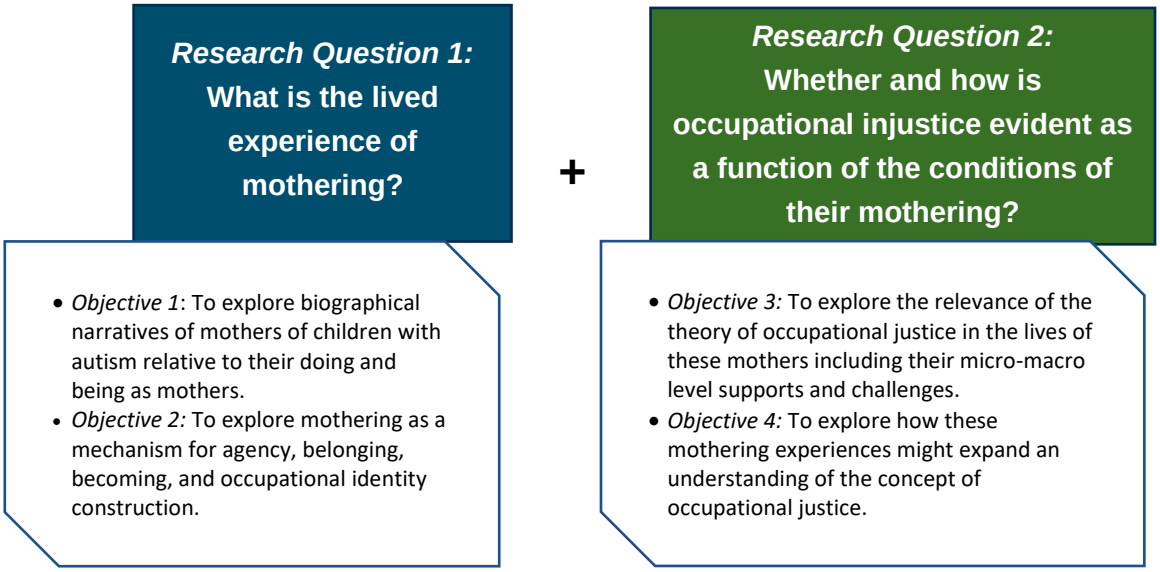
1.1.1 Research purpose and aims

This study sets out to explore the lived experiences of mothers, mothering autistic children attending mainstream school in Ireland. It aims to hear their voices and listen to their stories. It is occupation-focused and uses feminist and occupational justice lenses to examine their narratives to better understand these mothers and their mothering experiences. It endeavours to relate the doing of motherhood to sociocultural factors that influence mothers' occupational engagement. Based on the understanding that mothering is occupation and that occupations are a synthesis of doing-being-belonging-becoming (Wilcock, 1998; 2006; 2007), the following research questions and objectives (see Figure 1.1) were identified to guide the data collection and analysis of data from women mothering autistic children attending mainstream school.

[1] NOTE: References to *autistic children* as opposed to *children with autism* were inconsistent across mothers in the study. For this reason, in this thesis I have elected to use identity-first language (for example, autistic child) rather than person-first language (for example, child with autism) in acknowledgement of the preference of many autistic people and activists (Department of Children, Equality, Disability, Integration and Youth, 2024). This aligns with a neurodiversity perspective that challenges the medicalised view of autism as a deficit (Gleeson, 2024). In keeping with this, the study does not refer to children as having ASD (autism spectrum disorder) and aspires to discuss findings with a consciousness of neuro-positivity while staying true to the narratives of these mothers.

Figure 1.1

Research questions and objectives



To address these research questions and objectives, first the meaning of certain concepts that are core to the research are explained in the following sections.

1.2 Core concepts for context

To make better sense of the experience of mothering an autistic child – the focus of the current study – this section provides an overview of autism. The concepts of mothering, specifically mothering autistic children, and occupational justice are also introduced; each will be elucidated further in Chapters Two and Three respectively.

1.2.1 Understanding autism

Autism is a form of neurodivergence, a natural variation in human neurology which is characterised by differences in social communication, interaction styles, sensory processing, and behavioural patterns (American Psychiatric Association, 2013). Over recent decades, the reported prevalence of autism has increased significantly (Salari et al., 2022). This rise is widely attributed to a broader and more inclusive understanding of what it means to be autistic, increased public awareness, and improved diagnostic practices (Fuentes et al., 2021; Happé & Frith, 2020). Prevalence rates vary globally, with estimates from meta-analyses and systematic reviews ranging

from 0.4% in parts of Asia to 1.7% in Australia (Salari et al., 2022). Studies examining the prevalence of autism in Ireland are limited. Results of a screening study identifies the prevalence as one in 100 children in Irish primary schools (Boilson et al., 2016), keeping the Irish figures in line with approximations for North America (Cremin, 2018). However, based on the numbers of children with a diagnosis of autism attending mainstream school with specific and designated support classrooms, designated specific special education schools, and those in receipt of resource teaching, the Department of Education in Ireland estimate one in 65 children have autism, reflecting a prevalence rate of 1.5% (Department of Health, 2018; Sweeney & Fitzgerald, 2023). An updated figure by the National Council for Special Education (NCSE) (January 2024) in Ireland, through examination of their own 2022 data, noted a significant increase at 3.38%.

Autistic individuals, including children, often demonstrate unique ways of perceiving and engaging with the world. Some may find conventional social communication and interaction challenging or express themselves through highly focused interests and may engage in repetitive movements such as hand-flapping or rocking (Lord et al., 2018). These features often reflect an autistic individuals' alternative modes of learning, their method of self-regulation and expression. Sensory differences: such as heightened sensitivity to noise, light, or touch are also common and can make environments, such as busy classrooms overwhelming (Hume et al., 2014). The diversity of autistic experiences is vast; the heterogeneity of experiences can also be impacted by co-occurring difficulties such as anxiety, attention deficit hyperactivity disorder, and/or oppositional behaviours which can further shape an individual's experience (Lord et al., 2018; Mannion et al., 2013; Masi et al., 2017; Simonoff et al., 2008), in particular when understanding and appropriate support are lacking (Gleeson, 2024).

Historically, autism was viewed from a medical model perspective, where autistic traits were described as deficits. Contemporary understandings have shifted considerably, moving toward more affirming and inclusive perspectives and paradigms. Earlier psychoanalytic theories inaccurately attributed autism to emotionally distant parenting, causing undue distress and blame for families, in particular mothers (Russell, 2020). A more recent understanding – the neurodiversity paradigm – first introduced by autistic sociologist Judy Singer, frames autism as a valuable form of human diversity (Baron-Cohen, 2017) and encourages society to view autism as such (Baron-Cohen, 2017). This paradigm emphasises the unique strengths and abilities of neurodivergent individuals, appreciating that their diversity is intrinsic to their identity and

selfhood and that recognition of this is a matter of human rights and respect (Baron-Cohen, 2017; Dallman et al., 2022; Sonuga-Barke et al., 2024).

1.2.2 Mothering – a socially constructed occupation

Within the lexicon of occupational science[2], mothering is understood to be a meaningful occupation (Bar & Jarus, 2015; Horne et al., 2005; Larson, 2000) that is neither natural nor unnatural to the mother because it is learned (Arendell, 2000; de Beauvoir, 1949 (translation 2009); Sethi, 2020). As such, it is considered both a practice and process (Nurse et al., 2023), a behaviour and experience (LeVine, 2010), that is realised differently across populations and generations (LeVine, 2010; Nurse et al., 2023). Mothering is multifaceted, layered, grounded in individual context, and operates without a standardised formula (Maher, 2005; Nurse et al., 2023). A 'mother' is not only (or always) a biological role (Brock, 2015, p.264; Francis-Connolly, 1998; 2000; 2015). Instead, the definition of *mother*, the meaning and demands of the role, are determined by society and culture (Brock, 2015).

Motherhood is considered an activity (Everingham, 1994), a varied practice (DiQuinzio, 1993; Maher, 2005), and best understood as a verb (Chandler, 1998). According to Chandler (1998, p.273) "to be a mother is to enact mothering", i.e. to engage in the occupation. Mothering is the practice of the mother (Brock, 2012) whose skills, honed through interactions with the child being mothered (Barnard & Martell, 1995), are refined across time (Arendell, 2000; Mercer, 2004) and practiced in social contexts (Llewelyn & McConnell, 2005). The maternal role is relational and transactional (Sethi, 2020), contextually refined and defined, largely dependent on who mothers interact with, where and when. How mothering is performed reflects structures such as class and gender that intersect with the norms and ideals existing in their socio-historic contexts (Sethi, 2020). Although socially constructed (Moran & McCrea, 2024), mothering is lived as an individual and personal experience (Arendell, 2000; Brock, 2015; Esdaile et al., 2004; Nurse, 2023).

In contrast to conventional understanding, mothering is not a static position or linear occurrence but conceptualised as a dynamic and complex occupation (Arendell, 2000; Maher, 2005; Moran et al., 2023) with maternal identities that are not essential but temporally contingent (Maher, 2005). Practices of mothering shape the experiences of mothering and the formation of various

[2] Occupational science is an interdisciplinary academic discipline that studies people as occupational beings (Clark et al., 1991; Wilcock & Hocking, 2015).

mothering identities (Takševa, 2018). In occupational terms, this may be understood as occupational engagement shaping identity. Social norms construct mothering practices as being restricted to child rearing (Berger et al., 2022) operating within discrete roles (Sethi, 2020). Mothers can, alternatively, be viewed as holistic occupational beings with multiple roles (Sethi, 2020) whose mothering occupations are continuously constructed by everyday practices and interactions.

Motherhood, mothering, and the maternal are related terms that some authors, for example Brock (2012), consider important to distinguish. Mothering denotes an active (Maher, 2005), social (Moran et al., 2023; Nurse et al., 2023) practice. As a verb it has a patent relationship with *doing*, occupational engagement and participation, and is the term primarily used in this study when referring to maternal practices and processes. However, related terms, such as motherhood and maternal, will also be used according to their relevance. Feminists understand the term motherhood to be either perceived as *institution* or *experience* (Rich, 1976) with the former embedded in the patriarchy[3], male defined and controlled, and the latter female-defined, mother-centred and potentially empowering to women (O'Reilly, 2019b). Motherhood in the current study refers to the state of being a mother; whether it is experienced as empowering or patriarchal will be clarified through its use in the subsequent text.

Despite varied extant literature on motherhood and mothering (Nurse et al., 2023) its focus is predominantly on normative/idealised mothering under normative conditions. Normative mothering refers to societal expectations of how mothering should be performed and is represented by "the "ideal" or "natural" mother, as defined by dominant cultures" (Wagner et al., 2023, p.245). In contrast, non-normative mothering refers to mothering that deviates from conventional societal norms and expectations. In the current study non-normative mothering reflects a form of mothering that is non-standard and which can resist the idealised norm of the 'good' mother (Schmidt et al., 2023).

Within academic scholarship, research into mothering is categorised under four interrelated areas – mothering activities and experiences; social and structural contexts; relationships with children and others; mothering identities and meanings (Arendell, 2000). The central focus of the current

[3] A "social formation of male-gendered power" (Ortner, 2022, p.308). Otherwise described as the organisation of society in which men hold the power and authority (Cambridge Academic Dictionary, 2025) and is related to the subordination of women (Mawa, 2020).

study is on mothers' lived experiences within their social and structural contexts. However, as explained in detail in Chapter Four, the generation of biographical data in this study also allows for cross-case analysis of focal mothers' occupational identities and mothering adaptation. Consequently, this study speaks to several areas of mothering research and strives to forward the understanding of non-normative mothering through the examination of findings from both occupational science and feminist perspectives.

Mothering is activity-based, represented by a suite of occupations (Maher, 2005) that are extensive and varied in their meaning (McMahon, 1995; Odgers et al., 2024). Notwithstanding differences in the performance and experience of mothering (Odgers et al., 2024), mothers also share common activities and routines (Ruddick, 1989/1995) which allows for a level of categorisation. Widely accepted functions of mothers identified in Ruddick's seminal work (1989) are delineated as: ensuring the child's survival/preservation, growth/development and social acceptance. In other words, mothers' function to protect, nurture and train. In line with Ruddick, Sethi (2020) notes that the roles mothers play are multiple, interconnected, and also include caregiver and mother as learner.

Becoming a mother brings change to almost every aspect of the mother's life heralding a period of occupational imbalance in which mothers are engaged mostly in obligatory occupations rather than occupations of choice (Horne et al., 2005; Uthede et al., 2023). Motherhood signals entry into a social role with associated expectations and pressures (Brock, 2012) marking a development in the subjectivity and identity of a woman (Hollway, 2016). Consequently, mothers can experience a sense of loss of self in response to motherhood (Berger et al., 2022; McCabe Tartiere, 2020). The mother role is thought of as self-sacrificing, devoted, loving and maternal (Larson, 2000), synonymous with selflessness (Barkin & Wisner, 2013); motherhood is an obligation and a responsibility, a commitment, a moral choice (de Beauvoir, 1949 (translation, 2009)). To de Beauvoir the joy mothers find in their child is that of generosity. It is the joy of giving, serving, and creating happiness. Motherhood represents the ultimate in devotion to another (Arendell, 2000).

While mothers construct multiple identities and subjectivities across time (Gilbert et al., 2022) and play active roles in shaping their own realities and mothering identities (Nurse et al., 2023), the socially constructed ideal of the *good mother* can place mothers under pressure to be wholly knowledgeable about, available to, and responsible for child rearing (Malacrida, 2023). Such social norms can influence which mothering occupations are and are not acceptable (Berger et al., 2022).

LeVine (2010) suggests that mothers follow a maternal cultural script that guides their practices in line with their available resources and assimilated normative standards. Neoliberal norms consider mothering to be a highly individualised practice and holds mothers accountable for their mothering choices (Schmidt et al., 2023). The social norms that prescribe mothering promote a certain type of mothering – ways of being, doing, thinking, and feeling – that is acceptable to society. Feminism recognises the impact of broader social norms and structures on mothering practices and its perspective on mothering is explored in the Chapter Three.

Feminists note that the prioritisation of the neoliberal[4] agenda in the development of autonomous, productive citizens creates socially constructed expectations of mothering that may not reflect the reality of many mothers' everyday experiences particularly those mothering children with disabilities (Coles et al., 2023) but that, nonetheless, may influence their perception of the mothering role and experiences of mothering (Tabatabai, 2020). Societal understanding of mothering is shaped by dominant discourses of motherhood and families that shift those who deviate from the accepted norm to the margins (Chiaraluce, 2018). Societal assumptions of mothering are challenged by those mothering under non-normative conditions (such as mothers in the current study) who are often unable to maintain the standards expected of idealised motherhood and whom, through their everyday mothering, may subvert mothering stereotypes and categorisations (Coles et al., 2023; Malacrida, 2023).

While motherhood can be both enriching and limiting for any mother, becoming a mother to an autistic child results in changes to lifestyles and daily occupational patterns (Santoso et al., 2021). It can be all consuming – taking up much of the day, putting pressure on time use (Kim et al., 2018; Woodgate et al., 2008), reducing time and energy for other activities and mothers' ability to inhabit their roles as expected (Marsack & Perry, 2018; Owens-Schill et al., 2024; Santoso et al., 2021). Career, social life, friendships, and marital relationships may be impacted leading mothers to question their identity (Chiaraluce, 2018). Mothering in this respect is seen as problematic, creating imbalance (DeGrace et al, 2014) and marginalisation through restricting opportunities for socialisation (Lancastle et al., 2022), limiting time spent in personal leisure activities (Kim et al., 2018; Rizk et al., 2011) and preferred occupations (Sedgley et al., 2017), disrupting the progression

[4] The neoliberal agenda has two central goals – to decrease the role of the State in the provision of services and to increase competition through deregulation and the opening up of domestic markets (Ostry et al., 2016). Its ideology places emphasis on autonomy of choice, independence, and personal responsibility, with consequent negative implications for the lives of children with additional needs and their mother-carers (Tabatabai, 2020).

of expected narratives (Chiaraluce, 2018; Moorthy et al., 2023; Owens-Schill et al., 2024) and occupational identities (Horne et al., 2005). Mothering autistic children is acknowledged as an experience of family marginalisation (Chiaraluce, 2018); conversely, it can also be experienced as intensely rewarding. Mothers refer to their relationship with their child with tenderness regardless of the extent of their child's challenges and needs (Moshe et al., 2024). By focusing on their child's progress and their own personal development, mothers demonstrate resilience and experience reduced caregiver burden (Lancastle et al., 2022). While literature exists on the experiences of mothering children with autism, it has not been examined through the use of Biographical Narrative Interpretive Method, nor have these mothers' shifting occupational identities been explored, and there is minimal literature from the perspective of occupational justice.

1.2.3 Occupational justice

The term *occupation* is often considered to be synonymous with *doing* (Pierce, 2001). Occupations are the things people need, want, and are expected to do; they bring meaning and purpose to life (World Federation of Occupational Therapist (WFOT), 2024; Wilcock, 2006). Occupations contribute to identity formation, provide us with opportunities to participate in society, to express ourselves, support our health and wellbeing and enable us to fulfil our roles. Occupational engagement goes beyond performing and doing to incorporate a subjective element (Kiepek et al., 2022) and is believed to involve a synthesis of doing-being-belonging-becoming (Wilcock, 1998; 2006; 2007). While occupation can be a platform for agency, it is also how social order and structures are maintained (Angell, 2014).

Occupational justice is a form of social justice that emphasises the right of individuals and communities to flourish and fulfil their potential through engagement in meaningful and purposeful occupations that promote health, wellbeing, and societal participation (WFOT, 2019). An occupationally just society allows individuals, families, and communities to meet diverse needs by engaging in occupations (Abu Mostafa, 2023; Wilcock & Townsend, 2014) enabling them to thrive by pursuing what they find most meaningful (Wilcock & Townsend, 2009). Occupational injustice arises when an individual's everyday participation, sense of belonging, and occupational engagement are restricted (Townsend & Marval, 2013) by factors beyond their immediate control (Sakellariou & Simó Algado, 2006). Structural determinants, including cultural values, influence access to opportunities (Hammell, 2020) and services like health and education, shaping outcomes of occupational injustice (Boland, 2018). Engagement options are further constrained by

inequitable social factors, such as gender and disability, limiting autonomy, agency, and freedom of choice (Brock, 2012; Frohlich & Abel, 2014).

In the context of mothering, occupational justice explores how mothers' ability to nurture, protect and socialise their child (Ruddick, 1989/1995) and fulfil other meaningful occupations is influenced by social, cultural, and systemic factors. Societal norms often dictate that mothers adopt the primary responsibility for caregiving (Chiaraluce, 2018; Malacrida, 2023) which, depending on conditions, can lead to role strain and occupational imbalance (Woodgate et al., 2008). Occupational justice recognises the barriers that mothers may face in flourishing and finding fulfilment through their doing- being, belonging, and becoming (Townsend & Marval, 2013) in and through mothering. It acknowledges mothers' occupational rights to choice, balance, diversity, and meaning in their daily occupational engagement (Hammell, 2020, 2008; Townsend & Wilcock, 2004a) and its relevance to the lived experiences of mothers is a central concern of the current study.

In this study, mothers' narratives are understood through an occupational justice lens informed by feminism. Feminism's focus on inequalities, perpetuated by the structures in which mothering practices are embedded, enables the identification of challenges to these mothers' occupational rights that may be exacerbated by the conditions of non-normative mothering. Illuminating these as occupational injustices holds focus on mothering as an active practice in context. Feminism, as it does for other categories of women, can provide recognition of, and insight into, the perspectives of mothers on their lived experiences (O'Reilly, 2019a), while appreciating the contribution of the interaction between their biographical data and their social and structural contexts in shaping these experiences.

1.3 Situating the study

To enhance the readers understanding of the later presented findings, the following section provides situational context to the study. It explains the perception of mothering as a practice and process in Ireland as well as the current structures and policies that impact autistic children in Ireland.

1.3.1 Mothering in Ireland

In Ireland, motherhood has been used as a political, cultural, and social symbol (Kennedy, 2004; Cronin, 2023). Dating from the creation of the state in the 1920s, the family was considered the seat of social order and essential to the welfare of the fledgling Irish state, while the mother within the family, was also endowed with social responsibilities, indispensable to the common good of Irish society (Allison, 2013). Strong gender role stereotyping and traditional patriarchal ideologies have long existed in Ireland as part of the legacy of the dominant role of the Catholic church (Share et al., 2012; Cronin, 2023). The ideology of motherhood and domesticity were integral to the process of modernising Ireland in the service of Catholic-national hegemony (Wills, 2001). Maternal duties in the home, reinforced by the Constitution and Catholic church rhetoric (particularly in relation to the Virgin Mary), led to defined gender and familial roles (Lentin, 1998). Both the family and reproduction continue to be hallmarks of society in Ireland (Allison, 2013).

Within the Irish Constitution (1937), woman and mother are collapsed (Allison, 2013; Conrad, 2001). By referring, in Article 41.2, to a woman's life rather than work within the home, the Constitution naturalises domestication and motherhood as a woman's vocation (Conrad, 2001). The Constitution upholds the reproductive and nurturing role of mothers, obligating them to their duties within the home (Government of Ireland, 1937), and consequently minimising the opportunity and contribution of women to enact their citizenship distinct from their role as mothers. Riddick (1994) comments that the business of women is reduced to reproducing the Irish national subject due to the combination of Catholic pro-natalism and domestic patriarchy. The Irish Human Rights and Equality Commission (2018) note that the Constitution contributes to gender stereotyping and embeds a value system in the constitutional framework that undermines gender equality. Article 41.2 has been described as paternalistic (Hogan, 2005) and offensive to women, limiting their freedom of choice in delineating their obligations towards home and family (Scannell, 1988). Notwithstanding this perception and various calls for Constitutional amendments (The Irish Human Rights and Equality Commission, 2018; UN Human Rights Committee, 2008), the 2024 referendum to change Article 41.2 was defeated.

The Catholic church has retained control in part over education and has some political influence, however, as Ireland has modernised and urbanised, its role in defining cultural values has weakened and Ireland has become more secular and pluralistic (White, 2017). Wills (2001) proposes that Irish women, despite a strong commitment to family and motherhood, have tried to find a personal identity within a nationalist and traditional construction of the female role,

balancing the collectivism of the traditional with the individualism and privacy reflected in modernity. The defeat of the constitutional referendum is explained as a poorly managed campaign. Yet, alternative interpretations describe the outcome as a demonstration of Ireland's appreciation for maternal and familial solicitude and a revolt against the ideology of the political classes (Short, 2024). Cronin (2023) maintains that, regardless of recent changes to the role of women, Irish society remains traditional and repressive in relation to the responsibilities and expectations of either mother or father. Cultural norms and structural forces, reflected in societal attitudes, maintain the differential gender roles of either parent.

1.3.2 Autism policy and support services in Ireland

Ireland's approach to autism is underpinned by various national and international policies such as: the Task Force on Autism (2001); the Education for Persons with Special Educational Needs (EPSEN) Act (2004); the Disability Act (2005); the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) (ratified by Ireland in 2018 and which upholds the rights and freedoms of people with disabilities, including autistic children, to participate in society); the National Disability Inclusion Strategy (NDIS) (2017-2021) (Government of Ireland, 2017) (addressing broader systemic barriers that affect people with disabilities including autistic individuals); and the Autism Innovation Strategy (2024) (Government of Ireland, 2024). Increased policy emphasis on educational and social inclusion in Ireland (Byrne et al., 2018), coupled with an increase in autism diagnoses, results in more autistic children attending mainstream schools than ever before and a corresponding need for greater societal awareness of autism. The Autism Innovation Strategy, launched in August 2024 by the Government of Ireland, is an 18-month plan designed to address the unique challenges faced by autistic individuals, promote better understanding and accommodation of autism within society. It focuses on four key pillars: fostering an autism-affirming society, ensuring equal access to public services, creating accessible and inclusive communities, and building capacity for support. The strategy complements broader disability initiatives by addressing the specific needs of autistic people and their families.

The Disability Act (2005) provides children with a statutory right to an assessment of need (AON) if it is thought that they may have a disability (National Disability Authority (NDA), 2011). The AON falls under the remit of the Children's Disability Network Teams (CDNT) in the Health Service Executive (HSE) and establishes the child's health and education needs (Department of Education, 2024). However, significant delays in the assessment process have been reported due to resource constraints varying across geographical areas (NDA, 2020). Under the programme for Progressing

Disability Services for Children and Young People, the HSE have published a roadmap identifying service challenges and desired improvements to quality, accessibility, equity, and timeliness of services delivered by the CDNTs, as well as recommending the integration of children's public services across sectors (HSE, 2023). On publication of this roadmap in 2023, a conservative count of children on waiting lists for services delivered by CDNTs nationally numbered 16,522 children with a national average of 34% vacancy for healthcare professionals on these teams. More than 7,600 applications for AONs are made to CDNTs annually with 6,197 AONs awaiting completion in June 2023. The lengthy waiting list for diagnostic assessments for autism through the public system (HSE) is evidenced by anecdotal report (AsIAm, 2025; Goldsmith, 2024). A Report of the Review of the Irish Health Services for Individuals with Autism Spectrum (HSE, 2017) identifies the need for an assessment pathway that included a tiered approach examining the complexity of presentation. The subsequent establishment in 2025 of a HSE Service Improvement Programme for the Autistic Community aims to increase the capacity and processes that lead to autism diagnoses in Ireland.

As a complex disability, encompassing a broad spectrum of needs, autistic children require a diverse range of supports (Smith-Young et al., 2020; World Health Organisation, 2017) and educational provision (Jones, 2022) that evolve over time. Services are often delivered by various government departments and providers, necessitating coordination and collaboration across healthcare, education, and social support sectors (Chafe & Audas, 2014; Smith-Young et al., 2020; World Health Organisation, 2017). This is acknowledged by the HSE which, in collaboration with its partner agencies, aspires to ensure children can learn, have fun, develop skills and interests and form relationships through a range of inclusive experiences (HSE, 2023). The CDNTs aspire to use a family centred model of care; focus on children's strengths; set goals collaboratively with the family; and engage with relevant personnel across all domains within the child's life to enhance their development and experiences. By way of providing financial support to carers of children with severe disabilities, including autism, carers may apply to the Department of Social Protection to receive the Domiciliary Care Allowance (DCA) which is a monthly payment of €360 for a child aged under 16 (Department of Social Protection, 2019-2025).

Since the early 2000's, the educational context in Ireland for autistic children has adopted an inclusive approach (Cremin, 2018). In 2004, the Education for Persons with Special Educational Needs (EPSEN) Act was drawn up, with significant implications for autistic children in Ireland. Regardless of disability, the Act makes access to and benefit from a suitable education a

constitutional right of all children (Government of Ireland, 2004). Unless it is detrimental to their education or to that of others in the environment, the Department of Education's policy supports educating children in an inclusive environment. In this way the Act establishes the fundamental right of all children to attend mainstream schools (Kenny et al., 2020). Pupils may fully integrate into a mainstream classroom for the entire school day or, alternatively, access additional support through attendance in a specifically supported classroom environment within a mainstream school. Pupils in mainstream classes are taught alongside their peers without special education needs. Depending on their need, they can be provided with curriculum differentiation, resource teaching hours (4.25 per week), and/or a special needs assistant (SNA) (Cremin, 2018). The state's expenditure on educational support services for autistic children is highest in relation to the employment of SNAs, which according to Roddy and O'Neill (2019), implies that their priority is on managing behaviours rather than on developing teachers' skills to enhance children's capacities. The number of autism specific classes in mainstream primary schools in 2023 was 1698 and 780 at post-primary level, with increases noted year on year (NCSE, 2023). The increasing numbers of autistic children in mainstream education, together with the heterogeneity of the condition, justified limiting the inclusion criteria, in the current study, to mothers of autistic children in mainstream school in the hope of producing focused findings that hold relevance to a growing population of mothers.

1.4 Study design

The custom of storytelling is deeply imbedded in Irish society (O'Hagan, 2024). Reflecting this tradition, narrative inquiry, with its capacity to attend to the particular in the lives of participants (Josselson, 2007a) and give them voice in a way that can challenge hegemonic narratives (Rogers & Rose, 2019), was deemed an appropriate approach for the qualitative design of this study. Narrative inquiry – a qualitative method and design – is concerned with the experiences of its participants expressed through their stories (Clandinin, 2007). It involves the telling and interpretation of these narratives with respect to the social milieu in which they were lived and retold (Clandinin & Connelly, 2000). Gathering biographical narrative data allows a person's lived experiences to be explored in more detail. It acknowledges that stories are only fully intelligible when situated within their sociohistorical context (Corbally & O'Neill, 2014) and appreciates the interplay between individual agency and structural determinants (Chamberlayne & King, 2000). To adequately explore the everyday experiences of mothering in context I determined that in-depth analysis was required and might best be achieved through the collection of unstructured

in-depth interviewing (a core data collection method of narrative inquiry (Chase, 2011)) in line with the Biographic-Narrative-Interpretive-Method (BNIM) (Wengraf, 2001).

The Biographical Narrative Interpretive Method (BNIM) was identified for use, given the attention it pays to subjective experiences while understanding that these are exposed to contextual influences in their telling and interpretation (Casey et al., 2016; Corbally & O'Neill, 2014). As will be explained in Chapter Four, it provides a framework for data collection and analysis that translates, elucidates and gives meaning to the participant's life stories (Corbally & O'Neill, 2014). A particular strength of BNIM is the structured framework it provides for both data collection and analysis which enhances the trustworthiness of findings. BNIM retains the individuality of narratives through analysis of how participants tell their stories relative to the sociohistorical context of their biographical chronology. This enabled the current study to make sense of mothering experiences from a feminist and occupational science perspective while also being cognizant of the external factors at play in their lives that potentially result in conditions of occupational injustice.

1.5 The study's significance

This study follows through on the call for documentation in the public domain of the lived experience of contemporary mothers (Leane, 2008; Nurse et al., 2023) and those of mothers of autistic children within current neoliberal and biomedical contexts (Douglas & Klar, 2019) so that mothering work can be understood and best supported. This research contributes to the body of knowledge on mothering in occupational science by determining learning from personal narratives on mothering autistic children in Ireland. More notably its contribution extends the relevance of occupational justice to a population who, though not necessarily from a socially disadvantaged grouping, may experience discrimination and marginalisation due to sociocultural structures, systems and attitudes. In this study I contend that these mothers are constrained from full and preferred occupational participation by the structures that include the attitudes of society. Understanding mothering as an occupation requires the examination of factors that support or prevent mothers from doing and being what they want and need to be. The detail of everyday lives is often overlooked (Hasselkus, 2006) and as an occupation within the everyday lexicon of society, mothering can be taken for granted (Larson, 2000) making it particularly vulnerable to unquestioned normative standards and expectations. This study, through its employment of narrative inquiry describing the lived experiences of mothers of autistic children, generates

empirical data on a form of non-normative mothering. Mothers, on the edge of dominant mothering discourses, such as those mothering autistic children (Chiaraluce, 2018), may interact with structures and contexts in a way that leads to experiences of occupational injustice. Frank (2012) called on occupational scientists to explore the value of occupational justice concepts through empirical research and critical analysis. The current study enhances the conceptualisation and utility of occupational justice theory through its practical application to mothers of autistic children.

The embeddedness of narrative within contexts highlights interactions with structural factors (Bruner, 2004). This allows for a feminist interpretation of these experiences and the identification of occupational injustices, should they exist. Mothering may be an outlier in feminists' concerns (O'Reilly, 2019a; Takševa, 2018; White, 2010), however a priority of feminism is to draw attention to inequalities, particularly those of a structural nature perpetrated against marginalised groups (Hay, 2020). By situating mothers' narratives within a sociohistorical Irish context an opportunity to examine the impact of relevant societal structures in Irish culture on mothering is created. Applying a feminist lens to exploring and interpreting mothering narratives utilises a transdisciplinary theory that gives the study relevance beyond occupational science and in this way strengthens the conceptualisation of occupational justice theory.

The study appreciates the often overlooked and undervalued daily lives of this population. Despite the likely adverse mothering conditions, including that of the sociocultural contexts, and mothers' possible occupational engagement limitations, the current study also recognises the potential use of mothering as a mechanism for change and growth. Non-normative mothering may contribute to the construction of alternative mothering identities, create a sense of alternative belonging, and support expressions of agency. To this end, this study intends to provide rich and contextualised accounts of the everyday lives of mothers of autistic children in Ireland, represent restrictions on mothers' occupational participation, as well as the scope to *become* through engagement in mothering occupations and the enhancement of their everyday experiences.

1.6 The structure of the thesis

The thesis comprises of a further eight chapters. The following chapter provides an overview of the concepts from occupational science that are considered foundational to the study, relating these to mothering, before directing focus to the literature on the occupation of mothering

autistic children. Chapter Three explores the theoretical constructs underpinning the study, describing mothering as an issue for occupational justice and feminism. The study's methodology – narrative inquiry and the biographical narrative interpretive method (BNIM) – employed to meet the research objectives, are described in Chapter Four. Findings are presented in Chapters Five to Seven beginning with the reflexive thematic analysis of the complete data set (n=17). Following the thematic presentation of four BNIM cases selected for in-depth study in Chapter Six, a cross-case analysis in Chapter Seven discusses these cases in relation to occupational identity and mothering adaptation. The ensuing discussion in Chapter Eight refers to the findings as a composite set in the context of related literature, which is explored under two central themes of significance to the study's focus on expanding understandings of these mothers' experiences of occupational justice. The final chapter synopsises the study's conclusions and identifies the implications of its findings for positive change in these mothers' lived lives.

1.7 Conclusion

Mothers in Ireland have held a central position in the everyday life of the family and state related to the common good (Allison, 2013). This creates assumptions regarding roles and expectations for their occupational engagement. Mothering, as a learned occupation (Llewelyn & McConnell, 2005) and a form of doing-being-becoming-belonging (Wilcock, 1998; 2006; 2007), represents the many and varied occupations of the mother. Mothering an autistic child creates additional complexity to what is already considered a multilayered and nuanced role (Nurse, 2023) and moves the practice into a non-normative occupational experience (Chiaraluce, 2018). Given the dearth of children's autism services, the care burden of mothers can increase with potential repercussion for their experiences of occupational justice. Conversely, out of these circumstances, possibilities for mothering to be recognised as a mechanism for growth and expression of agency and identity may exist. Data collected through the application of the biographical narrative interpretive method, with its appreciation for the mother in the context, allows feminist and occupational justice lenses to be used to understand these mothers' lived experiences, to highlight injustices as well as growth, and to contribute to mothering knowledge in occupational science.

Chapter Two

Key concepts and relevant literature: Occupational science and mothering autistic children

2.1 Introduction

The focus of this study is firmly centred on the lived experience of the occupation of mothering an autistic child. Before positioning mothering as an issue for occupational justice and feminism, the current chapter illuminates the foundational concepts from occupational science relative to which this varied occupation will be examined. Occupational balance, occupational identity, and occupational possibility are each dealt with and explicit relationships with mothering emphasised. The chapter aims to deepen the understanding of these concepts so that better sense may be made of the findings in their address of research objectives one and two. Furthermore, the chapter engages with experiences of mothering autistic children, examining how this is portrayed in the literature and relating this mothering to the aforementioned concepts. This enables mothering as an issue for occupational justice and feminism, presented in the following chapter, to be understood relative to the conditions of mothering autistic children found in the literature.

2.2 Introducing occupation, engagement, and participation

Occupation is often considered synonymous with *doing* and used interchangeably with the term *activity* (Hasselkus & Dickie, 2021; Pierce, 2001). The World Federation of Occupational Therapists (WFOT) claim that "occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do" (WFOT, 2024). The American Occupational Therapy Association (AOTA) (2020, p.79) expand on the WFOT's definition by adding that:

> Occupations can involve the execution of multiple activities for completion and can result in various outcomes. The broad range of occupations is categorized as activities of daily living, instrumental activities of daily living, health management, rest and sleep, education, work, play, leisure, and social participation.

Occupations are complex, individual, and subjective (Kiepek et al., 2022). Engagement in occupations is considered to encompass more than performance, to include subjective experiences (Black et al., 2019; Wilcock, 1993). The subjective nature of occupation is identified as a key feature distinguishing occupation from activity (Schell et al., 2019). Some extend the subjective element of occupation to claim occupation as a time-bound, non-repeatable experience (Pierce, 2001). While *activities* can be described objectively without context, occupations reflect personalised and meaningful engagement in interaction with the context (Schell et al., 2019). Even when the overt performance of an occupation (i.e. doing) may appear similar between individuals, the subjective experience (i.e. being) can vary greatly (Hayward & Taylor, 2011). Performing occupations involves active doing of tasks, activities and roles in a complex interaction with the environment that supports participation (Baum et al., 2015).

Occupations are described as both meaningful and purposeful to the individual performing them (AOTA, 2020; Hinojosa & Kramer, 1997). They fill and structure time (for example, Creek, 2003; Hinojosa & Kramer, 1997) and take place across time (AOTA, 2020). Occupations function as a form of expression and meaning making (Wilcock & Townsend, 2014), that contribute to the individual's sense of identity (for example, AOTA, 2020; Christiansen, 1999; Creek, 2003; Hinojosa & Kramer, 1997; Kielhofner, 2008; Laliberte-Rudman, 2002), allowing for choice and expression of agency (Laliberte-Rudman, 2002). Occupations support participation in society (for example, Baum, 2003) and are often engaged in with other people (AOTA, 2020; Olson, 2004; Zemke & Clark, 1996). They are both individual and collective. The social, temporal, and cultural contexts influence the occupations perceived as normal and expected (Christiansen & Townsend, 2013). Engagement in one occupation has the capacity to support or promote other occupations (AOTA, 2020). Occupations are political and gendered (McGrath, 2017) and of sociocultural meaning (Stamm et al., 2006). Participation in meaningful occupations supports fulfilment of roles, responsibilities, and the individual's contribution to society (Yerxa et al., 1989). Occupation is necessary for human survival (Kronenberg & Pollard, 2005; Townsend & Wilcock, 2004a). Though, generally understood to benefit health and wellbeing (Yerxa et al., 1989), not all occupations are either healthy or promote wellbeing (Twinley, 2013).

Occupation is perceived as a synthesis of doing-being-belonging-becoming (Wilcock, 1998; 2006; 2007). While occupation may be synonymous with *doing,* Wilcock (1998) proposes that a dynamic balance between doing and being is needed in order to become the person we are best fitted to

become. What people do builds societies, both good and bad. *Being* may be otherwise described as existing or living; unlike becoming, it is not future orientated. Experiences of doing are often imparted onto being. For example, the sense of being in an occupational role, such as mother, implies an expectation towards doing and probably becoming. To achieve wellbeing, enablement of people and communities to become what they are best suited and desire to become is required (Wilcock, 1998). *Becoming* is related to change and development (Hitch et al., 2014). Influenced by the work of Hammell (2004) and Rebeiro (2001), Wilcock (2006; 2007), introduced to the triad of doing-being-becoming, an additional dimension *belonging* illustrating people's connectedness, through occupation, to others and place (Hitch et al., 2014).

Descriptions of occupational *engagement* that permeate the literature often associate it with concepts such as value and meaning, active involvement, balanced engagement, subjective experience, identity development, and socio-environmental interactions (Black et al., 2019). Each speak to the nature of occupation, to conditions conducive to engagement, or to the outcome of engagement. Occupational engagement includes objective and subjective aspects of experiences and is considered to be a multidimensional interaction of the body, mind, and spirit (AOTA, 2014). The concept of meaning is central to that of occupation and essential to its relationship with wellbeing (Hasselkus, 2011; Kuo, 2011; Reid, 2008; Shank & Cutchin, 2010). Meaningful engagement in occupation can lead to participation in desired situations and activities (AOTA, 2020). Participation is described by the World Health Organisation (2001) as involvement in a life situation. Occupational *participation* makes occupational engagement relative to others and embeds it in a cultural context. It is explained as the active engagement and involvement in desired occupations in ways that are "personally satisfying and congruent with expectations within the culture" (AOTA, 2020, p.67) and that contribute to the wellbeing of the individual and community (Baum et al., 2015). It encompasses having choice and demonstrating agency; fostering social connections and a sense of belonging; contributing to and influencing others (Borell et al., 2006; Hammel et al., 2008), balancing the needs of the person with those of others, and involves a transaction between the person, their occupation, and their environment (Hammel et al., 2008; Mallinson & Hammel, 2010).

Adopting the terminology of doing-being-belonging-becoming through occupational engagement or participation allows the current study to understand occupation as more complex than activity performance. It extends definitions of occupation beyond that of *doing*, recognises meaning as essential to occupational engagement, and draws together the needs of the individual (biological

and social) with the community through its relationship with occupational justice (Wilcock & Townsend, 2014). For these reasons, a doing-being-belonging-becoming perspective on occupation and occupational engagement is adopted in this study. Before applying this understanding of occupational engagement by elaborating on the occupation of mothering an autistic child, section 2.3 explains the concepts of occupational balance, identity, and possibility by drawing on the terminology of doing-being-belonging-becoming and making the concepts relevant to the focus of the current study.

2.3 Occupational balance, identity, and possibility

Occupational balance is considered a subjective condition (Matuska, 2012), defined by Dhas and Wagman (2022, p.373) as "an individual's perception of having the right amount and variety of occupations in one's daily occupational pattern". Studies identify a relationship between wellbeing and participation in a range of satisfactory and meaningful occupations (balanced occupational engagement) (Günal et al., 2021; Wagman et al., 2020; Wagman & Hakansson, 2019; Yu et al., 2018). According to Wilcock (2006), perceived occupational balance and wellbeing is profoundly influenced by congruence between an individual's occupations and their need to do (for example, mothering), to be (for example, a mother), and to become (for example, a good mother). It is known that becoming a mother to an autistic child results in changes to lifestyles and daily occupational patterns (Santoso et al., 2021). It can be all consuming – taking up much of the day, putting pressure on time use (Kim et al., 2018; Woodgate et al., 2008), reducing time and energy for other activities and other roles (Marsack & Perry, 2018; Santoso et al., 2021). Despite their efforts to cope through balancing their occupations, mothers report finding the stress of caring impacts their daily occupations (Woodgate et al., 2008). Caregiving in this respect can be seen as problematic, creating imbalance through limiting mothers' time spent in personal leisure activities (Kim et al., 2018; Rizk et al., 2011) and preferred occupations (Sedgley et al., 2017).

Authors such as Eklund et al. (2017), Liu et al. (2023), and Wada et al. (2010) discuss perspectives that are embedded in theories of balance. These are related to time use and its allocation to occupations; congruence between occupations and an individual's values, interests, aspirations; fulfilment of roles including personal capacity and external resources to meet the demands; and compatibility between occupations so that one does not interfere with the participation in another. A focus on the prioritisation of occupations of personal meaning (Stein et al., 2011), satisfaction with personal occupational performance, and the fit between the demands of

occupations and personal resources (Eklund et al., 2017) has redirected scholarship on balance away from that concerning the variety and patterning of occupations across time. Occupational balance is multidimensional, complex, and shaped by socio-cultural contexts (Liu et al., 2023). The additional demands of mothering an autistic child, stemming from societal structures and sociocultural expectation, threaten occupational balance in a perceived and practical way and, as such, I contend may be experienced as occupational injustices (further explained in the following chapter).

Occupational identity is a component of an individual's personal identity, holds a more specific meaning than the concept of self-identity (Bryson-Campbell et al., 2013; Martin-Saez & James, 2021), and is defined as the "composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation" (Kielhofner, 2008, p.106; Schell & Gillen, 2019, p.1205). It relates to the understanding of who one is relative to what one does (Martin-Saez & James, 2021). According to Christiansen (1999), identities form as life stories unfold across time. McGrath (2017) describes the *doing* of identity through meaningful and purposeful interactions with the world and in this regard sees occupation as a "practical form of subjectivity" (p.137). Similarly, occupations are thought to be the mechanisms that enable individuals to develop and express their identities and are the core concept of the individual as an occupational being – occupations build life stories that form identities (Christiansen, 1999).

Identities and meaningful occupations are considered mutually dependent (Cotton, 2012). Engagement in occupation has the potential to provide opportunities for identity growth (Laliberte-Rudman, 2002). Likewise, occupational identity is impacted substantially following significant challenge to occupational performance leading to its revision (Unruh et al., 2002). The diagnosis of a child can challenge mothering performance and disrupt the mothering role (Lutz et al., 2012) demanding some resolution of issues before occupational identity can be successfully reconstructed (Unruh et al., 2002). An occupational disruption involves the temporary discontinuity of occupational performance (Gupta, 2012; Whiteford, 2000). It results from a significant life event, such as becoming a mother (Horne et al., 2005; Whiteford, 2000), and can be resolved with support (Hughes, 2009). Occupational disruptions can create loss of occupational identity through their association with changes to the perception of self as capable (Vrkljan & Miller-Polgar, 2001), feelings of uncertainty (Cotton, 2012) and frustration (McCready & Reid, 2007). The construction and reconstruction of occupational identity is an active process that requires person-environment interaction (Laliberte-Rudman, 2002) within environments that

support its construction (Kielhofner, 2008). Adapting to new occupational identities can be challenging (Nizzero, 2017), while rebuilding identities can require reorganisation of everyday life (Ammann, Satink, & Andresen, 2012) and the reprioritisation of the importance of various occupations (Horne et al., 2005).

Perception of the self in the past influences present-self and future *becoming* (Martin at al., 2011). Building an occupational identity is an active, dynamic practice (Martin-Saez & James, 2021). Its construction is ongoing and gives direction to future action (Kielhofner, 2008). To maintain a sense of consistency in identity, occupations are approached in similar ways across time (Laliberte-Rudman, 2002). Like Christiansen, Kielhofner (2008) believes that occupational identities evolve across the life span, adapting to experiences and perceptions of occupational competence. Competence is the capable expression of identity (Christiansen, 1999). Motherhood heralds a new occupational experience for identity formation requiring the development of new occupational competences. Christiansen asserts that competence in occupational performance helps shape identities, and identities, that are acceptable to the individual, assist in the development of a sense of coherence and wellbeing.

Choice and control are two concepts thought to be related to the development of positive occupational identity. To reap rewards through occupational engagement, including those that shape identity positively, control over the occupation is important (Laliberte-Rudman, 2002). For example, Laliberte-Rudman (2002) claims that without control, caregivers can lose interest and motivation to engage. A secondary analysis of studies that explore the relationship between occupation and identity finds that occupational choices are made to be in line with a sense of personal identity and intended to reveal social identities (Laliberte-Rudman, 2002). Christiansen (1999, p.550) claims that "when we exercise choice, we are expressing our selfhood and unique identities." However, the emphasis on choice in popular conceptualisations of occupational identity potentially lacks relevance beyond Western culture in that it assumes people have choice in the occupations that contribute to their identity and that their internal drives and conscious decisions drive their occupational engagement (Laliberte-Rudman & Dennhardt, 2008). Depending on the individual's situation and circumstances, factors other than choice, such as duty and obligation, can influence what the individual does (Cote & Levine, 2002). Motherhood has been considered an obligation and responsibility, a commitment and a moral choice (de Beauvoir, 1949 (translation 2009)). The idea that aspects of mothering are perceived as obligated choices may have resonance for many mothers, particularly those of autistic children.

Although occupational identity is formed through the efforts of the individual, it is also witnessed by others (McGrath, 2017) constructing the occupation of mothering as both personal and public. In coining the idea of an *occupational subject* McGrath (2013) portrays the individual as one who actively builds an occupational identity with others and for others. This has relevance for discourses on maternity in which the *mother subject* builds an identity, preserves a role, and engages in activities that exist because of another person and whose everyday mothering life is shaped by her membership of that dyad, or family, or community. McGrath (2017) recognises that individuals position themselves in relation to structures in the public arena and are also positioned by others in relation to these structures. In applying this to issues of maternity, mothers may be understood to have relationships with structures such as rules, regulations, policy, distribution of resources, power, and status. Their interactions with these structures are relative to their perception of their personal relationship with them but also to the relations they are presumed, expected, and supported to have by family, professionals, and community.

As gender is a form of social positioning with individual and social factors having influence on women's lives (McGrath (2017) on Young, 2005), what women as mothers do is both publicly witnessed and open to sociocultural sanction. A woman's agency in choosing how to interpret her role is restricted or enabled by the circumstances of the history, economics, society, culture, and politics that the woman lives through, which must be negotiated in building an occupational identity (McGrath, 2017). People are interconnected; their relationships are interdependent and influence both the actions available to them and those that they choose (Galvaan, 2012; 2015; Hammell, 2023). Multiple structures open up and close down the opportunities for occupational engagement. Such structures, often represented by invisible and unchallenged assumptions and ideologies, lie within the manifold contexts in which people build their selfhoods, occupational identities, and lives (Dash et al., 2023). As discussed further in the Chapter Three, theories of justice centred on individual agency can inadvertently misdirect the focus to individual factors instead of attending to structural causes (Bailliard, 2016).

Roles, such as motherhood, are reflected in the formation of occupational identities and are a function of sociocultural convention (Pollard & Sakellariou, 2012). Motherhood is an intersection of the category of women (O'Reilly, 2019a), and mothers are assumed to engage in socioculturally sanctioned, normative maternal occupations. Sociocultural assumptions, that encourage women's roles as mothers, homemakers, and carers, can influence and limit their possibilities for

occupation in relation to education, employment, career advancement, and financial security and independence (McGrath, 2017). The concept of occupational possibility describes the opportunities for occupational engagement that are seen as ideal, supported, and available in a given sociocultural and historical context. Occupational possibilities are the form and type of doing that society assumes and permits of people, including mothers, and that are promoted by societal systems and structures (Laliberte-Rudman, 2005; 2006; 2010).

Certain practices create occupational possibilities for some, privileging their way of life, and not for others (Dash et al., 2023). Sociocultural assumptions about who can do what, can limit occupational possibilities and affect potential in the development of an occupational identity (Dash et al., 2023). Tension between what is potentially possible and practically possible, generated by the constraints of circumstance and context, may limit mothers in their occupational engagement. McGrath (2017) describes this struggle between possibility and practicality as *occupational friction*. Social expectations of mothers to engage in mothering by committing themselves wholly to their child's wellbeing has implications for their personal occupational possibilities and consequent engagement (Dash et al., 2023). Neoliberal ideals of self-responsibilisation[5], together with prevalent mothering ideologies, place expectations on mothers as to how they should be and what they should do and, in this way, normative discourses on both parenting and autism limit mothers' occupational possibilities (Dash et al., 2023).

2.4 Mothering an autistic child

Mothering narratives concerning the everyday life with an autistic child are not binary, but nuanced (Chiaraluce, 2018). Mothering an autistic child is presented in the literature as challenging on a practical, emotional, and relational level (Bobadilla, 2024). Mothers' lived experiences are largely described as distressing; their mothering as over-burdened and poorly supported. Mothering an autistic child is portrayed as a busy juggle of additional responsibilities and roles. Mothers are typically the primary carers and homemakers, who make sacrifices and adopt roles for the benefit of the child and family, while fathers are positioned as breadwinners (Bagatell, 2016; Brewer, 2018; Chiaraluce, 2018; McAuliffe, 2019). Mothers struggle to balance demands of the caring role while also meeting the needs of the whole family and engaging in the various activities of mothering (Bobadilla, 2024). Their disproportionate burden of caregiving is

[5] Neoliberal discourses on responsibilisation promote self-management, self-audit, and moral accountability (Trnka & Trundle, 2014).

related to their assumed role in the family as the person with primary responsibility for their child (Bobadilla, 2024; Chiaraluce, 2018; Malacrida, 2023) and the restrictions on personal time incurred by caring (Marsack & Perry, 2018; Kim et al., 2018) – they experience both increased objective (more tasks) and subjective (more stress) care burdens. Mothering an autistic child is conceptualised as supporting, as understanding, as accepting, and as providing (Bobadilla, 2024).

Coordinating alternative schooling and additional meetings with professionals (Kuhaneck, et al., 2010), and identifying, organising, and attending therapeutic services falls within the domain of mothers who are often expected to practice therapeutic interventions in the home (Angell et al., 2016; Chiaraluce, 2018; Brewer, 2018; Kim et al., 2018; Stoner & Stoner, 2016). Mothers complain that they are required by healthcare staff or lack of resources to take on the role of mother-as-therapist, leading to a perception that work in the home was relentless and never ending (Safe et al., 2012). Hodgetts et al. (2014) explain that the many roles' mothers perform in the care of their child, their lack of discretionary time, the loss of opportunities in paid employment, their sacrifice of leisure participation, and the accommodation to their lifestyles, each contribute to their perception of occupational imbalance. Caring for an autistic child dominates mothers' time, leaving little time for themselves (DeGrace, 2004; Jones & Passey, 2004; Kim et al., 2018; Montes & Halterman, 2007; Olsson & Hwang, 2003). In addition to the time-demand of managing their children's autism-related needs, everyday activities with these children are also more time consuming (Safe et al., 2012). The literature presents an evidently gendered division of labour which goes predominantly unquestioned (Dash et al., 2023).

Emotional and practical challenges of mothering an autistic child create health issues. Mothers report not meeting their basic need for sleep impacting their mental and physical health (Safe et al., 2012; Woodgate et al., 2008). They are consistently found to show higher levels of distress than mothers of children with other disabilities (Estes et al., 2009; Pisula, 2007; Weiss, 2002) and, than fathers of autistic children (Estes et al., 2009; Yamada et al., 2007). The risk of mental health problems such as depression is also higher in mothers of autistic children (Abbeduto et al., 2004; Davis & Carter, 2008). Mothers' distress is understood to stem from a difficulty in fully comprehending their child's autism (Pisula, 2007) and how to parent amidst unpredictable child behaviour, uncertainty about their child's future (Bobadilla, 2024; Pisula, 2007), and lack of support from services (Nealy et al., 2012; Pisula, 2007; Safe et al., 2012). Mothers struggle to balance the needs of the whole family, their child, and their own emotional needs (Bobadilla, 2024). Aspects of caring for an autistic child can increase mothers' feelings of inadequacy (Luong

et al., 2009), insecurity, incompetence (Sen & Yurtsever, 2007), parental-efficacy (Hastings & Brown, 2002), guilt, sorrow, and stigma (Byrne, et al., 2018; Gray, 2002b) in their mothering role. The permanency of autism has been associated with maternal stress (Sharpley et al., 1997) as has the child's decreased affective emotional response (Duarte et al., 2005), and limited relatedness between the child and others (Akdemir et al., 2009; Duarte et al., 2005).

Caring for an autistic child is a lifelong role, the realisation of which can be experienced as stressful (Marsack & Perry, 2018). Mothers express grief for the loss of a life they once had (Anderson et al., 2020), for an imagined life (Ho et al., 2018), and for the child who may never become the adult they had envisioned (Anderson et al., 2020; Joosten & Safe, 2014; Safe et al., 2012). Reinforcing discourses of burden and stress are portrayals of loss – the loss of friendships, employment, imagined lives, and goals (Dash et al., 2023). Engagement with roles, relationships, and occupations beyond that of caregiving can also be negatively impacted by mothering an autistic child (Altiere & von Kluge, 2009; Gray, 2002b; Olsson & Hwang, 2003; Sen & Yurtsever, 2007). Mothers can often sacrifice their work and social life to allow time to understand, navigate and access autism support systems (Hodgetts et al., 2014). Needing to be available to provide therapy and ensure consistent routines results in mothers foregoing employment or reducing their hours to part-time work (Joosten & Safe, 2014; Brewer, 2018). Those who have not left their jobs, Brewer (2018) notes, find their performance at work affected by lack of appropriate childcare or inflexible healthcare appointments. Even when mothers reach a point in their child's life in which they feel they can return to work, they continue to need flexibility so that they can respond to their child's needs (Stoner & Stoner, 2016). Discourses on normative families contribute to these mothers' difficulty in reconciling reality with a presumed future (pre-diagnosis) and expected way of life (Chiaraluce, 2018). Although desired intensely, parents feel isolated from (Boshoff et al., 2016; Byrne et al., 2018; Woodgate et al., 2008) and grieve their perceived loss of normalcy (Ho et al., 2018). The concept of the normal family is problematic yet is one to which service providers and families of autistic children often subscribe (Gray, 1997, 2001). Dash et al. (2023) conclude that parents assimilate normative family ideals which they aspire to but are unable to achieve.

Mothering an autistic child can put strain on spousal relationships (Bobadilla, 2024; Olsson & Hwang, 2003) and relationships with friends and family (Sen & Yurtsever, 2007). It can exclude mothers from social activities because others do not understand their child's diagnosis or behaviour (Altiere & von Kluge, 2009; Boyd, 2002; Woodgate et al., 2008). In turn mothers are embarrassed of their child's behaviour and can deliberately isolate themselves (Gray, 2002b;

Chiaraluce, 2018). Self-stigma, Eaton et al. (2016) claim, contributes to feelings of inadequacy in meeting the expectations of the self as a good parent. In interactions with society, mothers adopt several behaviours such as making excuses for their children's behaviour (Blanche et al., 2015; Dababnah & Parish, 2013) and avoiding social situations (Byrne et al., 2018; Dababnah & Parish 2013; Chiaraluce, 2018). They are known to use behaviour management strategies shaped by others' expectations which can contribute to the stress they experience (Joosten & Safe, 2014). Mothers often find it difficult to source suitable family activities or babysitters as their child can require monitoring or need additional support in activities of daily living (DeGrace, 2004; Kim et al., 2018). Consequently, they do not have time or opportunity to engage in social activities (Olsson & Hwang, 2003; Rizk et al., 2011). Families of autistic children are often rejected (Schall, 2000) and shamed (Dababnah & Parish, 2013) by friends, extended family and the community and experience both subtle and overt judgement on their competence as parents (Dababnah & Parish, 2013; Schall, 2000). Reduced understanding and support from friends and family (Sen & Yurtsever, 2007) results in stigma and isolation impacting the experience of mothering an autistic child (Byrne et al., 2018; Cloete & Obaigwa, 2019).

Some mothers struggle to maintain a sense of personal identity beyond that of a carer (Chiaraluce, 2018; Woodgate et al., 2008). Even when mothers have time and opportunity to socialise, they often have little energy to do so resulting in the prioritisation of activities according to meaning being a critical factor in mothers' discretionary time use (Rizk et al., 2011). Chiaraluce (2018) explains that the accumulation of disruptions to everyday perfunctory activities create problematic family performance and identity ruptures, with mothers experiencing changes, even loss, of their identity as sister, daughter, friend, and spouse. Stress and guilt are attributed to unfulfilled personal expectations and roles (Safe et al., 2012). Family life can revolve around the needs of autistic children (DeGrace, 2004). Beyond the relentless daily difficulties, DeGrace (2004) claims that autism shatters families' dreams, noting that thinking about the future is "the only thing that's more depressing than the present" (p.546). Mothers of autistic children often look upon the future with fear (Dababnah & Parish, 2013; DeGrace, 2004; Joosten & Safe, 2014; Nealy et al., 2012; Santoso et al., 2015; Schall, 2000), particularly with regard to their child's employment opportunities, ability to adapt to adulthood (Nealy et al., 2012), and future independence (Santoso et al., 2015).

Research indicates that mothers of autistic children share similar experiences in terms of an overall phasic cycle of associated emotions. The initial awareness of autism signs, children's

challenging behaviours, and difficulties in obtaining a diagnosis are often very stressful periods (Gray, 2002b; Nealy et al., 2012). Bobadilla (2024) claims that mothers respond to the diagnosis with depression, avoidance, sadness, and anxiety. Gray (2002a) notes there is usually an improvement as parents discover effective intervention and coping strategies, followed by another challenging phase when the child enters puberty. Post-diagnosis, stress is attributed to barriers regarding funding and access to services (Nealy et al., 2012). A common theme among parents is the consistent lack of autism resources (Ilias et al., 2018; Cohen & Miguel, 2018; Gray, 2002a, 2006). Time wasted in gaining a diagnosis and initiating therapeutic and educational services can be experienced as disempowering and frustrating (Gray, 2003; Jones & Passey, 2004). Systemic barriers to navigating health and education systems include difficulties with access to information, funding, waiting lists, uncoordinated services, non-existent services in local areas, and uninformed professionals (Brewer, 2018; Hoogsteen & Woodgate, 2013; Woodgate et al., 2008).

Autistic children can find change and new situations challenging (Joosten & Safe, 2014). To make life more predictable for their child, many families change their daily routines, rituals, and activities to accommodate their child's needs (Swinth et al., 2015). Mothers note routine-making is essential for the maintenance of a structured lifestyle (Joosten & Safe, 2014; Kuhaneck et al., 2010; McAuliffe et al., 2019; Safe et al., 2012) which in turn reduces the cognitive demand required to orchestrate daily activities (McAuliffe et al., 2019). The structure imposed by accommodating the child's needs not only supports the child, facilitating the family to function, but also allows the mother to select activities that reflected her personal values (McAuliffe et al., 2019). In this way, routines offer control which serve as a coping mechanism.

Notwithstanding the advantages of establishing family routines, managing these is considered primarily the mother's role (Blanche et al., 2015; McAuliffe et al., 2019; Nealy et al., 2012) and is deemed an arduous task that some mothers take on unwillingly (McAuliffe et al., 2019; Safe et al., 2012). Mothers of autistic children are portrayed as responsible family managers and routine-makers; their role in maintaining household order is largely unquestioned (Dash et al., 2023) and perceived as an accepted and expected responsibility of the "good mother"' (McAuliffe et al., 2019, p.72). While essential for smooth family function, routines, paradoxically, interfere with the spontaneity of family life (Chiaraluce, 2018; Dash et al., 2023; Safe et al., 2012). Developed as a means of achieving family normalcy, fixed routines restrict participation in irregular activities such

as birthday celebrations or those activities that represent the norms of a community and culture (Bagatell, 2016; Chiaraluce, 2018), serving to further exclude and isolate the family.

On receiving their child's diagnosis, mothers set about mobilizing resources (Altiere & von Kluge, 2009), seeking to arm themselves with information (Altiere & von Kluge, 2009; Byrne et al., 2018; Dababnah & Parish, 2013; Kuhaneck et al., 2010), and becoming more confident as their knowledge of their child and autism increases (Altiere & von Kluge, 2009). Knowledge about autism, services, rights, resources, education, and funding are considered power (Kuhaneck et al., 2010). Becoming an autism advocate is typical of many mothers (Altiere & von Kluge, 2009; Blanche et al., 2015; Boshoff et al., 2016; Joosten & Safe, 2014; Runswick-Cole & Ryan, 2019) and considered a necessary daily occupation that is a primary duty for parents of autistic children (Boshoff et al., 2016; Rizk at al., 2011; Stoner & Stoner, 2016). Advocacy is very time consuming (McCabe, 2007); it takes various forms and involves learning about autism and the system, enquiring of the right people, and accessing services. Parents go to great lengths, demonstrating commitment and perseverance to access services for their child (Woodgate et al., 2008). Although experienced as intensive, complex, and challenging, advocacy helps parents cope in an active way (Boshoff et al., 2016). It can give parents energy and a sense of their own significance (Stoner & Stoner, 2016) as well as functioning as a mechanism for parents to regain control of their lives (Boshoff et al., 2016; Stoner & Stoner, 2016) with the potential for empowerment, positive transformation, and societal benefits (Boshoff et al., 2016).

Informal practical and emotional community supports, and family cohesion, are important in facilitating mothers' resilience (Santoso et al., 2015). Friendships often form with other families of autistic children (Joosten & Safe, 2014), between mothers who understand each other's situation and who can offer practical and emotional support (Safe et al., 2012). Such friendships exist only because they each have autistic children (Phelps et al., 2009; Schall, 2000). Additional forms of coping and mechanisms used for support can involve mothers' active participation in religious activities (Blanche et al., 2015; Dababnah & Parish, 2013; Phelps et al., 2009; Santoso et al., 2015) and alignment with politically active disability groups (Gray, 2001); while others, not wanting to "wallow in autism" (Joosten & Safe, 2014, p.254), opt not to participate in formal support groups but seek support from family, friends, and professionals (Adams & Galvaan, 2010; Bitsika & Sharpley, 1999; Clifford & Minnes, 2013; Kuhaneck et al., 2010). Mothers desire both support and acceptance (Lin et al., 2011); learn to ask for help (Joosten & Safe, 2014; McAuliffe, 2019), and those who receive it tend to be less stressed, less depressed, and have improved

emotional wellbeing (Altiere & von Kluge, 2009; Boyd, 2002; Phelps et al., 2009; Pottie at al., 2009).

Mothering an autistic child does not always, or only, lead to decreased wellbeing and quality-of-life (Bayat, 2007; Phelps at al., 2009; Woodgate et al., 2008). However, studies identifying positive experiences are limited (Stein et al., 2011). Staying positive, identifying moments of joy (DeGrace, 2004; Kuhaneck et al., 2010) and working towards the best possible future (Joosten & Safe, 2014) are coping strategies that mothers of autistic children use. Having a child with a disability can be stressful but need not be wholly negative (Case-Smith, 2004). Families of autistic children learn to become more patient and understanding towards life (Phelps et al., 2009). Acceptance (Byrne at al., 2018) and seeing beyond the label of autism is a key coping strategy for mothers (Kuhaneck et al., 2010). In a family with an autistic child, it is necessary to adjust expectations for family life and reframe the construct of family (Chiaraluce, 2018; Ho et al., 2018; Swinth et al., 2015). Accordingly, mothers' priorities, perceptions, and expectations alter over time (McAuliffe et al., 2019; Safe et al., 2012).

Summarising the experiences of mothering an autistic child as a form of doing-being-belonging-becoming demonstrates how mothering can be appreciated as an occupational experience. *Being* a mother of an autistic child can be stressful and effect mothers' health and wellbeing. Mothers report finding some of their child's behaviours and ways of interacting with others, challenging, which contributes to this impact. Friends, family, and the broader community often understand little about autism, which tests mothering competence and their occupational identity. Mothers can feel judged, unsupported, and isolated. Given the work in caring for an autistic child, mothers typically juggle multiple roles, including that of therapist, struggle to find time for self-care and experience occupational imbalance. In *doing* mothering of autistic children the importance of creating predictability in everyday life is highlighted. Taking responsibility to orchestrate family activities and developing routines to create predictability, facilitates mothers gain a sense of control over their day to day lives, to support children's occupational participation, and to allow the family function. A dearth of support services contributes to the busyness, imbalance, and distress of mothering. *Doing* mothering is inextricably connected to who mothers are, their roles, and aspirations. Underlying aspirations towards a family life that is unattainable, is a problematic normative lens. This reflects the relationships between the occupation of mothering and macro-level conceptualisations – how the mother *belongs* in society. Though the concept of family is reframed, connection with a community and the support of others is important to the

occupational participation of these families. Mothers often connect with other mothers of autistic children for both emotional and practical support, which enhances a sense of *belonging* through mothering. Mothers grieve their pre-diagnosis social, productive, and familial roles as well as the loss of the mother they imagined they would *become.* Given societal assumptions of caring and motherhood, they recognise the implications of their child's diagnosis on their occupational possibilities as mothers of children with additional needs. The permanency of autism coupled with the uncertainty for their children's futures, means mothers look forward with fear. However, the literature also recognises that having an autistic child can have a positive impact on the family as mothers work to ensure the future becomes its best version possible. Berger et al. (2022) claim that occupational science needs to pay further attention to the influence of social ideologies on mothers' doing-being-belonging-becoming through mothering. To meet this end, the current study will apply a justice lens that orientates examination of the interactions between mothers of autistic children and society at meso- and macro levels and explore the construction of mothering practices perceived as positive or negative for this group.

2.5 Conclusion

This chapter has explained foundational concepts in occupational science and related them to the occupation of mothering, including mothering an autistic child. The mother, as an occupational subject creates her occupational identity by doing with and for others (McGrath, 2017). Mothering occupations are the means of expressing mother-identity which is constructed relative to sociohistorical environments and personal experiences of occupational competence and adaptation (Kielhofner, 2012). Reconstruction of occupational identities following disruption, such as the birth or diagnosis of a child, demonstrates its dynamic nature and the centrality of person-environment transaction in its formation. The mother is positioned and positions herself relative to resources and structures. Her occupational engagement and identity are personally and socially sanctioned in response to a consciousness of normative expectations and practices, which in turn can limit participation and create friction between what is practical versus occupationally possible. Mothering an autistic child presents additional challenges that move practices beyond the mothering norm. Inadequate support and resources result in busyness and little time for self-care. Personal beliefs and societal expectations demand that these mothers engage with structures and practices that are outside how they imagined mothering, that fill their time and reduce their possibilities for alternative occupational engagement and identities.

Mothering has been given attention in the occupational science literature, particularly in relation to mothering children with disabilities, but has received less attention as a potential site for occupational injustice. The following chapter develops this idea by exploring the lived experiences of mothering as a justice issue relative to occupational justice and feminism.

Chapter Three

Mothering as an issue for occupational justice and feminism

> The profound, intense, and life-altering motherhood experience is eulogized, lamented, and parodied in popular culture, wherein "mother" has become both a swearword and an instance of the sacred divine (Isaac, 2023, p.37).

3.1 Introduction

The study draws on feminism to understand aspects of the mothering experience as examples of occupational injustice and in this way helps to further conceptualise occupational justice theory, augmenting its practical application. As a central lens in the study's understanding and interpretation of mothers' lived experiences, this chapter examines the theory of occupational justice and suggests contributions that feminism might make to furthering the theory's reach and conceptualisation. To make this relevant to mothering, the chapter explores how feminists engage with the practice and process. Building on this, the chapter concludes by considering mothering as an issue for both occupational justice and feminism, in so doing provides a justification for the research questions guiding the empirical endeavours of the study.

3.2 Introducing the theory of occupational justice

The most basic premise of occupational science is that people are occupational beings (Townsend & Wilcock, 2004a) and that participation in occupation is fundamental to our health and wellbeing (Hammell, 2020; Wilcock & Townsend, 2014). Viewed in this way, occupational participation is perceived as a right (Hammell, 2020; 2008; Townsend & Wilcock, 2004a), more specifically, an occupational right. In an occupationally just world individuals have the right to participate in meaningful occupations for the maintenance or improvement of their own wellbeing and quality of life and that of their communities (Hammell, 2008; Stadnyk et al., 2010). Occupational justice is defined as "the fulfilment of the right for all people to engage in the occupations they need to survive, define as meaningful, and that contribute positively to their own wellbeing and the wellbeing of their communities" (WFOT, 2019, p.1). An occupationally just society would enable

each person, their family, and community to meet their varied needs through engagement in occupations that support their strengths (Wilcock & Townsend, 2014) and enable them to flourish by doing what they decide is most meaningful (Wilcock & Townsend, 2009). Occupational justice is concerned with meaningful choice and social inclusion through occupation (Canadian Association for Occupational Therapists (CAOT), 2016). Inclusive participation is advocated for all persons in society, regardless of "age, ability, gender, social class, or other differences" (Nilsson & Townsend, 2010, p.58). When individuals' occupational needs are met, when they have the opportunity and resources to participate in the full range of meaningful and enriching occupations that are afforded to others, they are experiencing occupational justice (Townsend & Wilcock, 2004a).

Denial of opportunities or resources to participate in occupations of meaning is unjust (Wilcock, 1998). Given the necessity of occupation to human survival (Kronenberg & Pollard, 2005; Townsend & Wilcock, 2004a), restriction of an individual's occupational engagement is perceived as a denial of their access to their humanity (Gupta & Garber, 2017). If external conditions are disabling, individuals' wellbeing is not enhanced, and they experience injustice. When people are "barred, trapped, confined, segregated, restricted, prohibited, unable to develop, disrupted, alienated, imbalanced, deprived, or marginalised in ways that exclude them from participating optimally in the occupations they need and want to do" they experience occupational injustice (Wilcock & Townsend, 2014, p.547). Occupational injustice exists when a person's everyday participation and citizenship in doing-being-belonging-becoming through occupation is restricted (Townsend & Marval, 2013) due to reasons outside the individual's immediate control (Sakellariou & Simó Algado, 2006). Conditions for occupational injustice are created by contextual factors and are often political or economic in nature (Darawsheh et al., 2022). Impositions or restrictions on occupational participation can result in what is termed: occupational deprivation, occupational marginalisation, occupational alienation, occupational imbalance, and occupational apartheid (Durocher, 2017; Townsend & Wilcock, 2004b).

The most prevalent form of occupational injustice is that of *occupational deprivation* (Durocher et al., 2014a). Occupational deprivation occurs when external conditions restrict or preclude an individual's, or community's, engagement in necessary and/or meaningful occupations on an on-going basis. External factors restricting participation can be social, interpersonal, environmental, geographical, historical, political and economic (Durocher et al., 2014a). People need to

participate in a range of occupations for health, social inclusion and citizenship. Being denied such opportunity results in occupational deprivation (Townsend & Wilcock, 2004a).

A second term that specifies an occupationally unjust outcome is *occupational marginalisation*. This involves the exclusion from occupational participation and related choice and control based on informal and implicit norms and expectations (Stadnyk et al., 2010) and results often in relegation to occupations of lower status (Durocher et al., 2014a; Stadnyk et al., 2010). In short, societal norms and expectations prevent people from being offered the opportunity to engage (Durocher, 2017) and the power to exert choice in occupations (Wolf et al., 2010).

When people experience life that is purposeless due to the engagement in occupations that lack personal meaning, they are experiencing *occupational alienation* (Townsend & Wilcock, 2004b). While those who are occupationally alienated are not being afforded the opportunity to engage in occupations of meaning (much like other forms of occupational injustice), alienation is less about preclusion and more about the imposition of occupations that are devoid of meaning, neither valued nor enriching to the individual (Durocher, 2017; Stadnyk et al., 2010; Wolf et al., 2010). Occupational alienation occurs when external forces modulate occupational choices in a way that do not fit with the individual's potential or aspirations (Thibeault, 2007). It results in prolonged experiences of "disconnectedness, loneliness, emptiness, lack of a sense of identity, a limited or confined expression of spirit, or a sense of meaninglessness" (Townsend & Wilcock, 2004a, p.80).

Occupational imbalance results in being over or under occupied or not occupied at all (Townsend & Wilcock, 2004a; Wolf et al., 2010). It holds an explicit temporal dimension in that its focus is on spending too much time engaged (or none at all) in one occupation at the expense of other areas (Stadnyk et al., 2010; Durocher et al., 2014a). At a population level, occupational imbalance describes the situation where some are afforded many opportunities for occupation and others little or none (Durocher, 2017; Townsend & Wilcock, 2004a). As wellbeing requires diversity of occupations, imbalance jeopardises this and in turn it becomes an issue of justice (Townsend & Wilcock, 2004b).

Occupational apartheid represents a form of formal institutionalised occupational injustice. It occurs when individuals' participation is restricted due to policies that discriminate between people based on their personal characteristics (Durocher et al., 2014a) and has less relevance in

the current study. How occupational rights relate to consequent experiences of occupational injustices when rights are not upheld, is depicted in Table 3.1.

Table 3.1

Occupational rights mapped to occupational injustices (adapted from Townsend & Polatajko, 2013, p.81)

Participation	**Choice**	**Meaning**	**Balance**
Right to develop through participation in occupations for health and social inclusion.	Right to exert individual or population autonomy through choice in occupations.	Right to experience occupation as meaningful and enriching.	Right to benefit from fair privileges for diverse participation in occupations.
Deprivation	**Marginalisation**	**Alienation**	**Imbalance**

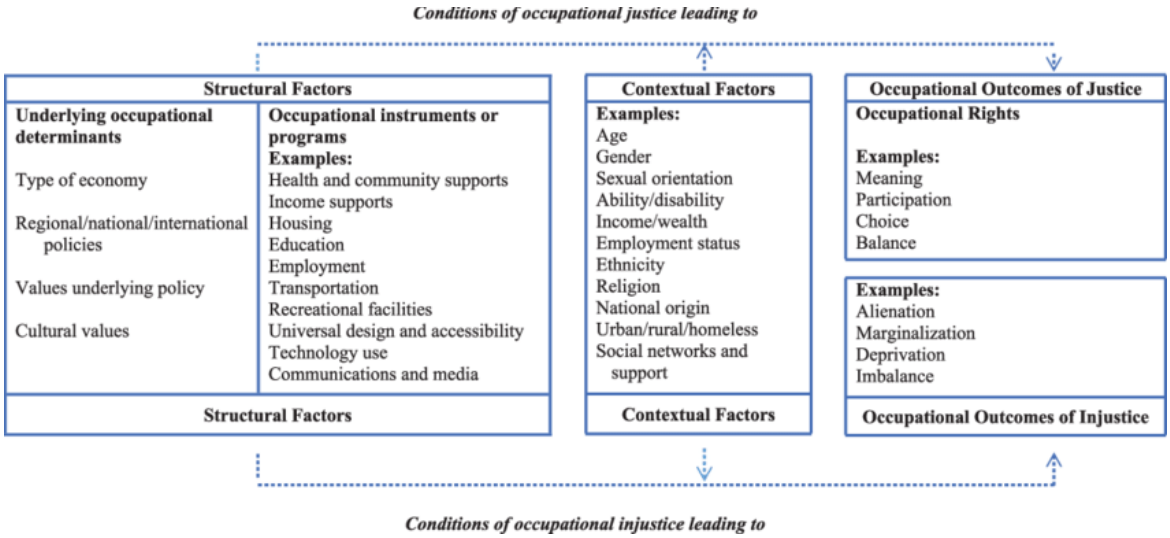
Occupational rights pertain to participation in occupation, choice in occupation, meaning in occupation and balance in occupation and result in occupational deprivation, marginalisation, alienation, and imbalance when individuals experience occupational injustice.

The evolving[6] theory of occupational justice draws attention to the effect of broader contexts on people's occupational lives. It appreciates the impact of societal structures on the participation of individuals and communities, orientating enquiries beyond the individual towards marco-level analysis (Kinsella & Durocher, 2016). Inequalities in quality-of-life are usually due to contextual factors such as unfair access to resources and other social justice issues (Padilla et al., 2004). Oppression is represented in social attitudes and ableist thinking, is perpetuated by structures, systems, and practices (Laliberte-Rudman, 2019), and is evident in public policies, institutions, and governments. Structural determinants, impact the availability of opportunities for occupations that enhance wellbeing (Hammell, 2020). These structures, which include cultural values, shape the provision of services such as health and education which, in turn, shape possible occupational injustice outcomes (Boland, 2018). See Figure 2.1 for a representation of contextual factors and occupational outcomes.

[6] The term occupational justice was first mentioned by Wilcock in 1998 (Wilcock, 1998b) and built on Townsend's 1993 discussion of social justice in occupational therapy. This led to a collaboration between both authors in the early 21st century to further develop the concept (Wilcock & Townsend, 2000; Townsend & Wilcock, 2004a; 2004b).

Figure 3.1

A Framework of Occupational Justice (adapted from Stadnyk (2007))



Human activity takes place in contexts with preconditions that can limit people's options for engagement (Ottersen et al., 2014) so that their behaviour choices are not the products of autonomous action (Frohlich & Abel, 2014). Frohlich and Abel (2014) explain that inequitable social factors, such as gender and disability, constrain action and freedom of choice. Systems of oppression can come from unconscious norms, actions, habit, feelings, and media images and are often performed with no intent to injure yet can compound the acceptance of the hegemonic structures that uphold privilege for a dominant group (Bailliard, 2016). While occupational injustices may be determined by structural causes and social factors, systemic level injustices are played out at the level of the individual in their day-to-day lives (Kinsella & Durocher, 2016), making the everyday occupational participation, such as the practices of mothering, political endeavours (Angell, 2014; Pollard et al., 2008; Ramugondo, 2012).

Occupational justice recognises that power and oppression create conditions for injustice (Gupta & Garber, 2017) and is not alone in this regard. Feminism and social justice are aligned in their recognition of the impact of societal structures and norms on rights and opportunities (Kelsem & Williams, 2010). Rather than being represented by one unifying concept, feminism has different branches each with their own priorities and perspectives (Lay & Daley, 2007; Morrison & Araya, 2018). Feminist theory holds women's issues in central focus as it aims to challenge injustices based on gender (Lay & Daley, 2007). Social justice feminism extends liberalism and liberal feminism in its focus beyond individual liberties to that of the promotion of positive rights that

create conditions essential for the individual to thrive (Kalsem & Williams, 2010). In this regard, I contend feminism echoes the philosophy of occupational justice, and I will contribute to existing literature on occupational justice by making these connections explicit in relation to the study's population.

According to social justice feminism, no one group's subordination is elevated over another's nor privileged over another's suffering. Although this idea may have grown out of a consideration for the intersecting nature of oppression, I suggest that it has application beyond typically oppressed groups to others so that all stories are told regardless of the degree of subjugation. Rights are not hierarchical (Nussbaum, 2011). In highlighting the occupational injustices of those living in extreme conditions, the lives of those experiencing more subtle forms of occupational injustice (micro-occupational injustice) are obscured (Bailliard, 2016). Perceiving some injustices as less important than others, minimises the impact of these on people's lives (Galvin et al., 2011). The moral nature of inequality (Frohlich & Abel, 2014) indicates that all individuals, as moral ends, are worthy of justice (Bailliard, 2016). As such, the current study asserts that deprivation, marginalisation, and other occupational injustices are experienced globally, including in prosperous societies. Furthermore, in accordance with altered circumstances, even lives preconditioned for advantage, given their socioeconomical status and educational attainment etc., can experience the impact of societal structures that reduce possibilities for participation. Micro-injustices (subtle/implicit injustices) can have a real and prolific presence in an individual's life slowly impacting on their mental health and their freedom to choose how to live. Micro-occupational injustice similarly implicitly targets ways of being and doing (Bailliard et al., 2020) and has relevance for the everyday practices of mothering autistic children in mainstream schools.

Individuals are not all the same; they vary in their capacities and skills to participate in society and are unable to equally access resources, even those distributed equally. Occupational justice supports a 'justice of difference', based on the appreciation of individuality and difference in terms of people's occupational needs, wants, and capabilities (Stadnyk et al., 2010). For occupational opportunities to be accessed fairly, people must be provided with variable, appropriate, and equitable, rather than equal, supports (Hammell, 2020). The groupings to which people belong, for example, mothers of autistic children, can form the basis on which they experience exclusion, marginalisation, and injustice (Hammell, 2008; Young, 1990). When groups are denied the right to participate in social life, they are denied their citizenship and to be excluded from this is an injustice (Franzen et al., 2013).

Because not all group characteristics fully represent each group member (Young, 1990), a nuanced view of the group is required (Bailliard, 2016) and can be achieved through person-centred narratives (Bailliard et al., 2020; Hammell, 2020). The current study aims to understand participants' experiences of mothering their children through elevating their biographical narratives and interpreting these through a justice lens that appreciates the individuality of rights. Occupational justice promotes multiple and varied occupational opportunities to support engagement and achievement (Townsend & Wilcock, 2004b; Wilcock, 2006; Wilcock & Townsend, 2009) and the enablement of differences in participation (Townsend & Wilcock, 2004a). Creating conditions of occupational justice aims to bridge the gap between individuals' wellbeing and sociocultural environments that restrict what individuals can do and be (Hocking, 2017). Given the subtlety of micro injustices occurring at the level of the individual, I suggest that bridging this gap demands taking seriously personal narratives to accurately problematise issues and suggest meaningful routes to overcome injustice.

As a theory, it has been commented, that occupational justice needs further conceptualisation (Durocher et al., 2014b; Hammell, 2017; Rudman, 2010). The many types of occupational injustice may add confusion to the concept which itself needs to be clearly and consistently defined (Durocher et al., 2014a; Hammell, 2008; 2020). For Hammell (2020), occupational injustice is understood simply as a violation of occupational rights and is little purposed by the delineation of specific occupational injustice forms. I tend to agree that delineating forms of occupational injustice can complicate rather than clarify, however, by going beyond claiming occupation as a right (Hammell, 2020) to positioning the abuse of these rights as occupational injustice, I believe the field of occupational science has been opened up to emic and etic level analysis, situated in micro to macro contexts.

Occupational justice aligns with some forms of social justice, for example, Sen's[7] capabilities approach with its emphasis on doing and being (Bailliard, 2016; Bailliard et al., 2020; Smith & Hilton, 2008). However, most forms of social justice insufficiently describe the occupational nature of people (Olivares-Aising, 2018) and do not provide a language to enable exploration of justice

[7] Sen's Capabilities Approach shifted the economic rhetoric of utilitarianism to a focus on individuals' capability to do what they value doing. It is an assessment of quality-of-life emphasising individuals' opportunities and freedoms to achieve their valued functionings i.e. their doing and being (Bailliard, 2016; Nussbaum, 1999). Nussbaum listed the Central Human Capabilities (necessary elements of human functioning) and identified a threshold of capabilities below which the individual cannot function as a human.

issues related to what people do (Townsend & Wilcock, 2004b). Occupational justice theory offers a new language, a new set of beliefs, values, and ideas and is changing the debate within occupational science by framing participation concerns within the human rights discourse (Frank, 2012). An occupational perspective creates narratives that reveal the impact of injustices on everyday doing, making justice concerns an issue that is immediately relatable and relevant to everyday lives (Hocking, 2017). Through gathering the biographical narratives of mothers of autistic children, and examining these through a justice lens, the current study will highlight the sociocultural conditions of everyday experiences that support or restrict occupational participation, and it will do this through the use of storied accounts of lived experiences that I believe are immediately accessible and relatable.

Critics also condemn the logic underpinning occupational justice which favours Western principles of neoliberalism and modernity (deBrito et al., 2024). Worldviews on what justice is, and how it is achieved, are varied (Bailliard, 2016) and the relevance of neoliberalism and modernity principals to societies outside the global north are questioned (deBrito et al., 2024; Santos et al., 2014). The current study is located in the global north, and, in this respect, these mothers are living in neoliberal and modern societies that value independence, self-responsibilisation, and autonomy of choice. For this reason, I suggest that occupational justice theory can make sense of these participants' experiences, irrespective of its application beyond this society. The conceptual power of occupational justice, and its pragmatic, theoretical, political, and moral significance, constructs occupational justice as a theory rich with potential (Kinsella & Durocher, 2016). It invites us to engage our moral imaginations in pursuit of a better world (Kinsella & Durocher, 2016), regardless of where this world is situated globally. Such endeavours suggest a unique moral purpose (Hocking, 2017) that compels further exploration and application of occupational justice as a concept with relevance to diverse peoples living in varied sociocultural conditions.

The literature calls for the use of alternative theories to enable reflection on the epistemological underpinnings of occupational justice and realign it with critical epistemological approaches (Santos, 2014). There is scope within feminism to provide alternative conceptualisations of knowledge and experiences of the world and the current study will draw on feminism to contribute to the evolving conversation on occupational justice. Being available to new ontologies, and open to new ways of constructing society at various levels, will enable occupational justice to be achieved (Olivares-Aising, 2018). A feminist perspective is attentive to issues of difference, questions power and scientific oppression, and is committed to social justice (Hesse-Biber et al.,

2004). It has the capacity to uncover the inequalities and subtle injustices in many occupational choices made by women that appear to represent their agency and autonomy but are influenced by behaviour norms and expectations in society (McGrath, 2017). Although feminism has not developed one central theory (Gerlach & Magalhães, 2021), common principles unite its varying forms. These include centring women's experiences and valuing their daily lives, identifying conditions that oppress women; advocating for societal change; and, understanding that many factors, not just gender, can impact women (Lay & Daley, 2007). Such a worldview provides the diversity of epistemology and ontology needed to complement the theory of occupational justice in its application to the population of mothers in this study.

Mothering is an occupation with a broad reach within the occupational science literature, yet the evolving theory of occupational justice has paid it less attention. Occupational justice has often been used to explore the occupation-related conditions in the lives of marginalised populations (for example, Crabtree et al., 2016; Cunningham & Slade, 2019), older people (for example, Kottorp et al., 2016; Causey-Upton, 2015), and people with disabilities in particular those with mental health concerns (for example, Townsend, 2012; Kearns Murphy & Shiel, 2019). While many of these populations may include or reference mothers, with the exception of Molina et al. (2021), few empirical studies have purposely and explicitly examined the occupation of mothering and its relationship with occupational justice. By identifying how some mothering practices and concerns may be experienced as occupational injustices, particularly for those mothering autistic children, this study will demonstrate the scope of occupational justice in contributing to the understanding of mothering as occupation.

Occupational justice is a form of social justice that targets doing, the opportunity to do, and the right to participate (Bailliard et al., 2020). The current study adopts a broad focus on occupational justice and its outcomes; it leans on feminism to support its interpretations of the lived experiences of these mothers, the personal meaning of their doing-being-belonging-becoming, and the transactions between their doing and the contexts in which their lives play out. In so doing, I will be alert to overt and subtle injustices impacting occupational engagement and participation as well as the potential for resistance and becoming through mothering. The following section provides an overview of mothering from a feminist perspective before considering mothering as a justice issue for both feminism and occupational justice.

3.3 Feminism on mothering

The unquestioned assumption that women take up occupations and roles related to care and reproduction reflects gender beliefs that women are inherently nurturing, and maternity is a natural condition for them (Nussbaumer et al., 2024). Because caring is considered an innate attribute, and mothering has become synonymous with caring, motherhood has been seen as natural to women (Berger et al., 2022). Feminists challenge the notion of essentialism and biological determinism as concepts that underscore gender difference, holding gender difference as central to, if not responsible for, male oppression of women. Motherhood's potential to reinforce biological determinism and suggest essentialism causes feminists to be uncomfortable with the issue of motherhood (O'Reilly, 2019a; White, 2010). Takševa (2018) explains that radical feminists related motherhood to women's powerlessness and the maternal to the women's oppression. Many feminists believe motherhood denies women the creation of their own subjectivities by contributing to structures that require them to marry, fulfil gender roles and become mothers (Takševa, 2018). To become a mother means sacrificing the autonomous self (Barkin & Wisner, 2013; de Beauvoir, 1949 (translation 2009)). As homemakers and child carers, women's lives, and by extension mothers', are confined to immanence (maintenance) while men have opportunity for progression and exist to transcend (de Beauvoir, 1949 (translation 2009)). A supposition underpinning the interpretation of maternal related feminist scholarship is that motherhood equates to loss; that paid work is where women make and find meaning, mastery, control and identity (Stephens, 2004). Many of the inequalities women experience, socially and economically (Jolly, 2017), are related to their role as mothers (Ennis, 2019; O'Reilly, 2019a). Feminism in general remains reluctant to appreciate mothering, recognise it as a category of intersection and give it the attention others believe it deserves (Gordon, 1990; Kawash, 2011; O'Reilly, 2019a).

Not all feminists have disregarded motherhood. Some believe feminism is confusing motherhood, *the experience*, with motherhood, *the institution* (O'Reilly, 2019a; Rich, 1976). Motherhood, the patriarchal institution, is male-defined and controlled; it is a tool of capitalism, patriarchy (Chandler, 1998) and a site of disempowerment for women (Takševa, 2018). Mothering, or motherhood as an experience, is female-defined, mother-centred and potentially empowering to women (O'Reilly, 2019b). In distinguishing between these two forms of motherhood, Rich (1976) destablises the patriarchal institution of motherhood. Motherhood and maternal subjectivities are given voice and can be examined outside a male-defined space (Takševa, 2018). These feminists disagree that motherhood means total loss of subjectivity and that all mothering

practices are wholly disempowering. Chandler (1998, p.283) comments that "there is something about mothering practices that both underlie and go beyond" the image, institution, and construction of motherhood. Many mothers gain pleasure and empowerment from mothering, with Takševa (2018) claiming it is not incompatible with the formation of female subjectivity. O'Reilly (2019a, p.49), reinforcing the importance of motherhood to mothers, notes that mothers "do not simply live as women but as *mother women*".

On the other hand, patriarchal motherhood constrains and limits mothers' agency, authority, advocacy-activism, autonomy, and authenticity (O'Reilly, 2019b). It denies mothers the opportunity to determine their own life practices and mothering occupations. Patriarchal motherhood, and ideologies such as intensive mothering, do not support empowered mothering and independence of mind (O'Reilly, 2019b). Social norms construct mothering occupations as restricted to childrearing, frame motherhood as a naturally feminine condition, and have the power to determine what mothering occupations are acceptable and what are not (Berger et al., 2022). Consequently, the problem with the institution of motherhood is less related to societal attitudes around mothering and more to do with who holds the power to shape and sustain these attitudes of mother-as-institution and mother-ideal (Kawash, 2011; Rich, 1976). It is this motherhood, perceived as an institution, male-defined and controlled by the patriarchy, that Green (2019) holds responsible for the resultant injustices experienced by mothers.

Motherhood's contribution to society is undervalued (Kawash, 2011; O'Reilly, 2019b). While seen as playing an essential role in passing on social values to the next generation, it is also taken for granted by society (Larson, 2000). The primacy of work in Western culture, in which it is acceptable and desirable to go out and earn money (White, 2010), has a detrimental impact on the status and value of care work. Most jobs involving nurturance are paid less than other jobs (Correll, 2004). Despite care work, such as mothering, performing an essential social function and subsidising the market economy, caring remains entirely undervalued by society (Bjørnholt, 2019; Craig, 2008). The standard response of feminism to the fact that childrearing marginalises mothers has been to encourage fathers to do more of it instead of working to raise the value of care work (Crittenden, 2001). White (2010) comments that it is precisely because care is undervalued that Article 41.2 in the Irish Constitution is so contentious. The care, training, and instruction of children by members of a household, does not feature in calculations of GDP or pay-related benefits (Perez, 2019; White, 2010) as it does not entail market transactions (Waring, 1988; 2017). Lack of recognition of unpaid work reflects, to a large extent, an under appreciation of mother's work, as much of the

responsibility for managing families' activities, including balancing paid work and unpaid care and household labour, remains gendered (Bjørnholt, 2019). Because neoliberalism discounts unpaid work, and employment policies assume an unencumbered "adult-worker model" (Bjørnholt, 2019, p.391), to be successful in this regime, women need to be as men and mothering cannot contest for status (Crittenden, 2001).

Compounding the issues and injustices associated with mothering is the ideal of the *good mother* and the concept of intensive mothering. Hays (1996, p.8) theorised *intensive mothering* as a gendered ideology promoting "child-centred, expert-guided, emotionally absorbing, labor-intensive, and financially expensive" practices. These ideologies shape mothers' perceptions of motherhood (Williamson et al., 2023), leave women aspiring towards an elusive ideal by applying considerable pressure on women to invest much time and energy into childrearing (Schmidt et al., 2023; Stone, 2007) and to be fully fulfilled by motherhood (O'Reilly, 2019b). *Good mothers* place their child's needs above their own (Dash et al., 2023; Hays, 1996; Schmidt et al., 2023) and prioritise child rearing even if they work outside the home (O'Reilly, 2019b). They are responsible and selfless, doing whatever it takes to enhance their child's development and wellbeing even if this means sacrificing their own occupations, goals, and health (Dash et al., 2023; Schmidt et al., 2023). By acting in the way they are trained to act (such as becoming the primary carer), women (mothers) reinforce their own subordination (Hay, 2020). Within this ideal, the mother is the primary carer, mothering is promoted as natural to the woman and a response to her desire to nurture (O'Reilly, 2019b).

The juxtaposition that can exist between women's lived experiences of being a mother and their ideals of motherhood (Laney et al., 2015) can alter their mothering behaviours in their effort to uphold these ideals (Williamson et al., 2023), and can contribute to feelings of shame and guilt, and impact their mothering competence (Choi et al., 2005; Stone, 2007). Powerful social norms not only regard home and children as primarily the responsibility of the mother (Fine, 2010) but hold mothers accountable for what their children become (Francis-Connolly, 1998; 2000). Irrespective of the child's age, Francis-Connolly (1998) reports mothers aspire to be perfect and experience feelings of guilt for not being good enough. Mothers feel judged by society against unattainable expectations with consequent experiences of insecurity about their doing and being as mothers. The unsympathetic and comparative attitudes of others contribute to their decreased sense of belonging and feelings of disconnectedness with others (Berger et al., 2022). Subscribing to good mother ideology is associated with lower parental self-efficacy (Henderson et al., 2016)

and life satisfaction (Rizzo et al., 2013), as well as higher levels of stress (Wall, 2010), anxiety (Henderson et al., 2016), and depressive symptoms (Rizzo et al., 2013). Childrearing often reinforces traditional gender roles in domestic duties and caregiving, perpetuating the intensive mothering ideology that positions the mother as the expert. Judgements and criticisms perceived by mothers reinforce the idea that if a woman is not a good mother, she is a bad mother (Williamson et al., 2023).

Normative cultural schemas hold *family devotion* and *work devotion* as opposed. Mothers are expected to respond to their families' needs but normative work practices also expect workers to prioritise their employers' needs. The incompatibility of these contradictory expectations (Schmidt et al., 2023) assumes one role will be prioritised over the other. A good mother will unconditionally devote her time and energies to her children; having less resources to then contribute to work, a mother cannot be perceived as an ideal worker. Reinforcing this claim, Berger et al. (2022) claims that mothers returning to work after the birth of their first child experience a sense of inadequacy in both roles. They feel expected by society to spend less time in paid employment than in their mothering activities yet as workers they feel less valued with colleagues assuming they would take time off to tend to children's needs (Berger et al., 2022). Mothers who wish to remain engaged in their careers can experience a double bind – pressure to be the ideal mother and ideal worker (Schmidt et al., 2023; Stone, 2007). Mothers are labelled as selfish if they want to keep their careers and as unproductive "leeches" if they choose to become stay-at-home mothers (Hay, 2020, p.165). These social constructions limit women's workplace opportunities and available occupational possibilities. The impact of having children on men's participation and opportunities is comparatively insignificant (Craig, 2008; Ennis, 2019). All-or-nothing workplaces (Scott, 2018) and gender inequality in the home plays a major factor in successful career women's decisions to become fulltime mothers (Stone, 2007), running contrary to a common belief that mothers feel an internal pull towards their child and domesticity (Fine, 2010). Framing this within a simple choice rhetoric, as has been depicted in the media, obscures the complexity of this decision (Williams, 2000).

A feminist lens identifies the injustices and discriminations experienced by mothers, demonstrating that these are largely related to the structures in which mothering practices are embedded. Oppression is made up of interconnected patterns of subordination, making the successful navigation of situations difficult, and the identification of a practical, one-fits-all solution to feminist issues of inequality, unattainable (Hay, 2020). However, a synthesis of the

literature allows me to conclude that a feminism's analysis of mothering suggests a way forward for mothers in countering injustices.

1. Green (2019) notes the importance of opposing the institution of motherhood and disrupting the gender essentialism of mothering identities and childcare practices. To engage in empowered mothering that challenges the dominant motherhood discourse is to afford mothers the agency, authority, advocacy-activism, autonomy and authenticity that is denied them in patriarchal mothering (O'Reilly, 2019b).
2. Just as feminism does for other categories of women, O'Reilly claims that recognition of the perspectives of mothers as particular to their lived experiences is needed. Consequently, motherhood should be recognised as an intersection for oppression and resistance (O'Reilly, 2019a) in the same way as other intersecting categories, with issues acknowledged as originating from structural mechanisms (Jolly, 2017). This is in keeping with social justice feminists' belief that no one group's subordination should be elevated over another's (Kelsem & Williams, 2010), a belief also advocated in the occupational therapy literature (Nunes Farias & Esquerdo Lopes, 2023).
3. Societal recognition of nurturance and care work as occupations of value and status is warranted. The possibility of a mother transforming her mother identity by, as Butler might suggest (1990), not engaging in mothering occupations is extremely unlikely (Chandler, 1998). The status of caring and nurturing is unlikely to be changed by the occupational disengagement or non-action of carers. Instead, caring should be understood as a social duty, valued as everyone's responsibility (Craig, 2008); and the compatibility of care work with the concepts of empowerment, agency and autonomy acknowledged (Takševa, 2018).
4. To be a mother is to enact occupations of mothering within a multifaceted, everchanging, and repetitive performance that is inseparable from the child (Chandler, 1998). Given the absence of any one stable and univocal mother identity or coherent universal experience, DiQuinzio (1993) suggests that 'mother' might be rethought as a subject-position rather than as a substantiated or naturalised identity. Alongside this, societal aspirations towards individualism and autonomy should be revisited so that new perceptions of the autonomy ideal, that fit with the maternal, are generated.

Feminists recognise multiple injustices experienced by mothers through their mothering engagement and identity, created and sustained by the patriarchal structures in which they practice. Illuminating these as occupational injustices holds focus on mothering as an active practice in context. O'Reilly (2019b) considers it crucial that mothering has its own feminism. It

has been much ignored by most branches of feminism yet, for feminism to remain relevant, motherhood, including its paradoxes and complexities, must be acknowledged (Kawash, 2011). In response, O'Reilly (2016a; 2019a) forwarded the idea of a matricentric feminism that recognises the maternal more as a practice than an identity. Like other forms of feminism, it aims to identify forms of women's oppression and challenge patriarchal structures, in this case the patriarchal institution of motherhood. Matricentric feminism is a feminism that values mothering; it understands that motherhood is central to lives of mothers but that it does not wholly define their selfhood. It aims to instead instate an image and experience of mothering that is empowering to mothers. Using a matricentric feminist lens to understand the occupational injustices experienced by the mothers in this study, centres analysis on mothers' stories while acknowledging the impact of the broader contexts and patriarchal structures in which their lives are embedded and on which their engagement in mothering occupations is contingent.

3.4 Mothering as a justice issue (relative to feminism and occupational justice)

Dominant groups within social hierarchies exert power and privilege over others through "social interactions, everyday activities and occupational opportunities" (McGrath, 2017, p.138). They determine not just who is valued but also what occupations are esteemed (Hammell, 2008). The dominant constructions of mothering a child with a disability is underpinned by patriarchy and psychologization (Runswick-Cole & Ryan, 2019). These families are often stigmatised, stereotyped (Papadopoulos, 2021) and considered broken (Runswick-Cole & Ryan, 2019). Similarly, when a mother's perception of being in the mother role deviates from societal expectations and norms, her ability to fulfil the requirements of her role are called into question (Wada et al., 2010). Caring for their autistic child necessitates engagement with additional and non-normative mothering roles and activities (Angell et al., 2016; Brewer, 2018; Chiaraluce, 2018; Kim et al., 2018; Kuhaneck, et al., 2010; Safe et al., 2012; Stoner & Stoner, 2016) that may be expected of these mothers (Blum 2007; O'Hare et al., 2023; Porter et al., 2024; Ryan & Runswick-Cole, 2008) but are not necessarily promoted as desirable (Laliberte-Rudman, 2010) by mainstream perspectives on motherhood. According to Gupta and Garber (2017) social institutions and services, such as schools and healthcare, reflect an expected way to live which, as a dominant force, is recognised as valued and normal. Alternative ways of living, or values, attitudes, and abilities, that are not in line with normative beliefs and abilities, are seen as undesirable and are not always accepted. This is

marginalising to those who may have no choice but to live non-normative lives. Barriers, often invisible, to participation for people who are valued less, exacerbate inequalities, and maintain the privilege experienced by normative groups (Gupta & Garber, 2017).

The complex interplay between social norms and the possibilities for mothers' doing and being influences the occupational participation and choice of women and mothers (Berger et al., 2022). Townsend and Wilcock (2004a) claim that people have a need to exert choice and control over their everyday, micro-level occupations to feel empowered, the absence of this can lead to occupational marginalisation. Choice is identified as a privilege of those living in advantaged circumstances (Laliberte-Rudman & Dennhardt, 2008). Mothers of autistic children engage predominantly in obligatory occupations rather than occupations of choice (Hodgetts et al., 2014; Rizk et al., 2011; Santoso, et al., 2015). Although potentially members of a socioeconomically advantaged grouping, as a subgroup of mothers, those with autistic children may have fewer choices and opportunities for meaningful engagement than other mothers.

It is thought that much of the occupational science literature on mothering is focused on experiences at the individual level and does not fully appreciate motherhood in its sociocultural context (Berger et al., 2022; Sethi, 2020). Mothers show an awareness of social norms and can feel judged by society on their mothering practices (Ryan & Runswick-Cole, 2008). In this way, social ideologies influence the doing-being-belonging-becoming of motherhood (Berger et al., 2022). Before having a child with a disability, Tabatabai (2020) claims that some mothers imagine a heteronormative life that includes commitment, marriage, a baby, and a home. These normative aspirations are communicated through communities and societal structures. Mothering roles are socially constructed (Runswick-Cole & Ryan, 2019) and sacrifice is often positioned as inevitable and expected of mothers particularly those mothering autistic children (Marsack & Perry, 2018). Describing mothers as carers who sacrifice themself to best mother their child can reinforce the belief that this is what *good mothers* should do (Dash et al., 2023) which limits available occupational possibilities and positions a mother-woman as responsible for everything to do with her child (Collins, 2021). The notion of the *good mother* adds complexity to the lives of those who are trying to combine mothering with other occupations and roles and also sets impossible standards for women who are wholly focusing on motherhood (Maher, 2005).

Mothering is everyday life. In fact, one reason for mothering to be problematised may be its state as an everyday, commonplace occupation. Everyday occupations, Hasselkus (2006) believes,

pattern our lives, and provide meaning. They are understood only through examining their detail, yet typically go unnoticed. Motherhood is both a common and individual practice (Esdaile, et al., 2004). The commonality provides mothers with a shared role and identity. However, the individuality of motherhood is often overlooked. Although everyday life matters, Hasselkus (2006) explains, we don't tend to describe everyday practices in sophisticated language, they are merely 'done'. Consequently, we generalise such occupations looking for states of commonality. The ubiquity of mothering, together with its association with care work of low status and non-renumeration, may devalue mothering and render it dismissible. According to Townsend and Wilcock (2004b), much of what we want and need to do in everyday life is related to unpaid employment i.e. non-productive occupations such as mothering. However, society's acute emphasis on productive occupations results in the invisibility of occupational deprivation and imbalance that extends to other occupational classifications where mothering is located. Given that most caring, including unpaid caring, is carried out by women, Waring (2017) considered this to be a feminist and economic issue of justice.

Unpaid care work is noted for its excessive workloads (Waring, 2017) and over-occupation (Atchison, 2009) leading to experiences of occupational imbalance. The busyness of tending to the needs of another can leave mothers without time and occasion to engage in diverse occupations required to sustain health and wellbeing (Hodgetts et al., 2014; Rizk et al., 2011; Santoso, et al., 2015). Regular interaction with education and health services (Byrne et al., 2018), and the requirement of mothers to act as home therapists, further contributes to their experiences of imbalance (Hodgetts et al., 2014). Imbalance, as a function of role incompatibility, is a result of competition between the demands of various roles for time or activity (Wada et al., 2010). Stein et al. (2011) conclude that, despite a desire to achieve occupational balance, mothers of autistic children struggle to do so without considerable support to modify their current lifestyle and occupational patterns. Opportunities for personal occupational balance that is mother-focused, rather than focused on child or family, are reduced when mothering an autistic child (Kim et al., 2018). Contextual and environmental factors in the form of services and support influence how mothers perceive balance and also how they experience and achieve it. One way of addressing imbalance created by the burden of care is to maximally use available services (Hines et al., 2014). However, the dearth of available services and appropriate supports for autistic children is an issue of concern for mothers (Gray, 2002a; Nealy et al., 2012; Pisula, 2007; Safe et al., 2012), one that impacts their child's participation and has consequent implications for mothers' experiences of imbalance as well as other forms of occupational injustice. Policies that govern systems of

education and health need to be cognizant of how their services impact on the families they support (Brewer, 2018).

Conflict between social ideologies and personal beliefs disrupts mothers' sense of life balance and their perceived ability to meet the demands of being a mother (Berger et al., 2022). Focusing on individualism and a person's agency in conceptualisations of balance and imbalance overlooks the complexity of human-environment transaction that occurs during occupational engagement (Liu et al., 2023). Mothering balance is shaped by more than a personal capacity and willingness to meet role demands but also by the congruence between occupations and the values of family and community (Yazdani, 2018). Individuals are less satisfied with their occupational balance if operating outside the accepted ideology of their social group (Wada et al., 2010) and perceive more balance when their occupations are in accord with social expectations relative to their normative life stage (Backman, 2004). This can be problematic for non-normative mothering. Mothers of autistic children perform outside their peers/social group of mothers. Their child's non-normative participation and their own intense relationships with multiple structures and supports serve to reinforce their difference making it difficult to perform in keeping with the norms and expectations of sociocultural ideologies.

Mothers have been found to experience a range of dichotomous feelings from delight to over-whelming responsibility and guilt (Dunbar & Roberts, 2006). Mothering that does not provide meaning and fulfilment can lead to experiences of occupational alienation. Usually, mothers are enriched by their child assuming that their circumstances are not very unfavourable (de Beauvoir, 1949 (translation 2009)). In this de Beauvoir recognises the contingence of mothering experiences on external factors. Mothers of an autistic child have been found to reduce their hours of paid employment and in many cases leave work so that they can attend to the many needs of their child (Brewer, 2018; Chiaraluce, 2018; Joosten & Safe, 2014). Thus, the variation in their occupations, connections with individuals outside the home, and opportunities for occupational engagement as a woman rather than as a mother of an autistic child, are considerably reduced. Operating within the private domestic sphere, on the margins of influential public life and burdened with social role expectation and unpaid care work, mothers of a child with a disability can lack voice and visibility (Rosaldo, 1974). Yet they must counteract this with advocacy for their child in response to a lack of services (Runswick-Cole & Ryan, 2019). Mothers' move further from a mythical norm as they "weave, ease, negotiate or batter a path for their children to lead flourishing lives" (Runswick-Cole & Ryan, 2019, p.1129). Mothers are expected to fight for their

children's rights (Runswick-Cole & Ryan, 2019) singling their mothering out as different, adding to their workload and burden of responsibility, reducing possibilities for alternative participation, and creating conditions for marginalisation and imbalance.

Occupational justice has relevance for all mothers, most especially those whose mothering is non-normative such as mothers of autistic children, and who potentially experience additional societal expectation to support their child within systems that are not tailored to meet the needs of neurodiversity. This study is essential to give voice to their mothering narratives. Importantly for motherhood, occupational justice makes accessible issues of social justice by translating these issues into people's stories of everyday life (Hocking, 2017). Experiences of everyday mothering of autistic children are made sense of using the language of occupational justice. The concept allows us to explore restrictions on participation and engagement in occupation (Townsend & Marvel, 2013). The doing-being-belonging-becoming of motherhood is a core dimension of many women's identity and occupational engagement. How mothering an autistic child plays out is dependent on the transaction between the mother-child and the sociocultural environment in which mothering takes place. Macro level structures and expectations, brought to our attention using feminist and occupational justice perspectives, can be a source of disempowerment for mothers, decreasing opportunity for other occupational engagement and limiting agency. However, for occupational justice to have utility and relevance to mothering discourses, it needs to be more thoroughly examined.

3.5 Conclusion

Mothering, both as a practice (an occupation with potential for experiences of injustice) and a role (motherhood as a female identifier) is relevant to feminism. Consideration of the contextual nature of maternal activity (Everingham, 1994) highlights the importance of appreciating the extent of mothers' transactions within multi-layered systems, the social norms and expectations impacting their practices, and the everyday activities and interactions on which their varied engagement in mothering occupations and roles are contingent (Berger et al., 2022). The principles associated with fairness, empowerment, sharing of resources and equitable access that underpin occupational justice (Wilcock & Townsend, 2000) align with those out of which feminism grew. A feminist understanding of mothering recognises the impact of broader social structures on mothering practices. This study will contribute to the growing literature on occupational justice within the discipline of occupational science. The application of a feminist lens to problematising

and analysing these mothers' narratives will offer a deeper understanding of the occupation of mothering an autistic child. Feminism will extend the reach of the theory of occupational justice by reflecting on the impact of motherhood the institution, the varied penalties incurred by mothers, and societal expectation for maternal performance, all of which are likely compounded for those mothering autistic children. Notwithstanding the recommended use of feminist theories to inform the recent drive for social occupational therapy practices (Ferreira-Marante & Veiga-Seijo, 2023; Morrison & Araya, 2018), feminism has been little drawn on in conjunction with the concept of occupational justice and mothering. In this study, feminism will provide a diverse epistemology to understanding occupational injustices and in doing so develop the practical application of occupational justice theory to this population.

Before presenting the study's findings on the lived experiences of mothering autistic children in Chapters Five to Seven, the following chapter details the study's methodology, reiterating the objectives of the research and explaining the steps taken to meet these objectives by answering the research questions.

Chapter Four

Methodology

We dwell across the globe in a vast multitude of complex interconnecting reflective storied social worlds. Our narratives are continually born, sparkle, flicker, silence and die; some get remembered (Plummer, 2019).

4.1 Introduction

Previous chapters presented the background to the study and provided a rationale for the exploration of mothering autistic children and experiences of occupational justice for this population. This chapter is in two parts, with Part 1 positioning the study ontologically and epistemologically, justifying the use of narrative inquiry as a methodological approach employed to explore how mothers' realities unfold in everyday life. Part 2 reiterates the research objectives, explaining how these, in turn, were operationalised using the Biographic Narrative Interpretive Method (BNIM) and providing a detailed account of empirical data collection and its analysis. The chapter closes by detailing researcher positionality and ethical adherence, as well as the limits and trustworthiness of the study.

PART 1

4.2 Choosing a qualitative research approach

Qualitative approaches are interpretative and naturalistic modes of inquiry (Lincoln & Denzin, 2003; Silverman, 2017) that explore the experience and meaning of phenomena to participants (Corbin & Strauss, 2008) without assuming there is a singular truth to be uncovered (Braun & Clarke, 2013; Pinnegar & Daynes, 2007). Epistemologically, qualitative research tends towards the production and analysis of narrative data (Alasuutari et al., 2008) often using open and responsive methods (Corbin & Strauss, 2015) to generate an understanding of the worlds that participants inhabit (Braun & Clarke, 2006). The qualitative paradigm is a move away from the positivist, realist

position of quantitative research (Pinnegar & Daynes, 2007) that seeks to objectively test variables (Corbin & Strauss, 2008) with a focus on prediction and control.

An objectivist ontological position supposes an objective reality existing autonomously of social actors (Silverman, 2015). Alternatively, a constructivist ontology assumes that people actively and continuously construe their realities (Bryman, 2012). In this study, knowledge is recognised to be contextual (immediate and historical-cultural-social), personal, practical, and experiential (Caine et al., 2022), therefore constructed, perspectival and always only partial (Braun & Clarke, 2013; Chase, 2011; Ronkainen et al., 2016). Qualitative researchers seek to understand subjective experiences and individuals' perceptions of their reality (Silverman, 2017). Grounding the current study in a qualitative, interpretivist paradigm appreciated that the phenomenon of mothering could be understood through the meanings that each participant brought and assigned to it (Merriam, 2009; Merriam & Tisdell, 2015), valuing each perspective of reality as unique and valid (Patton, 2002).

4.3 Framing the study ontologically and epistemologically

There is little consensus as to the ontological nature of narrative inquiry with some researchers being committed to relativism and others to (neo)realism (Smith & Sparkes, 2006). Epistemologically, some also take a realist position (for example, McAdams, 2005) while others are grounded in constructionism (for example, Spirtos, 2017). The current study adopted an ontology of relativism and an epistemology of constructionism within an interpretivist/qualitative paradigm. It did not make claims for the existence of an objective reality nor of any neutral methods to access this reality. The study assumes that there can be no theory-free understanding or measurement (Smith & Sparkes, 2006) because people, including researchers, are unable to stand outside their own social and historical positions to view the world as independent bystanders. Instead, the world is made up of multiple, created and mind-dependent realities (Smith & Sparkes, 2006, 2009a) which are influenced by time and context (Braun & Clarke, 2013; Patton, 2002). Knowledge is recognised as subjective, perspectival, and incomplete (Braun & Clarke, 2013).

The social construction of knowledge forwards the idea that we are active meaning-makers of reality and realities shift through our interaction with one another (Morioka & Nomura, 2021). Narrative inquiry might be perceived as inherently socially constructed, taking shape through the

telling and not telling of a story and being reconstructed by the listener in listening and again in interpreting (Chase, 2011). This study recognised that meaning and understanding are derived from our social engagement and discourses. However, it also acknowledged that our realities are born from more than our conversations and interactions in the social world (Craib, 2000). Our understanding of life and knowledge is constructed, corporally and cognitively, through experiences within the self and through interactions between the self and others and engagement with aspects of, and activities within, the natural, institutional, cultural, and political environments. Meaning is constructed from our embodied lived experiences (Smith, 2013).

4.4 Narrative inquiry – storied research

Human life is storied (Smith & Sparkes, 2006). Stories are understood as a vehicle through which humans make sense of their lives (Chase, 2008; Polkinghorne, 1988) and a primary method through which lived experiences are made meaningful (Daiute, 2014; Polkinghorne, 1988; Smith & Sparkes, 2009a). They have the power to "shape identity, guide action, and constitute our mode of being" (Smith & Sparkes, 2006, p.170) and have been a feature of human interaction since antiquity (Morioka & Nomura, 2021; Plummer, 2019). The term *story* is often used interchangeably with the term *narrative* (Bingley et al., 2008; Wells, 2011). Although there is not an agreed use of either term, for example, Polkinghorne (1988) and Taylor (2013) versus Riley and Hawe (2005) and Smith and Sparkes (2009a), narrative research has been described as the study of stories (Polkinghorne, 2007), and most descriptions of narrative research usually make some reference to stories.

All narrative researchers recognise the story as a significant, if not the fundamental, unit that accounts for human experience (Pinnegar & Daynes, 2007). While some see narrative inquiry as a rich methodology with corresponding procedures and processes for analysing the data (such as that used in this study), others employ stories as data sources only (Taylor, 2013). The adoption of any one approach to narrative inquiry depends in part on the topic of interest as well as the researcher's discipline, theoretical position, analytic practice, and methodological stance (Creswell, 2013; Wells, 2011). However, despite varying the emphasis they place on context, content, structure, or performance (Wells, 2011), all narrative researchers use stories, or storytelling activities, as their instrument of inquiry and primary data set (Cihodariu, 2012; Pinnegar & Daynes, 2007; Wells, 2011). Narratives are typically a form of linguistic interaction

involving the narrator and audience and the in-depth interview remains the most popular form of narrative data collection (Chase, 2011).

While the origins of narrative inquiry have been traced as far back as the early 1900s (Chase, 2008), the liberation movements of the 1960s and 1970s, such as civil rights and feminist movements, were central to the growth of the narrative as a vehicle to give voice to marginalised and unheard stories (Chase, 2008; Riessman, 2008). With the increased dissatisfaction by several disciplines with the adequacy of the positivist paradigm to research social phenomena and solve social problems, and the consequent emergence of qualitative approaches as valid epistemologies, space was created for narrative inquiry to be perceived as an acceptable method to investigate the human condition (Clandinin & Rosiek, 2007; Hinchman & Hinchman, 1997; Polkinghorne, 1988; Taylor, 2013). This has been referred to as the *narrative turn* (Polkinghorne, 1995; Riessman, 2008). As concern with matters of context, interactions, intersubjectivity, language, and power in the research relationship came to the fore (Chase, 2005; Riessman, 2008), narrative methods became increasingly popular in the social sciences for their ability to account for individual actions as well as social and cultural change (Chamberlayne et al., 2000).

4.4.1 Focuses of narrative inquiry

Within the social sciences, narrative inquiry tends to be defined in relation to either events or experiences (Wells, 2011). A focus on events requires the collection of stories about a particular event in sequential order to a particular audience to express a particular meaning (Gergen, 2009). Other narrative inquiry, such as the current study, hold experience central (Squire, 2008; Wells, 2011). According to Chase (2011), narrative inquiry is concerned with the life experiences as narrated by those who live those lives. Her definition of narrative inquiry as "meaning making through the shaping or ordering of experience" and as "a way of understanding one's own or others' actions, of organising events and objects into a meaningful whole, of connecting and seeing the consequences of actions and events over time" (Chase, 2011, p.421) speaks to the understanding of narrative inquiry accepted in this study.

With a focus primarily on experience, narrative inquiry has been considered to occupy fundamentally one of two positions orientated around either the *what* or *how* of storytelling (Casey et al., 2016; Smith & Sparkes, 2006), without mutual exclusivity (Casey et al., 2016). The method used in the current study attends to both. Conceived as a phenomenological inquiry, narrative research that prioritises *what* the story is about, its characters and plots, acts as a tool

for making sense of lived experiences (Casey et al., 2016). Chase (2011) explains that this approach to narrative research typically emphasises the quality of life-experiences, often focusing on the banal with a view to reaching new understandings of that experience. Caine et al. (2022) advise that this form of narrative inquiry begins with a focus on the experience rather than with the identification of another concept in that experience, i.e. the event.

A second principal, but alternative, approach to narrative inquiry positions narrative as a tool of social construction (Casey et al., 2016). These researchers prioritise *how* people narrate their experiences and construct their social reality (Smith & Sparkes, 2006). Appreciating that attending to context is as essential to understanding stories as to its words, Daiute (2014) believes attention must be paid to how a story is told. Narrative here is more than a form of internal reconstruction and meaning-making through narration. It also allows for meaning and reality to be created through the social process of storytelling, acting as a form of social action (Chase, 2011) and influenced by socio-historical contextual factors (Casey et al., 2016).

4.4.2 Purposes of narrative inquiry

To understand occupation, we need to regard it as an interactive whole (Wilcock & Hocking, 2015) by bringing inter-relationships and the webs of occupation into sharper focus. To this end, Wilcock and Hocking advise listening to people's voices, especially those of women and the disenfranchised. Narrative inquiry gives voice to the narrator. Stories, in how they are told and listened to, can challenge dominant narratives (Rogers & Rose, 2019), provide counter arguments and act as a mechanism for social justice (Wånggren, 2016). Wånggren describes how storytelling has been used to forward social change by "allowing people to learn, exercise agency, shape identities and motivate action" (p.402). In line with this idea of narrative as having the potential to be disruptive, Wilcock and Hocking (2015) suggest that the most effective way to raise critical consciousness of issues of occupational injustice is through the use of storytelling, describing first-person accounts that engage the listener at experiential, cognitive and affective levels. Storytelling, while both traditional and essential, is also capable of opening up avenues for change (Wånggren, 2016).

Narrative inquiry provides a research framework that addresses the individuality of the self and one that also gives meaning to events and shared perceptions with others (Morioka & Nomura, 2021). It takes us into the private world of others (Riley & Hawe, 2005), allowing us to see the life through others' perspectives, while interconnecting these with larger social structures (Rogers &

Rose, 2019). Consciously or unconsciously, through the telling of lived experiences the individual reveals aspects of their identity (Bamberg, 2011). Narratives are not only a form of expression and a way of sharing experiences but also a means of demonstrating the character of the narrator (Daiute, 2014). Smith and Sparkes (2009b) claim that, while the self and identity are constituted through narrative, identities are not something people have, rather, something they perform and do habitually in relation to others. Narrators are empowered to be selective in what and how they share their stories, and in this way, they are positioned to reveal a preferred version of the self that fits the social context of the narration (Riessman, 2008).

4.4.3 Narrative inquiry and context

Within the oral genre of narration or storytelling, meaning and experience are intimately linked to context (Bruner, 2004). The relational property of narrative inquiry contributes to its sense-making (Clandinin & Murphy, 2007; Clandinin & Rosiek, 2007). Narratives are molded by the narrator to be heard by a particular audience (Smith & Sparkes, 2009b; Wells, 2011). Conceptualised as both personal and social (Smith & Sparkes, 2009b), narratives are inherently a product of socialisation – co-constructions influenced by the interaction between narrator and listener (Chase, 2008; Riessman, 2008; Smith & Sparkes, 2009b). Stories, according to Rawling (2022), possess power to enable listeners imagine and anticipate, visualize and empathise with the characters. Both listener and teller play active roles in narrative inquiries; narrative researchers contribute to, as well as learn from, these meaning-making processes (Daiute, 2014) and both will change and learn as a consequence (Pinnegar & Daynes, 2007).

Time, place, occasion, ambiance, audience and narrator-status are all essential to oral narration (Chamberlain & Thompson, 1998). Narratives are generated by the individual but shaped by cultural norms and genres for expression (Bruner, 2004). The sociocultural impact of stories influences the narrative not only through the narrator's selective performance in response to the audience, but also through the availability of story structures and genres in any given culture – people can only draw upon the narrative resources available to them (Bell, 2002; Smith & Sparkes, 2009b). Stories are not told in a vacuum but occur within a time, place and culture that affects both what is/can be told and how they are/can be heard.

Wånggren (2016), coming from a feminist perspective, explains that the narratives told and attended to are relatable to concepts of power and authority. Stories may be influenced by power differentials playing out between the narrator and listener/researcher (Morioka & Nomura, 2021).

Dominant forces have the capacity to marginalise stories as well as decide the meanings of words (Wånggren, 2016). However, through narration, people can also resist dominant cultural assumptions. An example of such resistance, relevant to the current study, is alternative and non-normative discourses created by mothers of children with Attention Deficit and Hyperactivity Disorder (ADHD) in Austin and Carpenter's (2008) narrative exploration of mothering. Storytelling, as a form of social action through which people make sense of their experiences, has the power to construct selves and realities and also disrupt cultural discourses.

Narrative has a temporal thread and narrative inquiry is concerned with the living and telling of a person's life which is always in the making, never finished (Caine et al., 2021). To convey meaning and be best understood, stories rely on the common presumption that time moves linearly (Polkinghorne, 1995). Yet, Caine, Clandinin, and Lessard (2021) explain that experiences are part of ongoing life and not discrete instances; they are continuously being enmeshed and contextualised into life as a whole. People relate current events to those that went before and change narratives in light of new experiences (Bell, 2002). Temporality is consequently understood as a process of enfolding rather than enfolded.

4.5 Narrative inquiry in the current study

The capacity of narrative inquiry to attend to the particular, rather than seek generalisation (Josselson, 2007a), aligns with an exploration of the experience of mothering which values everyday life and enables mothers express the detail of their personal experiences through their unique narratives. The approach to narrative inquiry that most closely resonated with the current study's objectives is that which Chase (2011) labels *storytelling as lived experience*. This integrates the *what* of the story with the *how* it is being told – how it is communicated, in what way the self is presented, how the story conveys wider social meanings (Casey et al., 2016), how the phenomenon (mothering) is constructed in the telling, how the realities of everyday life are accomplished (Smith & Sparkes, 2006). The application of narrative methodology to capture the realities of marginalised populations and its use in research that focuses on feminist concepts of power, justice, and equality, speaks to its utility in meeting the concerns of the current study. In particular, this study requires an unstructured, open approach that would facilitate the experiences of mothering to be expressed with minimum interference from interviewer reasoning, while also enabling the in-depth interpretation of mothering narratives as lived experiences and identification of any relationship between mothering and issues of justice to

come to the fore. An approach meeting these requirements is the Biographic Narrative Interpretive Method (BNIM).

4.5.1 The Biographic Narrative Interpretive Method (BNIM)

The current study employed the Biographic Narrative Interpretive Method (BNIM). BNIM is described as both a method and interpretivist methodology (Corbally, 2015; Flynn, 2019). It provides a structured framework for data collection and analysis that has the capacity to translate, elucidate and give meaning to participants' life stories (Corbally & O'Neill, 2014). While BNIM subscribes to a social constructionist philosophy, its development as a method was also influenced by the grounded theory of Glaser and Strauss, linguistic analysis of Labov and Waletzky and biographical methods of Chamberlain, Rosenthal and Fischer-Rosenthal (Casey et al., 2016; Wengraf, 2001).

Unlike many other qualitative approaches that ask of the interviewee to generalise about and opine on their experiences, narrative inquiry invites specific stories (Chase, 2005) and regards the interview schedule (if indeed there is one) as a loose guide rather than a means of semi-structuring the interview (Chase, 2011). BNIM uses an intentionally unstructured approach to interviewing, reducing the power imbalance between the researcher and those being researched (Flynn, 2018), providing a framework that encourages an uninterrupted telling of the life story (Casey et al., 2016), and allowing participants generate their own themes (Hesketh, 2014; Wengraf, 2001, 2019b).

BNIM is a useful tool in studying retrospective events (Flynn, 2014) and in building rapport with participants (Hesketh, 2014). It aims to examine the person's life story (its biographical element), how this is told (its narrative element), while recognising that stories are subject to social and historical construction and interpretation (its interpretive element) (Casey et al., 2016; Corbally & O'Neill, 2014). BNIM explores the subjective experience but appreciates how social and historical meanings can become inscribed on the narrative (Casey et al., 2016); it shows appreciation of the biographic, psychosocial, and historical dynamic of people's lives (Corbally & O'Neill, 2014).

Bearing this in mind, BNIM was considered to be suitably equipped to appropriately address the aims of the current study. The study aspires to make sense of mothers' mothering experiences from a feminist perspective and in relation to occupational justice concepts. Yet within this, it is most important that the reality of those living these experiences is represented as opposed to the

issues most obvious to the researcher or pertinent to the literature. By preserving the distinctness and individuality of mothers' experiences, BNIM made this possible. However, BNIM also relates the personal meanings mothers applied to their life events to the chronology of their lives and, in this way, it anchors personal meaning within its historical and social context, making space for issues of justice and other macrolevel concerns of this study, to be explored. As an instrument of data collection, BNIM requires the application of established procedures and ways of interacting, while BNIM analysis employs a series of sequential steps to interpret the *what* and *how* of the biographical narrative. BNIM interviews are structured into subsessions, with the first interview combining what it refers to as subsession one and subsession two (SS1/2). It is in this interview, called the BNIM interview, that biographical narrative data is collected. The second interview, referred to as subsession three (SS3), confirms but does not collect narrative data, and has no fixed parameters guiding interview procedures or conduct. The operationalisation of BNIM is described in sections 4.7.3 and 4.8.

PART 2

4.6 Research purpose of the current study

The study's focus on lived experiences and occupational justice formed the central methodological considerations and shaped the development of the research question and objectives which were used, in turn, to guide the study and provide coherence.

4.6.1 Research question and aims

In relation to women mothering autistic children attending mainstream school, the central research questions guiding this study are:

1. **What is the lived experience of mothering?** And given this,
2. **Whether and how is occupational injustice evident as a function of the conditions of their mothering?**

Specifically, the study aimed to explore:

***Objective 1*:** The biographical narratives of mothers of autistic children relative to their doing and being as mothers.

Objective 2: Mothering as a mechanism for agency, belonging, becoming, and occupational identity construction.

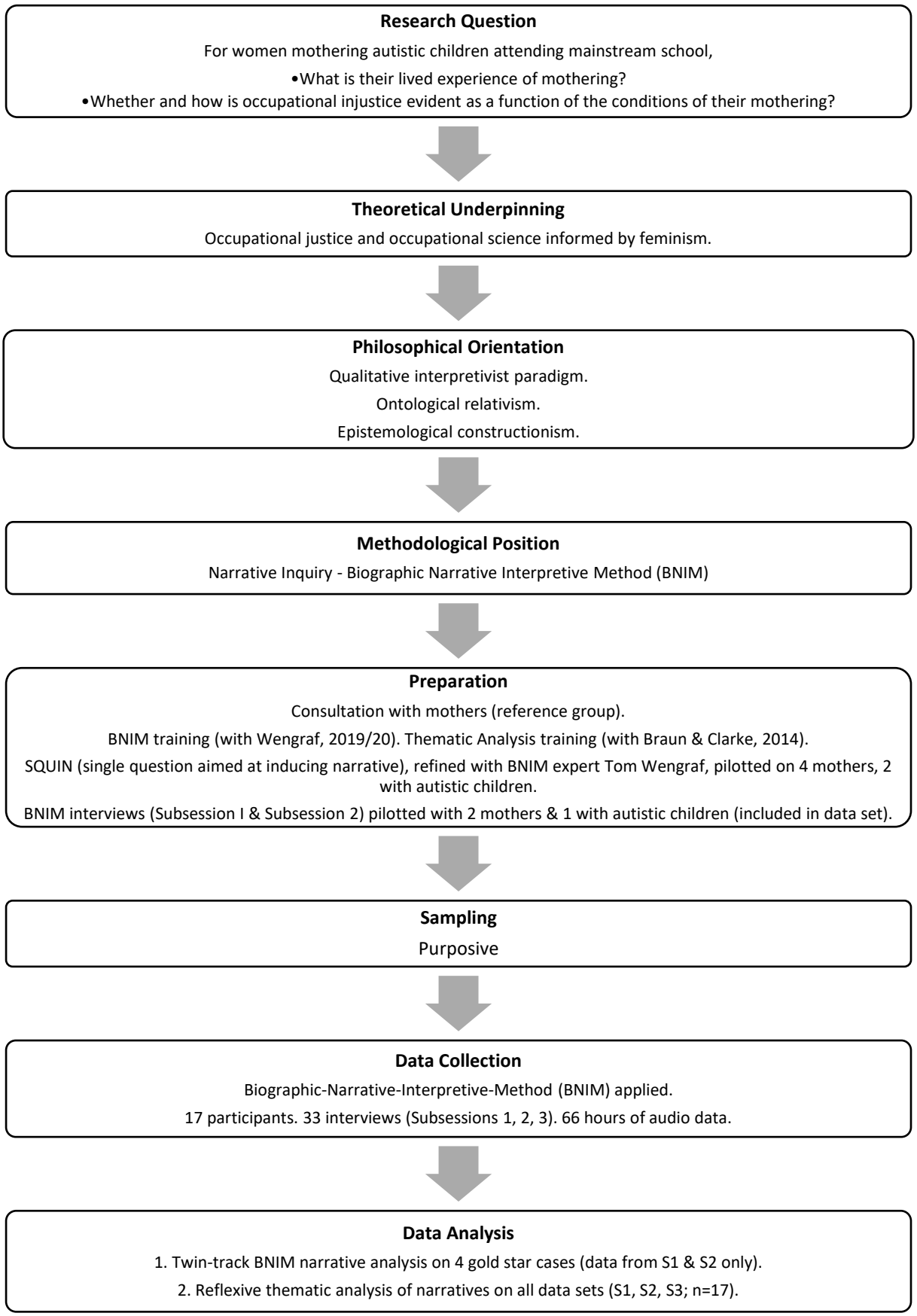
Objective 3: The relevance of the theory of occupational justice in the lives of these mothers including their micro-macro level supports and challenges.

Objective 4: How mothering experiences might expand an understanding of the concept of occupational justice.

4.7 Research design

This section explains how the study was constructed to meet its objectives, providing a rationale for decision making in keeping with narrative inquiry. It describes the study's sampling and recruitment, data collection and data analysis. Figure 4.1 is an overview of the research design.

Figure 4.1 ***Research design***



4.7.1 Preparation

Efforts were employed to ensure the study had relevance, credibility and utility. These included:

1. Three mothers with autistic children in mainstream school acted as a reference group and were consulted in the preparation and analysis stage of the study. They provided baseline representation of potential participants' opinions and understanding of the study. Each were satisfied that the study had potential to give them voice and honour their experiences. The literature, and formal supervision, were used to refine the research questions and objectives.
2. To enhance research competence, following the methodological decision to employ BNIM, I attended a three, full-day training course on BNIM interviewing (London, Nov 2019) and a three, full-day training course on BNIM data analysis (Trinity College Dublin, Mar 2020) delivered by BNIM expert Tom Wengraf. Although I had experience in both empirical data collection and qualitative analysis, BNIM training was considered essential to ensure my competence in applying the specific requirements and techniques of BNIM. Prior to this, I had also trained in, and used, the thematic analysis of Braun and Clarke (Qualitative Research International Summer School, Bristol University, 28 July-1 Aug 2014).
3. The BNIM interview opening question, the SQUIN (a single question aimed at inducing narrative) was refined with Wengraf (described in 4.7.3) and piloted with two mothers from the reference group, as well as two mothers without autistic children.
4. The BNIM interview was practiced with a colleague, then piloted in full on two mothers, one of whom has an autistic child. This mother is also included in the data set.

4.7.2 Sampling and recruitment

The study employed purposive sampling, deliberately recruiting participants based on their capacity to provide comprehensive information on the subject being explored (Braun & Clarke, 2013; Creswell, 2013; Patton, 2002). Following the receipt of ethical approval, participants were purposively recruited via social media advertisements and snowball sampling. Active recruitment to the study and data collection commenced at the end of May 2020. Given the length and depth of the BNIM interviews and its time-demanding analysis, the ideal sample size is small (10-15 participants) (Wengraf, 2019b). The information advertising the study (see Appendix 1 for recruitment poster) was tweeted on an account created specifically for the purposes of recruiting to the study. Netiquette dictates that the moderators of groups should be contacted prior to posting recruitment advertisements to an internet forum (Hewson, 2007). These procedures were

applied, and the advertisement was also forwarded for display on the websites of autism-related organisations, namely ASPIRE and the Irish Society for Autism. The advertisement was additionally posted by others, who read the original tweet, on at least two other Facebook pages related to autism – one operating at a national level and the other at a county level.

Participants in this study included any mother who wanted to share their story, good or bad, of mothering an autistic child attending mainstream school. No additional inclusion criteria were set. Minimising the inclusion criteria offered enough scope for diversity within the sample. However, narrowing the mothering experience to this population (criterion: that their child attends mainstream school) allowed greater potential for shared experiences and opportunity to explore patterns of meaning across data sets as well as within individual stories.

Those interested in the study contacted me directly for more information. Once it was established that potential participants met the inclusion criteria, they were forwarded a letter of introduction, the participant information leaflet (PIL) and consent form (in keeping with the stipulations of the study's ethical approval). Mothers meeting the inclusion criteria were requested to read the material sent them and take at least seven days to consider participation before an interview date was scheduled. A total of 20 mothers were given information about the study; one mother, recruited through snowballing, was found to be ineligible in preliminary conversations as her son was no longer in mainstream school, another two were unable to find free time to schedule the interview, the remaining 17 mothers participated in the study. Sixteen of these were interviewed twice. Of the 17 original participants, one learned of the study at a local support group meeting, four were told about the study by friends, a further five saw the advertisement on the websites of national organisations and the remaining seven responded to the original tweet and subsequent retweets.

Generalisation and data saturation were not aspirations of this study. The study did, however, interview a sufficient number of mothers and in considerable depth to fulfil BNIM requirements and to claim it as an in-depth study of these mothers' experiences. The sample held homogeneity in relation to the inclusion criterion centring around autistic children in mainstream schools. Otherwise, these mothers were each unique and varied in their daily lives in terms of their supports and responsibilities, their productivity and interests, their perspectives and backgrounds. See Table 4.1 for overview of sample demographics.

Table 4.1

Participant demographics

Pseudonym	Children	Employment Status of mother & father	Living situation
Imogen	Two boys, 8 & 11y/o. Eldest is autistic. Both have ADHD.	**Mother**: Studying & working PT* (from home). Self-employed. **Father**: FT*, M-F*.	Married. Living with husband and children. Urban East
Maeve	Two children, girl and boy, 16 & 11y/o Both autistic with ADHD.	**Mother**: Working PT (weekends) outside the home. **Father**: FT, M-F.	Married. Living with husband and children. Urban East
Paula	Two boys, 8 & 10y/o. Eldest is autistic and has mild intellectual disability (ID).	**Mother**: Working 4 days per week outside home. **Father**: FT, M-F.	Married. Living with husband and children. Urban East.
Tamsin	Two boys, 5 & 7y/o. Both mother and eldest child are autistic.	**Mother**: Works PT from home. Self-employed. **Father**: FT, M-F.	Married. Living with husband and children. Urban East
Myra	One boy, 15 y/o.	**Mother**: Working PT outside the home. **Father**: FT.	Married. Living with husband and child. Rural West.
Nessa	Two children. 10 y/o boy with autism & ADHD. 12y/o girl with ID.	**Mother**: Working FT outside the home. **Father**: FT, M-F.	Married. Living with husband and children. Rural West.
Sadie	Three children. 12y/o boy, ADHD, autism & dyslexia. 10y/o girl with digestive condition. 8y/o boy severe dyslexia & sleep apnoea.	**Mother**: Working 15 hour week outside the home. **Father**: FT.	Divorced. Living with children. Rural West.
Heather	Two boys, 9 & 11y/o. Eldest is autistic.	**Mother**: Stay at home mother. **Father**: FT, M-F.	Married. Living with husband and children. Urban East
Tess	Three boys, 11, 9 & 7y/o. 11y/o has dyslexia. 9y/o has autism, dyspraxia & ID.	**Mother**: Working FT outside home. **Father**: FT, M-F.	Married. Living with husband and children. Urban East.
Jane	Two girls, 8 & 11y/o.	**Mother**: Stay at home mother. **Father**: FT, M-F.	Married. Living with husband and children.

	Both girls and mothers have ADHD. Eldest is autistic.		Urban East
Eloise	One girl, 8y/o. Autistic and has ID.	**Mother**: Working PT outside the home and some hours from home. **Father**: FT, M-F.	Married. Living with husband & child. Urban West
Sadhbh	Five children, between ages of 17 and 2y/o. Eldest is autistic and transgender. 11y/o boy is autistic. 8y/o boy is autistic. 5y/o girl & 2y/o boy have no diagnoses.	**Mother**: Working PT outside home. **Father**: FT.	Married. Living with husband and children. Urban West.
Olivia	Two boys, 20 & 11y/o. Younger child is autistic.	**Mother**: Stay at home mother. **Father**: FT.	Married. Living with husband, children and their granny. Urban East.
Niamh	Two children, girl and bo y, 15 & 11y/o. Youngest is autistic.	**Mother**: Working four-day equivalent outside home. **Father** has similar hours.	Living with partner and children. Urban East.
Claire	One boy, 7y/o.	**Mother**: Works FT. **Father**: works at weekends & cares for son during week.	Married. Living with husband and child. Urban East.
Kate	One boy, 8y/o.	**Mother**: Works PT (mornings & weekends) outside home. Self-employed. **Father**: FT.	Married. Living with husband and child. Rural East.
Helen	Two boys, 18 & 17y/o. Youngest is autistic.	**Mother**: Works FT outside the home. **Father**: FT, M-F.	Married. Living with husband and children. Urban East.

Note. *PT means part-time; FT means full-time; M-F means Monday to Friday.

Note. **Gold star cases used in BNIM twin-track analysis.

With the exception of one mother, Sadie, all lived with their children's fathers; ten were mothers to two children; ten mothers worked part-time and three were stay-at-home mothers.

4.7.3 Data collection in sub-sessions one and two

Originally it was conceived that data collection would take place in-person. However, the timing of planned recruitment coincided with the first Covid-19 pandemic lockdown in Ireland. Given the

unknown longevity of the pandemic, it was decided to employ virtual meeting options rather than postpone data collection for an indefinite period.

On indicating a wish to participate in the study the consent form was again forwarded, together with the zoom link for the virtual interview. Mothers were asked to return the consent form prior to their interview. Those who forgot to do this, were instead asked to confirm their consent orally before their interview began; this was recorded to be GDPR compliant and recommended by the Assistant Data Protection Officer in the university.

Interviews took place at the time and day that best suited the mothers – early mornings before the family woke, evenings between work and teatime, weekends when families were away from home. All but one interview began on zoom, however, ten interviews (SS1/2) were continued on the telephone as WiFi connections were unstable. One mother requested a telephone rather than zoom interview as this enabled her to move about, engage in activities and look after her children, while participating in the interview. All participants were interviewed in their own homes (two sat in their cars for privacy). During interviewing, three mothers were interrupted by their children and another four were interrupted by their children's fathers.

Applying BNIM, interviews began with a preamble. I introduced myself and explained the structure of the interview – that it would include a short interlude following the participant's first uninterrupted narrative. In keeping with BNIM protocol, no further information on BNIM or the interview purpose or topic was discussed (Wengraf, 2019b). Sub-session one (SS1) began with the following single question aimed at inducing narrative (SQUIN):

"*As you know I am researching mothers' lives so could you please tell me your life story and particularly from when you started ever thinking you would become or be a mother. So, if you could tell me all the events and experiences that were important to you personally. I'm not going to interrupt; I'm just going take notes for questions for when you finish telling me about it all, but you can speak for as long as you like and start wherever.*"

The SQUIN is a single framing question (Corbally & O'Neill, 2014), designed to elicit a whole life story/history or partial and more focused life stories (Corbally & O'Neill, 2014). It is deliberately designed to provide the participant with space to fill with a narrative of her own creation (Wengraf, 2001). Although it may be focused, it needs to be broad enough to provide a useful

means of eliciting data that empowers the participant to start, construct and finish the story on her own terms (Jones, 2003; Nicholson, 2009). The SQUIN used in this study was *partial* in that it focused the narration conceptually to motherhood rather than trigger a full life story/history. Its development was guided by conversations with BNIM expert, Tom Wengraf, who emphasised the importance of maintaining breadth. Consequently, it prompted participants to begin narration at the point when they had thoughts about motherhood rather than from when they became a mother. The SQUIN was subsequently piloted with four mothers, two with autistic children, refined, and again refined after the first interview. See Appendix 2 for editions of the SQUIN.

While the participant was narrating her story, uninterrupted, I took note of topics mentioned. The length of this sub-session (SS1) was dependent on the participant and continued until she indicated she had clearly finished speaking. A short (for example, 15 minute) interlude ensued when I reviewed the narration and identified topics for further exploration in sub-session two (SS2). During this interlude TQUINS (topic-questions seeking narratives), or structured narrative-pointed questions, were devised that aimed to provoke more in-depth storytelling based on the highlighted topics in the SS1 narration. Sub-session one and two occurred consecutively in one lengthy interview, which is typical of BNIM (Wengraf, 2019b).

In sub-session two (SS2), the participants were invited to expand on the narrative elicited by the SQUIN by being gently pressed for more storied detail on their accounts. Questioning followed the precise order in which the topics were raised in the original narration, using only the words of the participant. No questions other than those that elicited narrative were permitted (Wengraf, 2019b). For example, I began with "You said…do you remember any particular moment when you thought/felt that way?" (See Appendix 3 for examples of TQUIN guidelines.) Most desirable was when the participant described a story as if reliving the experience. This is known as an in-Participant Incident Narrative or in-PIN. To achieve the in-depth storytelling desired in SS2, I was required to push respectfully for detail on the participant's narrative. In line with BNIM, first-round interviews (SS1/2) were long, ranging from 1.5 hours to almost 4 hours, averaging at 2 hours, producing approximately 35 hours of narrative across 17 participants. A personal debriefing session took place in the hour following the completion of SS2 in which I made dated, situated, free-associated (DS-FA) notes reflecting on the preceding interview (further described in section 4.11.1).

4.7.4 Data collection in sub-session 3

Sub-session 3 (SS3) was an optional follow-up interview which provided for the exploration of topics relevant to the research objectives that had not been explicitly discussed in SS1/2 and in which I used external questioning to further explore issues raised by participants in the first interview.

An interview guide for use in SS3 was devised. The guide centred around the experience of mothering and was divided into the following sections:

1. Past influences on occupational identity.
2. Transitioning to a new occupational identity.
3. Motherhood as occupational identity.
4. Situating mothering relative to other occupations.
5. Supporting mothering.

The questions were generated following review of the literature pertaining to feminist mothering, motherhood in occupational science, occupational therapy and occupational justice (see Appendix 4 to trace the development of the SS3 interview guide).

The purpose of SS3 was to gather the participants' perspectives and experiences of mothering as an occupation, an identity and a practice that was in a context and relation to society. The interview guide was first reviewed by an occupational scientist who suggested the introduction of questions related to coping occupations and the impact of mothering on engagement in other occupations, and secondly by a narrative researcher who confirmed the importance of including aspirations (questions on mothers' imagined futures and on the aspirations of a younger self for the present life).

The guide was made particular to each participant following a preliminary analysis of her SS1 and SS2 and review of the DS-FA notes. Aspects of the interviews that spoke to the participant's position on motherhood, or that were related to justice and feminism, were noted and integrated into the interview guide. Any SS3 questions that had been answered satisfactorily in SS1/2 were removed from the interview guide which was then shaped and amended for each participant. To demonstrate a sample of the SS3 interview questions, the guide used with one of the participants is presented in Appendix 20.

On consenting to a follow-up (second) interview mothers were sent a zoom link, consent form and copy of their life story chronology which had been teased from narratives provided in SS1/2. As with the first interview, the zoom link was re-sent the day before the interview was scheduled to take place. This served as a gentle reminder as well as making the link readily available for use. Participants who had not returned their consent form prior to the interview were asked to consent orally and permission to record was established before the interview commenced.

Participants were invited to correct and elaborate on their chronologies in SS3 as this was deemed a useful way to confirm the information, encourage reflection on their told-lived lives, and re-established rapport. SS3 provided opportunity to share early interpretations of SS1/2, seek elaboration and confirmation. The semi-structured nature of SS3 allowed space and flexibility for additional questioning relevant to each participant and provided me with the opportunity to explore the research topic more explicitly. The interview guide was worked through in its order but without rigidity. If a topic was raised of relevance to the research objectives, it was then further explored; if topics were discussed that pertained to later questions the ordering of the questions shifted.

SS3 took place between six weeks and three months after SS1/2. Wengraf (2001) recommends a minimum of one month between the initial and follow up interviews to provide time for preliminary analysis and adequate reflection by participants on the SS1/2 narratives. Sixteen of the 17 mothers participated in follow-up interviews producing over 31 hours of interview. Follow-up interviews ranged from one to three hours.

In total, over 66 recorded hours of interview were conducted; these were transcribed by a professional transcriber.

4.8 Data analysis overview

Narrative analysis as a method is distinguished from general qualitative analysis of narratives in that it deals only in stories and concentrates on interpreting, with varying emphasis, their content, structure and/or form (Bingley et al., 2008). Narrative inquirers believe that other interpretations and ways of explaining things are possible. They aim to describe the insights learned from stories without dismissing the first-person experience as an unimportant source of knowledge (Clandinin & Rosiek, 2007). The objective is not to enable generalisation but rather to interpret meanings

and delve into the nuances and interrelationships within experiences that might enhance understanding when applied to other similar situations (Josselson, 2011).

There is no singular method of analysis in narrative research (Smith & Sparkes, 2009a), however, narrative analysis is typically considered time consuming and difficult. Like many narrative inquiries (for example, Flynn, 2018; Spirtos, 2017), this study employed two analytical methods, treating all 17 mothers' data (33 interviews) to reflective thematic analysis (Braun & Clarke, 2022) while four BNIM gold star cases were analysed according to the BNIM analytical procedure. Gold star cases are those considered to answer the study's research question most fruitfully through narrative data. Wengraf (2015; 2019b; Wengraf, 2020) suggests selecting three such gold star cases. This approach aligns with the idea of 'data condensation' (Miles et al., 2020), which is supported in the broader BNIM literature (Flynn, 2018; Moen & Moen, 2018; Nicholson et al., 2013; Stringfellow, 2022; Turner & Turner, 2017) and believed to be integral to data analysis, as it refines, focuses, and organises data to draw meaningful and trustworthy conclusions (Miles et al., 2020).

4.9 Reflexive thematic analysis of participant narratives (n=17)

While BNIM analysis provides a rich and valuable understanding of socio-biographical lives of gold star cases (Chamberlayne et al., 2002), the method employed to analyse the remaining cases in a study is at the discretion of the researcher (2019b; Wengraf, 2020). Reflexive thematic analysis (Braun & Clarke, 2022) can be undertaken with varying guiding theories and different orientations to data and consequently was considered appropriate for use with narrative data. All interview data (SS1/2/3) from all 17 participants were thematically analysed with the aim of identifying patterns of meaning across data sets and provide a detailed and nuanced account of data (Braun & Clarke, 2006).

Applying the six-phase approach to reflective thematic analysis, a mix of semantic and latent codes were generated by working through each interview, participant by participant, using NVivo 12. Coding was regularly interrupted to write memos on individual cases or anomalies that arose in the data. Negative cases were also taken into consideration and thoroughly examined during this process. The visual tools within NVivo played a role in creating models that served as an effective visualization strategy, aiding in the identification of plots and patterns within the data (Bazeley & Jackson, 2013) (see Appendix 8). Comparisons between mothers were noted as well as their

different reactions to similar conditions such as gaining diagnoses (see Appendix 17). Coding, recoding and categorising codes into subthemes and themes was an iterative process in this study that included revisions across time of initial ideas about what the data could mean (see Appendix 9 for initial themes). Revisions also incorporated the considerations of theory (to expand interpretations) and self-reflection (to me help approach analysis from different perspectives). In this way, analysis was primarily inductive, though also deductive. Applying theoretical understanding to deductively analyse the data helped identify latent meanings underlying mothers' words and shifting subjectivities towards motherhood, enabling me to reconstruct coded data into meaningful units that represented my interpretation of what was said and fit with the constructivist design of this study.

To confirm that data was interpreted meaningfully and in a way that others could apply to similar situations, a member of the reference group was consulted on the TA report before finalising how best the study's interpreted findings might be thematically shaped and communicated. She could identify with the subthemes and confirmed that they represented her experiences (see Appendix 14 for our email correspondence). To further enhance understanding and reflexivity, collaborative coding was employed whereby a member of the interpretative panel (experienced qualitative researcher and authority on occupational justice; see section 4.10.2 for a description of interpretive panels) examined and discussed the codes and initial themes (some ideas recorded in Appendix 10). The phases of reflective thematic analysis, as applied in this study, are summarised in Table 4.2.

Table 4.2

Six-phase approach to reflexive thematic analysis used to analyse study data

Phase	Title	Description
1	Familiarisation with the data.	Interviews (n=33) were listened to, anonymised, re-read. Errors corrected, initial ideas and thoughts noted. DS-FA diaries were read. Data was imported into NVivo12.
2	Generating initial codes.	Interviews were coded in order, deconstructing data from its original chronology into initial, non-hierarchical general codes. Analysis was inductive. Codes were descriptive (semantic) and latent.
3	Generating themes.	Codes with similar meaning were combined and grouped under initial subthemes; they were presented as a chronological journey that described mothers' lived experiences and, for confirmability, were shared with a member of the reference group.
4	Reviewing potential themes.	Subthemes and codes were discussed with a member of the interpretive panel and revisions to presentation of subthemes to best represent the mothers' experiences were made. Concepts from occupational science and feminist theory were applied to assist in deductively understanding data and clustering codes around a central meaning.
5	Defining & naming themes.	Subthemes and topics were grouped into a coherent story under four central themes that each in a different way spoke mothers' lived experiences including those of occupational justice.
6	Producing the report.	The analysis was presented as themes and subthemes with suitable data extracts that demonstrated meaning.

Further information on the application of the phases outlined in Table 4.2 may be found in Appendices 8, 9 and 10.

Reflexive TA (Braun & Clarke, 2022) is underpinned by assumptions and practices that are in keeping with those of this study. Its theoretical flexibility allowed analysis to be informed by feminist approaches that give voice to lived experiences of possibly marginalised groups while also locating mothering within the occupational science and justice discourses. Its flexibility in capturing both semantic and latent meanings permitted relatable, descriptive accounts of mothers' experiences to be reported as well as interpretative explanation, which spoke to the ethics of this study. Reflexive TA also considers, as essential, the active and reflective practice of the researcher, encouraging continual reflection and recursive coding (Trainor & Bundon, 2020).

This study understood that my values and assumptions would influence the questions I asked and my reading of data and that this impact would warrant unpicking through reflexive practice.

4.10 BNIM analysis

BNIM analysis is both sophisticated and complex (Flynn, 2018). A merit of BNIM is the detail with which Wengraf (Wengraf, 2001, 2008; Wengraf, 2020) describes how narrative data might be approached and interpreted. The data treated to BNIM analysis was sub-sessions one and two of the gold star cases only.

4.10.1 Gold star cases

I familiarised myself with the BNIM narrative analysis by applying it first to the case of Imogen. The further three gold star cases to which the analysis was subsequently applied were Eloise, Sadhbh and Maeve. The cases were chosen to represent anomalies as well as commonalities among the mothers. Preliminary analysis identified factors that prompted their selection. The gold star cases provided much by way of narrative incidents and personal experiences of mothering. Eloise had professional experience of the health/education system, was an autism advocate, and her daughter had an intellectual disability and was minimally verbally communicative. Sadhbh was a mother of five children, three were autistic; both of Maeve's children were autistic, and like Sadhbh's son, Maeve's daughter was diagnosed in her teens. Imogen was representative of many participants in how she became alert to the possibility of autism, navigated diagnostic and therapeutic services, and coped with autism. All four women had back stories that reflected in their mothering and, in some respects, positioned them in contrast with each other. Across their S1 and S2 these mothers openly spoke of their experiences, provided in-PINS (detailed storied accounts) and at times shared their theories on motherhood and women. Aspects of their lives were common to some mothers and distinct from others; each had a unique and interesting story to tell resulting in their selection as gold star cases.

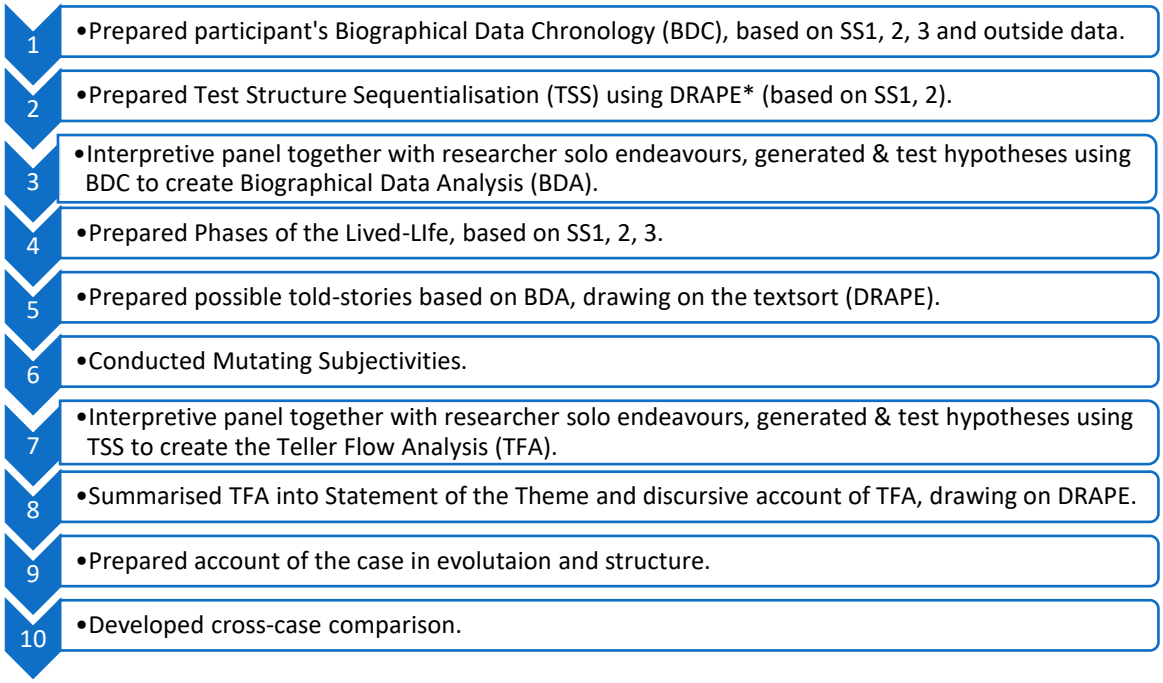
4.10.2 The twin-track approach to BNIM analysis applied to four gold star cases

The BNIM analysis, as conducted in this study, followed the recommended twin-track approach that distinguished between the life history (lived-life) and the life story (told-story) and involved

the application of a ten-step procedure to each gold star case. The process began with the preparation of two documents. The first document (and related to track one), the Biographical Data Chronology (BDC), was used to begin the examination of the patterns suggested by the objective lived-life. The second document, the Test Structure Sequentialization (TSS), was the starting point for track two, the identification of patterns of evolving, situated subjectivity suggested by the told-story (Wengraf, 2019b). Given the complexity of the BNIM analysis, at this juncture, the steps utilised in this study are presented in Figure 4.2 to enhance readers' understanding of the procedure.

Figure 4.2

Overview of steps in the BNIM analysis process



Note. DRAPE is an acronym for Description, Report, Argumentation, PIN (narrative of an incident), Evaluation.

Interpretation of narratives was concentrated on the BDA account of the lived-life (step 3 in Figure 4.2) and the TFA account of the told-story (step 7 in Figure 4.2), with each leading to two separate tracks of theorising.

The biographical data chronology (BDC) – commencing track 1

Participants' chronologies of their objective life events were teased from the information provided in the SS1/2 interview; shared, confirmed and embellished with facts from the SS3 interview. The

political and social circumstances and opportunities, known to be available to the participant in this time period were added to the chronology, as relevant, producing the Biographical Data Chronology (BDC). This comprised the first document in the life history track to be analysed.

The test structure sequentialization (TSS) – commencing track 2

The second document prepared was the Test Structure Sequentialization (TSS). This was a technical description of the structure of the interview, particularly that of SS1. It described the sequence of structural changes in the biographical account and allowed analysis of the told-story to focus on how the life was experienced and understood by the participant. The verbatim interview was scrutinised and sorted according to topic, speaker and textual structure (i.e. the way in which the topic was spoken about). The textual structure, called the textsort, was classified as *description, report, argumentation, PIN (particular incident narrative),* or *evaluation (DRAPE)*. A record was made of the page and line, the category of text (textsort), and brief description of the topic content. When the speaker, textsort, or topic changed, the corresponding page and line were recorded. The TSS proceeded until all data within the interview had been processed.

Hypotheses generation and testing in track 1

The Biographical Data Chronology (BDC) – the objective account of the mother's life – was used in the generation of the Biographical Data Analysis (BDA). Taking single factual events in the mother's life, as recorded in the BDC, specific questions were asked of the data that led to the development of hypotheses. Hypotheses were generated and tested first through my solo endeavours and then also by interpretive panels (described later). This demanded future-blind interpretation where analysis and hypothesising happened in the absence, or imagined absence, of information about the lived-life. BNIM requires that the analyst identify emotionally and cognitively with the participant to enter their world and in so doing produces an individualised biographic rather than a generalised account.

For each BDC datum examined, a hypothesis, guided by the questions: 'How could the participant have experienced this event? /What significance had it for the participant? /What happened next?' was posed. This developed the *original hypothesis*. Hypotheses counter to this was then developed (*counter* hypotheses), together with *tangential hypotheses*. For each of these three types of experiential hypotheses (original, counter and tangential), *shaping hypotheses* were generated by asking of each: if this occurred how could it contribute to the 'shaping' of the life?

Finally, *follow-on hypotheses* were developed by measuring the existing hypotheses against the question: 'what might follow next if these experiential or shaping hypotheses occurred?' Wengraf (2001) recommended that particular attention be paid to the production of hypotheses that were counter intuitive to those developed spontaneously by the analyst. It was important, at this stage, to put aside any knowledge of the told-story because the purpose in generating the BDA (from the factual events in the BDC) is to ask questions about the objective life that was lived. It allows reflection on the possibilities that existed for the participant and that were 'chosen, ignored, or rejected' (Breckner, 1998).

Hypotheses were then supported or refuted by subsequent interview data or remained as unrealised possibilities. Moving chronologically through the data, new datum was presented and treated in this same way in order to, first, generate hypotheses and, second, test these against new datum to confirm, refute or retain as possibilities. A narrative summary of the conclusion of this methodical challenge to the BDC data was prepared. See Appendix 5 for a sample of researcher-hypothesising.

Following this, the *Phases of the Lived-Life* document was produced, with each new phase being recognised as a turning point in the lived-life – several models of these phases were recorded containing between two and seven turning points for each life examined. At this point, consideration was given to how the participant might have otherwise told the story of her lived-life; possible ways of telling her story were imagined leading to the prediction and summary of at least three possible lives (see Appendix 18). This exercise of preparing *Possible Told Stories* served to multiply the analyst's sense of the possible and increase awareness of the perspective of the participant and her agency.

Hypotheses generation and testing in track 2

Track two in BNIM analysis focuses on the telling of the life story and, like track 1, drew on data from sub-sessions one and two only. The data was first examined for *Mutating States of Subjectivities* – where the mother's voice shifted from the current position on the experience to earlier states of subjectivity. Analysis of the told-story also employed a datum by datum approach, similar to that seen in the production of the BDA. However, contrary to using the BDC, the TSS acted as the basis for the development, and verification, of hypotheses producing the *Teller Flow Analysis* (TFA). Guiding this analysis were the questions: Why is this topic/experience being narrated now? Why is it being spoken about in this way?

The purpose of the TFA was to reconstruct the mother's perception and interpretation of her life events and experiences through examining the interactional effect of her actions and the structure and interpretation of her life. The aim was to understand the state of subjectivity and intersubjectivity that produces the flow of the narrative. The moment in the data that I sensed there was a significant pattern was considered a codable moment or thematic field or flow (Wengraf, 2001). These codable moments created datum blocks within the TSS and it was on these that the TFA hypothesising was constructed. See Appendix 6 for sample TFA generation from a TSS.

To generate *experiencing* and *follow-on hypotheses* (an original hypothesis, a counter hypothesis and tangential hypothesis for each datum block), a quote from the interview that best represented the thematic flow was considered (and hypotheses developed). The question: 'How was the participant thinking and feeling during these experiences?' guided the development of experiencing hypotheses; and 'How might these thoughts and feelings show themselves in the interview data?' guided the follow-on hypotheses. Hypotheses were verified and refuted as other data challenged or supported them.

When the interview data had been worked through in this way, a TFA document was prepared. This described the sequential flow of the themes – what was said about experiences and how this was expressed and provided a structural account of the flow – what was not said, why this information was presented and why it was presented in this way. After considerable deliberation, a S*tatement of Theme* that characterised and made sense of as much of TFA material as possible was developed. The actual told-story was compared with the possible told stories, hypothesised following the production of the BDA, to appreciate the significance of the TFA.

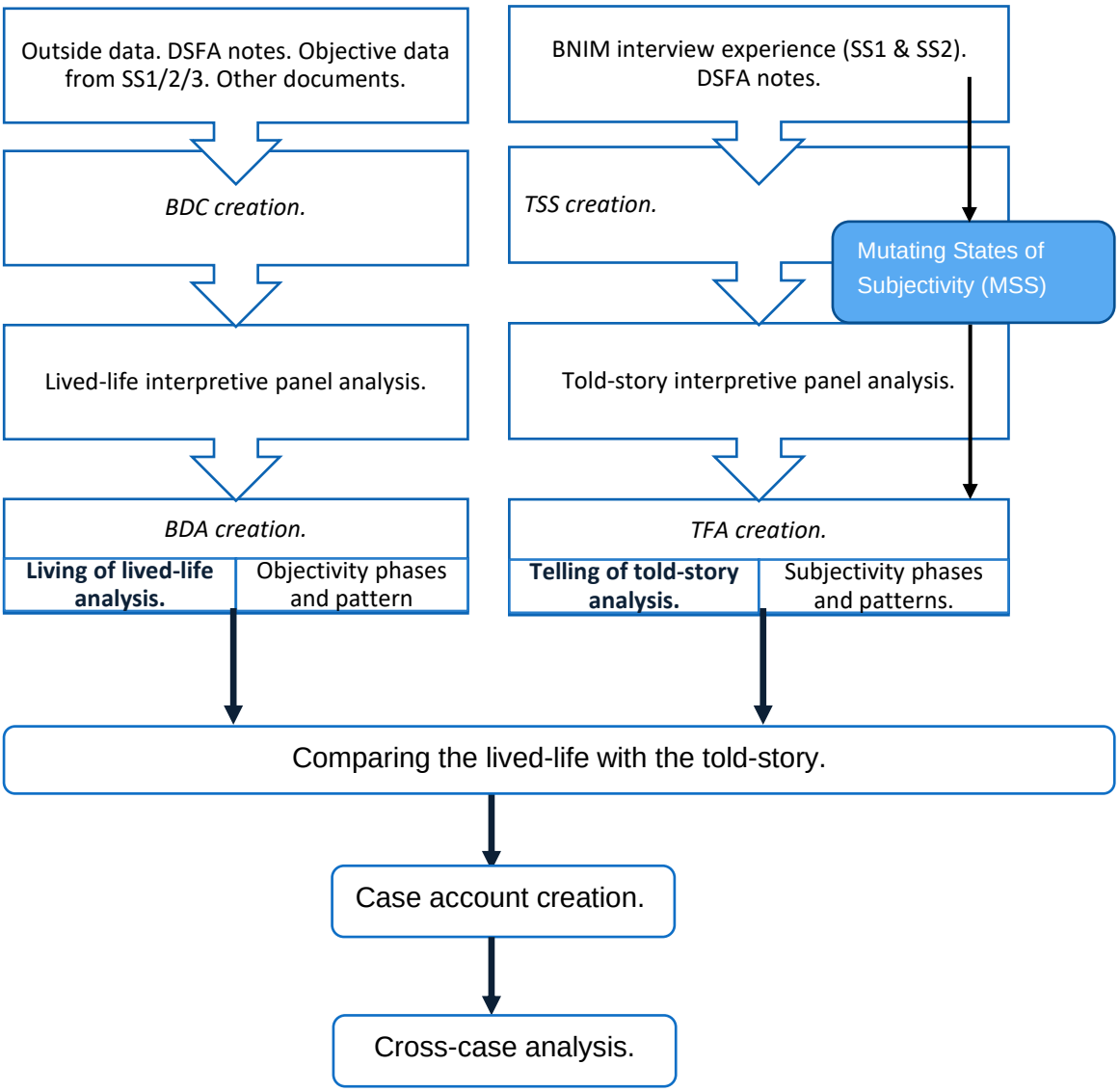
Comparison of the BDA and TFA

The penultimate stage in the analysis required making connections between the lived-life, as understood in the BDA, and the told-story described in the TFA. Omissions and underplays (moments that were given little importance) in the TFA were identified when compared to the objective lived-life. The question driving the comparison of the BDA and TFA was: 'How did a life lived in this way lead to a self-presentation, perspective, and story expressed in the way it was?' A case account of the individual was constructed by first developing the *History of the Case Evolution* (a formal account of the case-history that described the present and past perspectives

as they emerged across the life course). Added to this was the *Structure of the Case* (a sense of the overall structure of the case that articulated its central problem, as well as its relevance to the discipline's knowledge and theory and its contribution to understanding the phenomenon). A summary of the BNIM twin-track analysis method is presented in Figure 4.3.

Figure 4.3

Summary of the Twin-Track Interpretation Model



Note. Adapted from Corbally & O'Neill (2014) and Wengraf (2001).

Interpretive panels

Both tracks of BNIM analysis ideally incorporate interpretive panels (Step 7 in Figure 4.2) to assist in the interpretation of data and enhance the analysis process. Wengraf (2008) recommends that panels comprise of no less than three people of varied backgrounds. Each panel meets, firstly, to explore alternative possibilities and interpretations of the participant's lived-life and, secondly, to concentrate on interpretations surrounding the possibilities articulated in the told-story. Panel members are presented with interview text in a "chunk-by-chunk ignorant-of-the-future" manner, mirroring participants' experiences of their lives, which were also lived future-blind (Wengraf, 2008).

Wengraf (2001) recommends the use of interpretative panels to prevent what he refers to as the biographic inevitability illusion, where the researcher might have preconceived a (potentially narrow) interpretation of a narrative. As analytical tools, they prove beneficial in generating broader interpretive perspectives and exhaustively exploring alternatives (Kvale & Brinkmann, 2009; Paley & Eva, 2005). Corbally and O'Neill (2014) have found interpretive panels to provide a concentrated influx of interpretations in a condensed time period which accelerates the researcher's progress. Additionally, panels strengthen the credibility of findings as interpretations of the data are subjected to testing among peers (Corbally & O'Neill, 2014).

While it is desirable to commence BNIM analysis with interpretive panels, much of the initial analysis and interpretation of data in this study was conducted by me working alone. During the years in which data collection and analysis was taking place, the Covid-19 pandemic created difficulties for in-person groupwork. Outside lockdown conditions, people continued to show reluctance to meet in groups, spacial requirements between people applied, travel was more onerous and attendance, due to self-isolation requirements of close contacts, was undependable. Consequently, the interpretive panels were used in this study to inform, re-orientate and supplement my prior analysis rather than "kick-start" the analysis as recommended and desirable (Wengraf, 2008). A considerable time investment is desired and expected when applying BNIM (Wengraf, 2020). As I had undertaken approximately eight months (two per case), fulltime, independent work to complete the twin-track analysis procedure prior to hosting the interpretive panels, two five-hour panels (one for each track) were conducted rather than two two-hour panels for each gold star case. Following the panel work, I reviewed my original analysis and adjusted accounts of each case accordingly. With the exception of its adaptation to the use of interpretive

panels in relation to their timing and number, this study was wholly faithful to BNIM analysis procedures.

Hypothesising and testing, within the interpretive panel sessions, proceeded as described in the twin-track analysis. (See Appendix 7 for panel hypothesising in action.) Panellists were presented with chunks of data and asked to develop experiential hypotheses and follow on hypotheses as relevant to the analysis track. They were encouraged to be prolific and creative in line with Wengraf's recommendations (Wengraf, 2020). In personal communication he also warned that,

> I'm saying this as strongly as possible. I think it's important to know about what a heterogeneous panel can do well (a forcing house for the evolution of the researcher's awareness of their own hotspots and blindspots) and what it cannot succeed in doing (completing all the work of interpreting the raw material on any one interviewee).
>
> (Excerpt from personal email communication with Tom Wengraf (2023)).

A description of the panel members is provided in Table 4.3.

Table 4.3

Description of interpretive panel members

Lived-life panel members	A father, working fulltime in banking, with little knowledge of the intricacies of the education system and no knowledge of the health service.
	A mother of a mainstreamed autistic child who works parttime in creative industry.
	A fulltime occupational scientist and therapist with homeless mental health services and, who is not a mother.
Told-story panel members	A fulltime academic with considerable experience as a children's occupational therapist.
	A mother and artist who homeschools her child fulltime.
	A fulltime academic and mother of an autistic child in mainstream school.

Both panels, as evidenced in Table 4.3, were considered to hold a level of diversity of experience and attitude yet also to adequately represent the study population to ensure applicability and relevance.

To conclude, both reflexive thematic analysis and BNIM analysis were conducted to guarantee breadth and depth of analysis, and to ensure the findings presented in Chapters Five, Six, and Seven are credible and reflective of the central issues of concern.

4.11 Researcher positionality in relation to topic, method and narrative analysis

The research process is not value-free (Poerwandari, 2021). Acknowledging that the researcher acts as an instrument in qualitative inquiries (Creswell, 2013), exposition of the positionality and perspective of the researcher relative to the study is essential in the interests of fairness to those researched as well as the production of trustworthy findings. The reflexive practice of qualitative researchers recognises the influence of the researcher on the research process (Braun & Clarke, 2013) and this, I suggest, has particular resonance for narrative inquiry for at least two reasons. Firstly, narratives are not impervious to the context in which they are spoken but are co-constructed with the researcher. Secondly, the researcher's interpretation forms the basis of the analysis of data.

Given the pivotal position played by the researcher in both gathering and analysing the narrative data, reflexivity and introspection is required to make explicit assumptions on knowledge production and issues of power, identity and positionality (Day, 2012). Accordingly, reflexivity was used throughout this study as a process of developing self-awareness; this was facilitated by Patton's (2015) questions for *triangulated reflexive inquiry* (adapted for this study, see Appendix 11). Efforts were made to bring my biases and blind spots to the fore and make explicit how my background, perspectives, and knowledge-basis may have shaped the study from its inception. Identification and articulation of my positionality, by means of reflexivity, enhanced my efforts throughout the research process to find "empathetic neutrality" (Ormston et al., 2014, p.22). I have striven to represent the voices of the participants rather than my own. It is important to note however that the lenses I used to gather and interpret the data are drawn from sociology, namely that of feminism, and occupational science in the form of occupational justice, and, in this respect, are not neutral.

4.11.1 Introducing the researcher

As the researcher, present at every stage of the process, I carry with me my personal background and history that will have influenced this study. In an effort to reveal myself here I will describe myself, both on an objective and subjective level, in a way I think most pertinent to the research questions. With early career experience working with autistic children in their homes where their mothers were always present, everyday conversations with these mothers revealed the worry, love, anger, acceptance, and resentment they had for their situations. The interest I brought to this study in feminism and occupational justice were fuelled by these memories. I also worked in a university support service with autistic students where I had no involvement with mothers but much with mainstream education. My Masters through research focused on the context of emotional and behavioural difficulties in mainstream school and enhanced my understanding of the interaction between the individual and the multilevel systems in which we operate. As an occupational scientist and therapist, I greatly value engagement in doing and esteem social connection through participation in activities of meaning. My current employment in academia has increased my exposure to new and diverse ideas; taught me to be a critical consumer of knowledge and to accept that realities are a matter of perspective. This, together with my previous research experience and BNIM training (in data collection and analysis), positioned me well to engage in qualitative perspectival work.

While I provided little information on my professional background during interviews (in line with BNIM recommendations), for reasons of full disclosure as part of the informed consent process, my occupation was described on the Participant Information Leaflet (see Appendix 12). This in turn likely shaped the way in which mothers interacted with me and told their stories. For some, it is possible that this may have influenced their decision to participate in the study and for others it may have created a power differential that was compounded, or not, by the reputation of the university in which I work.

I am a mother of two. This fact alone prompts me to reflect on my own mothering when listening to and analysing the participants' stories. Recently it has been suggested by healthcare professionals that one of my children is autistic. My child's behaviour and needs are both similar and different to the sample of children referred to by participants in the current study. However, my mothering is not uncomplicated, and, like the participants, I draw on clinical supports causing me to straddle an insider-outsider positionality (Holmes, 2020). I was raised by a mother who was highly sensitive to the feelings of others, wholly non-judgemental, and, though unaware of the

construct of social and occupational justice, taught me to treat all people fairly and accept them as they are. My experience of being mothered, with complete dedication and little regard for her personal right to occupation, will undoubtedly have shape my endeavours as the researcher both positively and negatively.

Transparently sharing my background and personal values and beliefs that may influence the study, was one reflexivity technique employed in this study (see Appendix 13 for supplementary descriptive information). As well as keeping a reflective diary, as recommended when conducting thematic analysis (Vaismoradi et al., 2013), an additional method to enhance reflexivity required that I take the hour following each BNIM interview to write free flowing reflections (dated, situated, free-associated notes) on the interview interaction. This assisted with the examination of how I cognitively orientated the participant with my verbal and non-verbal communication and our emotional responses to each other. Throughout the analysis, I made annotations, recording my thoughts and commenting on the participants' reflexive moments, developing alternative and counter-hypothesis to think outside my own norms and standards.

4.12 Trustworthiness

The purpose and power of narrative inquiry lies in valuing the meaning the story holds for the narrator. Its quest is not for one truth assuming that the narration is an exact record of factual events (Riessman, 1993), rather it appreciates that, this is how the story unfolded for the narrator at the time of telling. It aims to understand the meaning the narrator attaches to these events (Polkinghorne, 2007), creates and lives by (Bingley et al., 2008).

Qualitative researchers are in a weakened position if the quality of their work is measured against the natural sciences using their perception and assessments of rigor. The design of studies, methods of data collection and analysis are different in qualitative narrative inquiry to that used by positivist researchers and natural scientists. Consequently, assessments of reliability and validity are reconsidered (Morioka & Nomura, 2021). Because narratives are relational (with neither party capable of objectivity (Pinnegar & Daynes, 2007)) and interpretive (may be interpreted in varied ways (Bingley et al., 2008)), threats to validity in narrative inquiry have been described as two-fold (Polkinghorne, 2007). The first is related to the distance between the meaning of the lived experience to the narrator and the story that they share – participants may choose not to tell aspects of stories or change their stories to fit the narrative context

(Poerwandari, 2021). Secondly, the gap between the meanings of the story and the researcher's interpretation of these may mean that the conclusions, based on the researcher's perspectives, may not represent the reality of the narrator's life (Poerwandari, 2021).

With the researcher being a part of the social context of the research (Morioka & Nomura, 2021) and an instrument of the research design, neutrality in this study was neither an aim nor a possibility. However, an acknowledgement of personal biases and knowledge-basis, described in the previous section, were deemed important to enhance the confirmability of findings. In BNIM analysis the interaction between the narrator and listener is considered in the Teller Flow Analysis. In narrative inquiry the researcher's position is not to remain detached in order to increase objectivity but to engage in honest introspection and critical self-awareness (Mitchell et al., 2018). To enhance researcher-intersubjectivity, a reflective diary was written throughout the study in addition to the requirement of BNIM to make post interview free-association written reflections based on my immediate reactions to the interview (Wengraf, 2001; Wengraf, 2020).

Applying the method of hypotheses production and testing to deepen and broaden the understanding of the lived-life and told-story, enabled me to attune to the particularities and minutiae of the case; move beyond the surface story; question the participant's actions, decision making, and perceptions. This process helped me to *listen into* the interpretive process and locate the voices within each narrative (Chase, 2005) resulting in a richer understanding of mothering practices and contributed to the utility and transferability of the findings. The use of interpretive panels in expanding and deepening interpretations has been noted (Jones, 2003). It was also considered that they enhanced the credibility and meaningfulness of findings by introducing a form of triangulation at the level of analysis.

Additional efforts that contributed to trustworthiness in the current study included:

- Refinement through informal and formal discussions around the research questions with reference group and supervisor confirming the relevance of the research purpose.
- Attendance at training courses by BNIM expert, Tom Wengraf, in the method of data collection and analysis to enhance competence.
- The SQUIN was piloted with mothers and redrafted with Wengraf.
- The optimum information about the project and methods was provided to participants before commencing data collection to satisfy the ethics board, inform the participant, and yet meet BNIM recommendations.

- Clarification from participants on their narration in SS1/2 was sought in the follow up interview (SS3).
- Participants' chronologies were shared with them before and during SS3 to allow them opportunity to make amendments.
- Peer examination of the study method and debriefing of findings was undertaken with the study supervisor in formal supervision to enhance the dependability and credibility of the study.
- Transparent trail of the application of both reflexive thematic analysis and BNIM analysis has been provided in the appendices.
- Interpretive panels of six individuals external to the study contributed to the analysis.
- Excerpts from interviews, i.e. the participants' own words, were included in the Findings' Chapters creating additional plausibility and providing thick description that enhanced the meaningfulness and transferability of findings.
- A detailed description of the field i.e. the narrative context was provided (sections 4.7.3 and 4.7.4) which enhanced the confirmability of the findings (Morioka & Nomura, 2021).
- A member of the reference group reviewed the findings in relation to their credibility (plausibility) and transferability (relevance and relatability). See Appendix 14.
- Findings have been discussed in relation to the literature on mothering. Relative to this literature, the interpretation of narrative accounts offered in this study are credible.

The job of the narrative researcher is to argue for acceptance of creditability of their evidence and interpretation by leading readers through a progression of evidence (including quotations from the raw data) and explanations of their interpretations, and by explaining the context of their analysis and why alternative interpretations were disregarded (Polkinghorne, 2007). Narrative researchers do not need to claim that their interpretation is the only possibility but argue that it is a viable interpretation based on the data, grounded in the narrative (Chase, 2011). This approach was taken in the current study as evidenced in the following Findings' Chapters.

4.13 Ethical considerations and actions taken to ensure wellbeing of participants

The criteria required for quality in qualitative research aligns with its standards for ethical behaviour (Fossey et al., 2002). In recognition of the co-construction of narrative, researchers

must appreciate that they too are subjective beings and relate to the participant responsively (Pinnegar & Daynes, 2007). This is an issue of ethics and refers to the conduct and competence of the researcher, which, when ethical and sensitive to the narrator and narrative, will tend towards more trustworthy data providing a basis for more trustworthy analysis. Josselson (2007b) notes that developing an ethical attitude is about interacting with participants humbly, learning from them, never sharing that which we know would do them harm. Lieblich, in conversation with Clandinin and Murphy (Clandinin & Murphy, 2007), agreed but added that the act of listening to others' narratives is a show of respect that legitimises their lived experience and, in this way, is itself an ethical practice. In the current study measures were taken that positioned the wellbeing of participants as essential.

- To ensure the study was of value to the focal population, the need for the study was established at a local level through consultation with the reference group.
- At all times, the interaction between the listener and narrator, the analyst and the data, was underscored by respect and appreciation. Potential participants were responded to promptly when they enquired about the study demonstrating commitment and a will to build trusting relationships with participants.
- The participant information leaflet (Appendix12) and consent form (Appendix 15) were shared, and the participant given a seven-day cooling off period to consider participation before being again contacted. All questions about the study were answered honestly and fully.
- Consent to participate was established at several junctures – when arranging interviews and again at the start of each interview.
- Interviews were conducted in a private space at a time and date most suitable to the participant. I indicated my willingness to be wholly flexible regarding time and date.
- Sufficient time was set aside to conduct interviews in order to answer questions and support mothers if they became upset.
- Permission to record was sought prior to commencement of the interview. Although the fundamental ethical issues are the same between online and face-to-face interviewing (Lobe et al., 2020), online interviews offer much control to the participant with regards to the ethics of research. They can withdraw at the click of a button and their anonymity is better protected as their addresses or phone numbers were not needed (Deakin & Wakefield, 2014).
- A subscription for a zoom account was paid to ensure security, confidentiality and privacy using the platform.

- In each interview, each participant was reminded that a copy of their interview transcripts would be made available to them on request.
- Following the pilot interview with Imogen it was anticipated that mothers may become upset at some point in the interview. I responded sensitively and calmly at these junctures, supporting the mother in a non-judgemental and non-rushed manner, and encouraging her to take a break as wished. It was considered imperative that mothers were no longer upset on completion of the interview. I endeavoured to finish the interview on a positive note or story through judicious selection of concluding questions and prompts.
- The participants' narratives were equally treated with courtesy in recognition that these narratives let us see into the lives of other people; their stories belong to them (Clandinin & Murphy (2007), in conversation with Polkinghorne). All possible identifying information was removed or anonymised and the information written in a way that would not cause harm or offense.
- With ethical approval, interviews were transcribed using a professional transcription service.
- Data was stored on an encrypted computer.
- In formal supervision, all names were replaced with codes such as P01 (i.e. participant one) and then pseudonyms. Further anonymity checks were made on the data so that all identifying factors were omitted and pseudonyms applied in the disseminations of findings.
- A document linking pseudonyms to the original names was held in hard copy in a locked filing cabinet.

The considerations of confidentiality, consent and conduct were fore fronted as being of particular importance in the development of the participant consent form and information leaflet (see Appendices 15 and 12). These provided information about the study purpose, design, method, and sampling strategy, as well as explanations around rights to the data, withdrawing from the study and information on data storage and retention. Ethical approval was granted in May 2020 (see Appendix 19). As well as the participant information leaflet and consent form, this application also included a copy of the advertisement that was tweeted and posted on websites during recruitment, and a data protection impact statement (DPIA).

4.14 Limits of the methodology

A person's narrative is shaped by culture. Narratives change over time with the layering of new experiences and perspectives and are limited by the story structures known to the participant

(Bell, 2002). Culture, personal history, temporality, and society are some of the factors that may limit the depth and breadth a story can offer at any one time. Plummer (2019) recommended counterbalancing the personal face of stories with concern for the social history and power in which the stories are embedded. In this way stories do not only take us deep into the psyche of the person but also deep into the social structures in which the person lived. A strength of BNIM's two track analysis is the attention it pays to the chronology of a person's life, drawing on information that situates the life in a social and cultural context, offering counterbalance.

A criticism laid at BNIM relates to the lack of attention it pays to the potential impact of the researcher on the narration due to the formulaic approach to data collection and analysis (Casey et al., 2016). However, BNIM is judicious in its efforts to minimise researcher-influence on spontaneous narrative generation during data collection, through careful consideration of information provided on the topic and methodology to the participant prior to interview; using a purposely open SQUIN; and pushing for further narrative using the participant's own wording and ordering of events. In the current study, reflexivity has been used to heightened awareness of how I and the participants co-constructed the data and of how my personal and professional background may have influenced data collection and analysis.

While the use of online research practices was forced to increase during the Covid-19 pandemic (Lobe et al., 2020), Deakin and Wakefield (2014) also acknowledge challenges particular to virtual methods pertaining to recruitment, ethics, rapport building, attendance, and technical considerations. It is generally perceived as more difficult to establish rapport and build a relationship with a research participant virtually. To counteract this, O'Connor and Madge (2017) recommended being flexible regarding the date and time of interview and providing the participant with information on the study and the researcher prior to interview in order to reduce the distance and feel connected. In this study the participant information leaflet and consent forms were shared prior to the study. Additionally, within the bounds of the BNIM guidelines, I introduced myself and the study through email openly explaining my affiliation and the purpose of the study and, again, in a little more detailed explained the interview procedure at the start of each interview.

Virtual data collection may have discouraged those who did not know how to use zoom or have access to WiFi from participating. However, once a participant emailed to enquire about the study, the possibility of telephone interview or even face-to-face, Covid-19 restrictions permitting, was

offered. All were accommodated in terms of form, time and date of interview in keeping with O'Connor and Madge's recommendation regarding flexibility. With the exception of one mother, who wanted to be interviewed via telephone, all opted for interviews on virtual platforms.

A recognisable limitation in terms of recruitment relates to the visibility of the advertisement – only those who followed autism threads on Twitter or were members of autism related groups were aware of the study. Compounding this was the likelihood that those who volunteered to participate represented the type of person who typically participates in research studies thus limiting the diversity of narratives captured. However, this study aspired to engage with lives, valuing the detail (Plummer, 2019) and recognising mothers' unique voices irrespective of surface level homogeneity. Moreover, it was hoped that, through snowballing, the study advertisement might have reached others beyond those who typically respond to such research requests.

Wengraf (2001) acknowledges it is possible, through the act of story selection and narrative performance, that the participant may present themselves in an unduly positive or negative light to preserve their self-identity. Analysis of the narratives using the twin-track method provides balance to interpretations. Additionally, many factors influence the telling of the story, preservation of the self is just one of these. In the current study, I was cognisant of this and, as advised in Caine et al. (2021), wove the threads together.

According to Plummer (2019), narrative inquiry can place too much emphasis on text without fully attending to the "real embodied, emotional human interactions" taking place around the narrative (p.40). BNIM analysis goes some way to addressing this over-textualisation of the world by not only contextualising the stories but also attending to *how* the story was told, examining what happened and what hypothetically might have happened next.

Data collection was dependent on self-report and subject to the limitations of participants' subjectivity and selective memory (Bryman & Burgess, 1994; Wengraf, 2001). While these can represent the constraints common to much research in the social sciences, as a methodology, BNIM demonstrates full concern with capturing the participant's subjectivity and integrating this with the chronology of the lived-life to reduce the impact of such (Flynn, 2018).

Despite the centrality of experience to this study and the ownership of stories firmly lying with the participants, member checking, whereby the accuracy of findings was assessed from the

participants' perspectives (Braun & Clarke, 2013; Creswell, 2013), was not conducted. The rationale for this was that analysis within the study was methodologically interpretivist and as such multiple realities and interpretations were possible. In this case, my interpretation formed the basis of this analysis. By way of providing participants with opportunity to feed into analysis, their chronologies were shared in SS3, expanded and amended by participants. SS3 also sought a level of clarification and confirmability of the initial interpretation of SS1/2. Participants were offered a copy of their transcripts. Additionally, through use of reference group consultation, formal supervision and peer group review, every effort was made to ensure interpretations were plausible and reflective of the narratives shared.

4.15 Conclusion

In providing the rationale for its methodological decisions, this chapter situated the study within the qualitative paradigm highlighting its ontological and epistemological stance of constructionism and relativism. It described narrative inquiry and justified its relevance for use in exploring the lived experiences of mothering autistic children in mainstream school. The purpose of the research, its central question and objectives, were reiterated, and the study's sampling procedures, ethical considerations, and methodological limitations described. To aid transparency and enhance the trustworthiness of findings, importantly, researcher-positionality, together with efforts towards reflexivity, were explained.

The application of both BNIM data collection and analysis procedures is a strength of this study and was driven by a need for open consideration of the topic, free from imposed categories (Flynn, 2014). Central to the study is belief in the value of personal stories of both the mundane and extraordinary to shine a light on everyday lives in context. Through assuming the interpretivist stance of narrative inquiry (Spirtos, 2017), the study aspired to move closer to understanding the experiences of the mothers whose narrated lives form the basis of the findings presented in the subsequent chapters.

Chapter Five

Findings: Presentation of reflexive thematic analysis

5.1 Introduction

This is the first of three findings' chapters. While Chapters Six and Seven present the findings following in-depth BNIM analysis of four cases, this chapter conveys the findings based on data collected from all 17 mother participants. To begin, each mother is introduced through a short synopsis of their narratives. This then opens the way for the presentation of the findings from the reflexive thematic analysis of their stories. The findings are structured under four themes: Mothers' active practices; Costs and concerns of mothering; Interface with society and relationship with occupational justice; Mothers' acceptance and growth.

5.1.1 Introducing the mother participants

To provide additional context to the findings that follow, that which was considered the essence of each mothers' narrative is presented in Table 5.1.

Table 5.1

The essence of the mothers' narratives

MOTHER	NARRATIVE ESSENCE	CHILD (AGE)
IMOGEN[8]	A carer and coper – a role she did not desire despite her acknowledged competence in it. Imogen protected her younger sister growing up with an alcoholic father. She moved country on marrying. She experienced high stress interacting with services in accessing diagnoses and supports. Both her sons had ADHD, Ethan was also autistic, and she had little practical help from her husband. Imogen's narrative moved from struggling to find her way in mothering her child and a position of total unfamiliarity re autism and services, to coping well. This required considerable sacrifice, career redirection and commitment to learning and adapting.	Ethan (11)

[8] As BNIM gold star cases, the lives of Imogen, Maeve, Eloise and Sadhbh, have each been interpreted and cross analysed in Chapters Six and Seven.

MAEVE[7]	Much housekeeping and childminding was required of Maeve growing up in a large family with an alcoholic father. When she left home she embraced the privileges of monied adulthood. On becoming a mother, Maeve struggled to connect with Ruby; she was unprepared for motherhood and unsupported by her husband. A significant crisis pre (teen) diagnosis reset the mother-daughter relationship and unified the parents. Conversely, Maeve had a very strong connection with Joseph. Both Ruby and Joseph had diagnoses of autism and ADHD. Although family dynamics improved (storyline: 'crisis made good'), she continued to be challenged by mothering (storyline: 'there's no easy way') and relied on her valued selfcare occupation (faith group) to support her in self-development.	Ruby (16) Joseph (11)
PAULA	Struggled to adjust to motherhood on her first baby Conor (first of two sons). Paula found Conor's externalising behaviour taxing and very effortful to manage across environments. She enjoyed industry and order, consequently her everyday life was impacted by the dynamic between mother-child-context. Interactions with Conor required Paula to modify her familiar occupational performance and to find a new way of being in the self. She sometimes worried about her capacity to manage situations, but she reached out to others for support; applying the advice of others she had experiences of success in influencing professionals' attitudes and behaviours towards Conor.	Conor (10)
TAMSIN	Motherhood was a surprising revelation that offered opportunity for growth and appreciation of her own capacity. However, with tendencies towards intensive-mothering and aspirations towards mothering perfection, motherhood also provided opportunity for self-flagellation. She struggled to meet personal expectations for doing. Tamsin's mother was reportedly hypercritical prompting Tamsin to make concerted efforts to reduce her own propensity for control and order in activities such as play. She identified as autistic which she perceived strengthened her connection with Matt (first of two sons).	Matt (7)
MYRA	The healing dimension of place and time were evident in Myra's narrative. Early in her journey into autism she embraced empowering advice that the 'parents are in charge' of the child's engagement with systems. She experienced several worrying episodes pre-diagnosis with her son at 7 (now 15) but perhaps due to the era and location had no difficulties accessing healthcare services including diagnostic assessment. Myra put effort into finding the right fit regarding the educational environment but ultimately desired a more supportive community. Duly, the family (Myra, husband and son) relocated to where she grew up. Her son entered a special class in mainstream and as time passed became fully integrated in mainstream school. At 15 he had hobbies, friends, and plans for his career. Myra's narrative reflected the impact of adequate formal and informal supports in allowing her to take control and reducing periods of 'not knowing'.	Noah (15)
NESSA	On becoming a mother, Nessa's life became much smaller. Feeling alone and unsupported, with her first child who had an intellectual disability, she moved home to where she grew up. Place, for what it offered by way of familiarity and social support, was central to her narrative. Her second	Kai (10)

	child, Kai, had autism. Socialising with two children with additional needs was effortful causing Nessa to rely heavily on extended family rather than friends for the family's social life and general support. Nessa's narrative was underscored by anger at the inadequacy of the health and education services resulting in the need for mothers to act as therapist, educator, and advocate, despite no training for these roles. She believed families needed someone to have their back.	
SADIE	The earthmother identity was coveted and adopted by Sadie as afforded by her context. She gained huge meaning from engagement in activities of babyhood that brought her organic connections with her children – connecting through doing and being. Despite having little attitudinal support from spouse or family, Sadie resisted the pressure they exerted to conform to mainstream mothering practices. Sadie was divorced. In the absence of social support, her currency was knowledge and access – as a team member of autism diagnostic services in paediatric health, she was well informed about autism and had ready access to relevant practitioners when Scott (eldest of three children) was diagnosed with autism. She found meeting her children's needs (all had additional needs) exhausting and consequently reduced her working hours. However, she was also empowered and understood how to heal through selfcare.	Scott (12)
HEATHER	Heather epitomised 'becoming through doing' in her adoption of the advocacy/activist role. The trauma of battling for a diagnosis for Seán (eldest of two sons), left scars that altered her way of interacting with others around autism. Heather redirected the energy (distress, frustration, disillusionment) following her dismissal by healthcare professionals, to advocate strongly for Seán. Thus, she gained in confidence (positive) as an autism spokesperson and also developed a singular focus on autism (which she cited as a negative with regards social and leisure activities). Having left her career, her role as activist offered her new and meaningful purpose that was wholly child and autism centred. Her narrative expressed no regrets, no loss, much accommodation and a disappointment with services and societal attitudes around autism.	Seán (11)
TESS	Somewhat disappointed by both motherhood and services, Tess had an image of becoming a creative earth-mother. However, her children, three sons, and her husband, a work-aholic, did not enable this to come to fruition. Her husband's long hours in work meant he was unavailable to parent. Although she was very busy working fulltime, bringing her children to extracurricular activities, attending Sam's additional healthcare appointments (autism and ID) and managing the additional needs of her eldest son (dyslexia), she concluded that motherhood was both wonderful and hard. Despite having ready family support, she was stressed and impatient instead of zen and creative and noted this as a change in who she knew herself to be. Tess pushed herself to attain aspects of the family life she imagined and made personal sacrifices to support her children to engage in normative activities and meet developmental milestones. She felt let down by services she had trusted but developed her ability to fight for her son's right to therapeutic support.	Sam (9)

JANE	Jane fully embraced her ADHD identity, that was diagnosed in the same year as that of both her daughters (her eldest was also autistic). Jane strove to become a mother; on becoming a mother she did not work outside the home but invested wholly in this role. Her dedication to mothering was orientated around acceptance, nurture and guidance; she did not align herself with normative mothering activities either pre or post diagnoses. Her own diagnosis gave her self-understanding, prompted her to question society's patriarchal view of motherhood, encouraged her to champion her own position as mother (not housekeeper) in the home environment, and to invest in the mother-the-protector role through advocacy in external environments (school and community) and through setting example at home.	Eve (11)
ELOISE[7]	Busyness, moving forward, and making good on many setbacks epitomised Eloise's life narrative. Despite many challenges, through positive, responsible, and action orientated *doing* Eloise created a mothering role, on the periphery of normative mothering though one that enabled her to *become through doing*. Eloise was battle-worn but not yet weary or worn out. In taking her advocacy into the public sphere as a form of activism, she almost professionalised this non-normative form of mothering. Eloise enjoyed using her skills and engaging with meso- and macro politics. She was proud of her advocacy campaign's wins but was also concerned that she was engaged in a never-ending fight for autistic children's rights.	Lucy (8)
SADHBH[7]	Despite not planning to become a mother, on doing so before finishing university, Sadhbh embraced the role as a privilege, never a loss. Sadhbh worked part time and acknowledged she was busy mothering – she had five children the eldest three had diagnoses of autism. She was an independent thinker. With no aspirations towards normative living nor normative mothering, she was readily able to accommodate her children within the home. While she held positive perceptions of her autistic children, she was angered by the inadequacy of support services that did not enable her children to flourish.	Alex (17) Íarlaith (11) Ríodha (8)
OLIVIA	As a child, Olivia lived with shame and stigma leading her to believe she was not worthy to become a mother. Yet, motherhood provided meaning and purpose, she devoted herself to mothering and considered herself competent in the role in relation to her eldest son. However, Olivia did not develop a strong sense of personal growth through mothering. She viewed herself as a vessel through which others could actualise – mothering was a supporting role while fatherhood was the essential to the family's function, wellbeing and future. Olivia was determined to model loving familial relationships in defiance of her experiences as a child. Olivia battled to be believed by professionals and gain a diagnosis for her Leon (second son). She drew no satisfaction from engaging acrimoniously with education professionals and was distressed by her own display of assertive behaviour. The delay in gaining a diagnosis further upset Olivia as understanding and accepting Leon was central to her values as a mother. Olivia separated the functions of home and State. Believing her son's wellbeing was her responsibility, she did not complain of having to use private services despite being able to little afford them.	Leon (11)

NIAMH	Motherhood for Niamh opened a door on an entirely new world – obligations and joys – to which she was previously oblivious. She found it tiring but magical. Mothering her autistic child Aidan (second of two children) created another dimension to her mothering that demanded new learning and new advocacy occupations. She sensed that she had grown through doing in her various roles across time (like a "born-again swan"). For confidential reasons, she was reluctant to disclose her son's diagnosis to parents or children within the school community, believing it was his business to tell. Niamh was not in a rush against time to intervene with therapies for her child's development, in fact she withdrew him from same as she believed they overwhelmed him. Her attitude was always considered. She objected to the conflation of mothering with housework and the consequent busyness of her domestic life.	Aidan (11)
CLAIRE	Claire connected with established friends and extended family but due to her Max's behaviour they did not create a community of belonging in their locality. They confined participation and activity to their nuclear family (mother, father, child). They relied primarily on private funds for therapeutic intervention while waiting on the public list for assessment. Claire regretted that they had not known better how to prioritise her son's needs when paying for therapy; she was angry at the system that she had trusted to offer early intervention. Despite her anger and assertive advocacy, Claire acknowledged her learning and empathy for people with disabilities. Claire and her family had not reached out to autism communities and, with the exception of contact with healthcare professionals working in private or public services, had not sought or received guidance from others who knew how to use the systems.	Max (7)
KATE	Kate devoted the majority of her time to Rufus' development. City-bred, she moved away from her social support (with husband and Rufus) in order to give Rufus an alternative rural childhood. She worked for her herself, in a parttime capacity and fitted her work schedule around Rufus' therapy schedule. Kate engaged in Applied Behaviour Analysis work with Rufus every evening after school. She embraced all forms of intervention – mainstream and alternative. Despite her immense investment of time and energy into his development and progression, Kate was unsure if she was giving Rufus what he needed, if there were more/other therapies she could try. Tuning into her son's response to interventions she consequently stopped and started them as she thought best. In this way, her intervention with her son and awareness of his needs, helped her grow in confidence so that she could better advocate for him with professionals. Moving to the countryside was brave but also spoke to Kate's ethos of alternative living, spirituality and reflection.	Rufus (8)
HELEN	Helen was a defender of the vulnerable, a role she adopted in her first family, protecting her siblings from her violent, alcoholic father. With little money for goods or food growing up, and aware of her deprivation, Helen was determined to create an entirely different second family with committed parents. Helen had a keen sense of injustice. Isaac (youngest of two sons) entered the community mental health services (CAMHS) in primary school; they discharged him without a diagnosis. Consequently, Isaac received his autism diagnosis at 17 when Helen requested a private	Isaac (17)

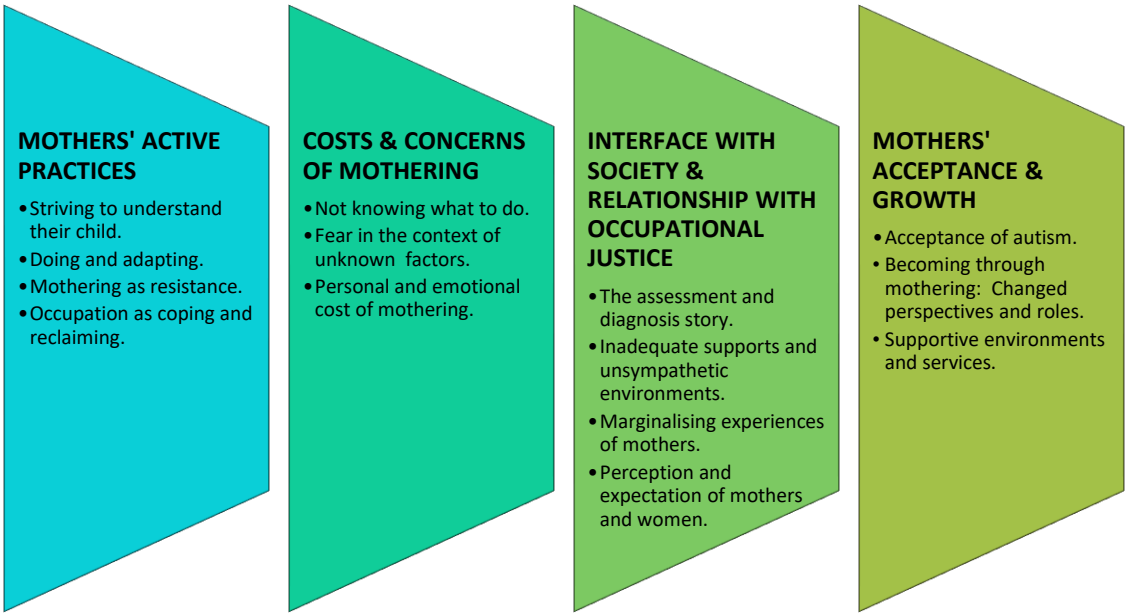
	autism assessment. She was highly conscious of the pressure on time to provide Isaac with opportunities for adulthood. The newness of his diagnoses (one month), coupled with his age (17), led to her anticipation of a bleak future.	

5.1.2 Introducing the findings from reflexive thematic analysis

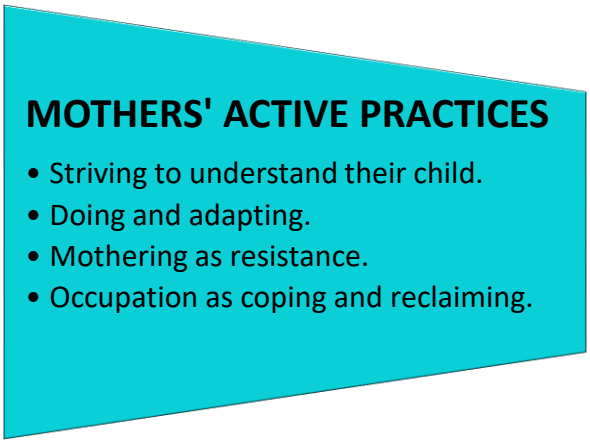
Using Braun and Clarke's (2022) reflexive thematic analysis (explained in the previous chapter) to analyse data collected from each mother (n=17), four themes that explored the mothers' everyday lived experiences of mothering their autistic child were identified (see Figure 5.1). By way of answering the study's research questions, the analysis fore-fronted firstly the active practices of mothers to *do* and *be* what their child needed; secondly it gave recognition to the concerns and challenges mothers experienced; thirdly, through examining the interactions between mothers and society, the analysis gave relevance to occupational justice; fourthly it identified mothers' personal growth as a function of their mothering efforts and acknowledged the positive impact of supportive environments. Where the concepts of occupational balance, possibility, and identity have relevance, this is made explicit in each theme. The findings are relayed in a story-like form in keeping with the study's narrative methodology. Throughout, subtopics (based on initial codes) within the overarching themes are in italics and highlighted in bold. A summary of the application of reflexive thematic analysis in the current study was provided in Table 4.2 in Chapter Four.

Figure 5.1

Overview of themes and subthemes



5.2 THEME 1: Mothers' active practices



This theme refers to the effortful engagement of mothers to be the mother their child needed through striving to understand their child; through actively adapting mothering practices to meet their child's needs; through using the occupation of mothering to resist normative expectations and advocate for their child; and through engaging in occupations to cope with the challenges of mothering and to reclaim aspects of the self. Paula's description of the mother as the person who "reacts and jumps up more" reflects mothers' responsivity to children's needs, and their willingness to fight for children's rights, that is exemplified in Theme 1. However, this theme also describes active practices that are planned and pre-emptive, requiring considerable changes to mothers' lives, as well as those that keep mothers sane. By speaking primarily to the concept of occupation as *doing* this theme premises this dimension in Wilcock's conceptualisation of occupation (as doing-being-belonging-becoming) described in Chapter Two.

5.2.1 Striving to understand their child

For some mothers, the early signs of autism went unrecognised for various reasons. Paula and Imogen had little experience of children's development and did not recognise Conor or Ethan's idiosyncratic behaviour as developmentally different or concerning; while Maeve and Niamh developed other plausible reasons (Joseph was shy; Aidan was regularly ill) that adequately explained their children's development, behaviour, and additional needs. However, on recognising developmental differences, or having these highlighted by childcare staff, and with the aim of better understanding their child, many mothers ***shared their concerns*** about their child's behaviour or development to family, friends, and the children's fathers. Helen said the typical response to her concerns was, "Ahh sure he is grand, you are imagining it, he is fine".

Having their worries dismissed was experienced as unsupportive, despite the possible benevolence of others' intent. Olivia explained that,

> As a mother you feel very much on your own in that respect because once you start voicing your concerns everybody tells you, 'You're overly concerned, and I wouldn't worry about it, and boys are different, and all children learn at different stages'. And even his dad was saying, 'I think he's grand, he'll be fine, don't worry'.

The diagnosis of autism had utility in providing an ***improved understanding*** of the child and therefore positioning mothers and others to better meet their needs. Sadie and Nessa observed their child being assessed and both claimed it revealed to them the extent of their child's challenges. It was like "scales falling from the eyes" according to Sadie. The diagnosis heralded a change in mothers' perception and a demand to learn about autism. Imogen reflected that understanding autism was "like learning a whole new perspective on the world". Jane recognised the benefit of a diagnosis in enhancing her child's self-understanding, claiming, "Eve literally skipped out of the office" singing "I'm not weird, I'm not stupid, I'm not bad, I have a medical condition". Having their ***concerns validated*** was a by-product of having a formal diagnosis. Paula felt, "Like sending a report to everyone just to prove, I think I did send the report for my parents [laugh]…to prove that it wasn't in my head, that it wasn't our parenting". The diagnosis was a formal recognition that their mothering situation was challenging.

Many mothers noticed differences and ***difficulties through comparing*** their child's development and occupational behaviour to that of other children – a sibling or a friend. In this way, occupation was used as a way of getting to know and understand their children's particular needs. As Tess stated, "I had to keep reminding myself as Sam got older not to compare them because he was a different child and [his older brother] was exceptional with the talking". Similarly, Nessa recalled holidaying with another family, "It was so much easier for them [the family friends] as such and whatever with their kids than it was with ours. Bringing them into restaurants and stuff like that, you know that socialising and whatever, it was hard work".

Over time, some mothers developed a greater understanding of their child, gained through experiences and observations of their child engaged in occupations. Children's challenges to engagement, identified by their mothers, were varied, and often, though not always, related to their ***social and communication difficulties*** which impacted their behaviour. Imogen said,

> He just plays by himself on the outskirts. Because if he plays even Tag, for example,

> because he doesn't have the social awareness, if he loses, he might punch somebody or he may not understand when the game is over…he is a very rule-based, so if somebody breaks any rule, he just starts screaming and yelling and giving out to them and other kids aren't going to want to engage with that.

And, explaining how Max relates to other children, Claire said,

> He gives them a look that I'd say would tell them not to come near me. And I know one little boy did say, 'oh I have got a Minecraft T-shirt like yours' and he went, 'wuh'…he doesn't like anyone talking to him that he doesn't know so he'd kind of a bit of a meltdown over it.

Mothers developed an appreciation of the impact of the environment on their child's behaviour and the ***importance of the person-occupation-environment fit***. In working to understand their child's challenges and needs, mothers recognised the variability of their children's behaviour and progress relative to the external environment. Helen described several incidents of being called by a primary school teacher to discuss Isaac's tendency to walk around the classroom. She described, "So at the beginning I bought into it out of embarrassment really but by the end of it I was just like, oh shut up, he's a five-year-old, you should go and retrain [laughs]". Conversely, Heather explained how Seán's school have "accepted", "loved" and "cared for him", stating,

> The school realised that he's an individual and the way to him is through nature and through animals and so they provided all these things and opportunities for him…They have a little garden at the back, and he has maxed that out. And even the caretaker would say, 'I made this for Seán you know and Seán can use this'…They show that they care, they know him, and they make a huge effort with him. It's nice, it really is…gosh for me that means an awful lot as a parent.

5.2.2 Doing and adapting

The ***diagnosis propelled mothers into action*** resulting in altered occupational engagement that changed the rhythm of their lives, their time use and routine. Kate explained, "He was diagnosed in the November, and I closed [the business] in the December for a year and a half to pump as much time into him". Kate and family later moved county to have more space and freedom for Rufus. Imogen changed her working hours to align with school times, before finally leaving paid work. Maeve moved her part-time work to weekends to ensure a parent was always at home during the day for Ruby who had left school at 16. Myra moved county to be closer to her extended family, as did Nessa. Sadie, Sadhbh, and Niamh reduced their working hours. Heather left work

and remained a fulltime carer. Tess and Eloise took carer's leave for a year. All mothers incorporated new ways of *doing* within the home, experienced new demands on their time following their child's diagnosis, and most spent additional money supporting their child's additional needs. Such adaptation to their mothering and lifestyles made space for experiences of occupational imbalance and identity discrepancy with mothers' investment in meeting their child's needs taking priority in their lives. Table 5.2 offers an overview of such changes.

Table 5.2

Lifestyle changes in response to child's diagnosis & thereafter to support mothering

Lifestyle Change	Mother
Moved school	Myra (Noah), Tess (Sam), Sadhbh (Íarlaith, Ríodha, Alex), Olivia (Leon)**.**
Moved house	Nessa, Myra, Kate
Self-funded therapeutic services	Maeve, Paula, Nessa, Heather, Eloise, Sadhbh, Olivia, Niamh, Kate, Helen, Claire.
Became an advocate for autism	Heather, Eloise.
Left paid employment	Heather (left employment indefinitely), Imogen, Myra, Kate (each took several years leave before returning to parttime employment), Eloise (took a year's leave before returning to parttime employment), Tess (took a year's leave).
Reduced hours of paid employment	Maeve, Sadhbh, Sadie, Kate, Niamh.
Joined support groups, connected with other parents of autistic children	Imogen, Kate, Niamh, Eloise, Myra, Heather, Tess, Maeve, Jane.
Attended parenting courses/ studied	Imogen, Heather, Maeve, Eloise, Sadhbh.
Internet supports – researched therapies and/or viewed autism posts	All mothers.

Mothers spoke about managing violent and aggressive behaviours, about their child acting out and having meltdowns, about flight risks and rigidity of thought, about coaxing their child to attend family functions or school. ***Tailor-made mothering,*** designed to meet the needs of their individual family and context, was seen as important. Mothers created predictable routines and prepared children in advance for activities. For example, Imogen tried to anticipate Ethan's needs to prevent meltdowns, explaining that to speed up breakfast at night-time she would,

> Prep the bottle, have it in the fridge, have the toast in the toaster to make it as quick as possible to keep him appeased…because otherwise, if you don't do it in a certain amount of time, it'd eventually be a meltdown.

Families rethought how they approached activities. To introduce eating in restaurants with Max, Claire and her husband planned carefully to maximise their control of the environment and activity, reserving a particular table in a particular restaurant and dialling-in their order in advance of their arrival. Claire recalled failed attempts at eating in restaurants. Once Max had a meltdown in the bathroom when someone used the hand-drier – they no longer use such facilities; on another occasion Max became distressed when a stranger (waiting staff) approached him with crayons and a colouring sheet. Some children struggled to cope with certain situations or activity demands and consequently mothers adapted and adjusted their mothering to avoid instigating behaviours that they struggled to manage. According to Heather, "You're parenting at a different level…you have to be ahead of the game, a lot of the time".

Mothers drew on inner resources in order to effectively manage situations when they arose. Paula, who described herself as neither imaginative or playful, was proud to resolve a 20-minute standoff with her son about which path to take home by doing "something that made him laugh and that broke it then". Mothers paid considerable attention to both the big activities (for example, attending school) and the small activities (for example, eating together and dressing) in daily life. They selected activities that met their child's ability and made adaptations in terms of activity structure or occupational form[9] (Nelson, 1988) accordingly. Tess became a cub scout leader to support Sam's participation and Claire used private swimming lessons as Max was unable to attend lessons in a group. Strategies were environment specific – those that were successfully implemented in school may not work at home where routines, structures, and expectations around behaviour and choice were different. For example, visual schedules that structured the school day did not offer enough flexibility in Paula's home.

Mothers worked to find strategies and ways forward which often required that they reconcile personal norms and values around child rearing, which they each held on becoming a mother, with their child's needs and challenges. Mothers learned to ***make exceptions, prioritise, and adjust expectations*** and aspirations for their child in an effort to ensure smooth functioning and engagement in everyday activities. As Kate said, "If he's to do socks, he'll never get to school", so modified her goal of teaching Rufus to dress himself and instead provided assistance. Following diagnoses, Joseph's and Ruby's mental health became Maeve's priority, whereas pre-diagnoses, she had different aspirations and alternative parameters marked success. Mothers' adjustment of

[9] Occupational form is an objective set of circumstances, independent of and external to a person.

values was in line with their understanding of their child's needs and capacity in the context of societal accommodations and available supports.

Upskilling through parenting courses and joining support groups, learning about autism in books, courses, and online, and gaining an understanding of the health and education systems were essential tools of this mothering. With ***effort, practice, and across time***, most mothers developed strategies that enabled them to provide their child with the support needed and a method that worked for them. In addition to routine and activity accommodations, mothers taxied their child to and from therapy; they explicitly taught them life skills and followed through on home therapy goals. Kate described dedicating several hours after school every day to supporting Rufus in his therapy homework, which added to her workload and altered her relationship with her child and family. Mothers invested time in understanding their child's needs so that they could provide both a supportive home environment and prepare others such as teachers. Heather labelled mothering autistic children *"*super-parenting*"*.

5.2.3 Mothering as resistance

The use of mothering occupations in acts of resistance and defiance were evident in mothers' narratives and demonstrated when mothers ***pushed back against professional opinion or demanded services***. Following Sam's diagnosis Tess took a year's unpaid leave from work to be available for Sam's various therapies. When it was explained that Sam was on a year-long waiting list for therapeutic support, Tess refused to leave the clinic. Her act of defiance in colonising this space resulted in Sam's scheduled therapy being brought forward by six months. Similarly, with Max on a waiting list for assessment and diagnosis for four years, Claire recalled engaging with the HSE in a stand-up argument to fund a diagnostic assessment prior to the deadline for applications for special needs assistants (SNAs). Comparable acts of defiance were demonstrated by Olivia and Heather in pressing for assessment and diagnosis, despite a lack of support from either professionals or family. Reflecting on the dearth of autism classes in schools in her local area, Niamh stated,

> I am going to face this head on, there is no way, you know, I have this very strong maternal urge that there's no way society is going to push my child out of his local community. He's a brilliant kid and he deserves the same as everybody else and the same opportunities...the school day is trying enough, the idea that he may have to travel an hour or an hour and a half to school in the morning and the afternoon is just crap.

Mothers challenged professional and public opinion; they spoke of championing autism at school open days and encouraging school fund raisers to be used for autism-related supports. Through continuous research into the systems of assessment, and persistent engagement with professionals to investigate their child's needs, Olivia, Heather, Imogen, and Claire doggedly demonstrated a commitment to better understand their children in the hope that a diagnosis would improve their children's lives and access to services. Heather described turning the "anger" she felt towards healthcare professionals into "drive" to advocate for the diagnosis and supports Seán needed; she was both energised and grew as an individual through advocacy.

> I've had to say, 'no that's not enough, you're not helping me enough,' and complaining and writing letters and taking it to the next level, I'm not afraid to take on people and say, 'no you're wrong.' And fighting against the system that doesn't listen to me…the system's broken, I've to work with what I've got, I've got to just keep going until I can get nothing else out of it. That's where I feel it brought out the best in me. I was very easy going beforehand, I let things go, I didn't want conflict, I didn't want confrontation and now it's like bring it on, honestly, I'm like, hey what do you mean no to me, I don't take no for an answer.

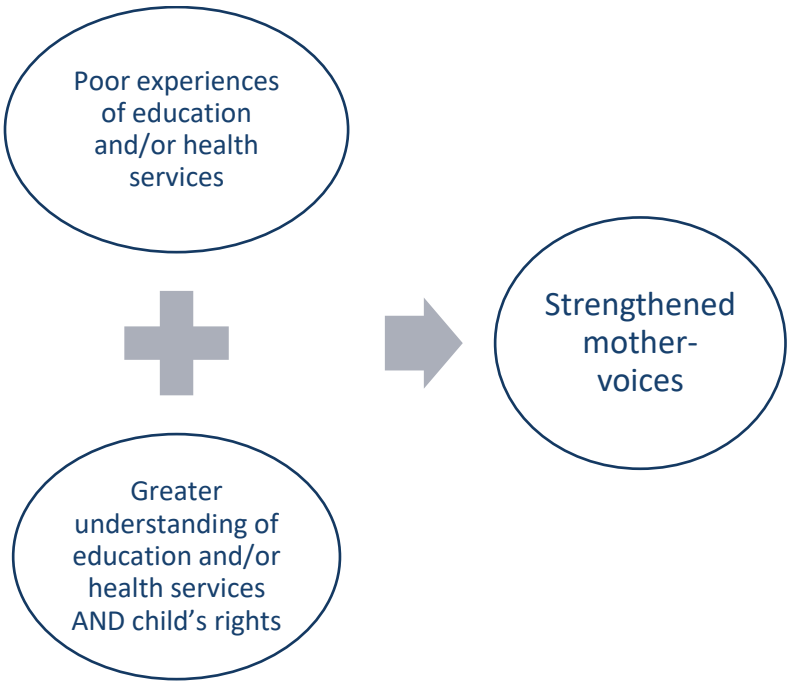
Becoming a mother-advocate was a concept that was present in all participants' narratives to varying degrees. Eloise rallied the troops by encouraging her fellow campaigners to join school Boards of Management, "use the voice, try and empower yourself, knowledge is power isn't it, if you know what I mean, equip yourself, have the language". Through advocacy, mothers showed resourcefulness, resilience, and agency. In the main, the role of ***mother-advocate was effortful but empowering and dynamic*** with mothers using their understanding of the health and educational systems to maximise what they could offer their child. Mothers battled for accommodations, services, and changes to structural supports for their child. Through participation in an autism support group, Niamh's adopted a rights-based attitude empowering her to ask more questions and expect more of services. Acts of resistance enabled mothers to harness unknown personal resources and skills and develop resilience in the face of hegemonic discourses and inadequate services. As Kate explained, "I won't have been good, previous to this, at having the loudest voice but you sort of have to get good at it".

The more mothers interacted with system delays and resource deficits in healthcare and education, the more empowered they became to speak out for their child and family needs. Therefore, the interaction between poor experiences of health and education services and

mothers' growth in understanding of these systems, coupled with an increase in awareness of their child's rights, had the potential to empower mothers to fight for what their child needed (see Figure 5.2).

Figure 5.2

A noted outcome from the interaction between experiences and understanding of systems



Mothers were also aware that they needed to be ***judicious in their selection of battles to fight***. The advocacy role demanded of mothers, skills of assertion and diplomacy and an ability to negotiate, compromise, flatter, and influence. Heather explained how she ignored some comments and behaviours because at times diplomacy was required to get what her son needed. Nessa debated whether confrontation was necessarily worth the effort particularly in relation to teachers whose relationship with her child was short-lived. In this way their advocacy was selective and considered. Fundamental to mother-advocacy was a deep care for and understanding of their child's needs across contexts. This understanding not only gave their advocacy direction but also commitment and confidence to persevere.

Mothers put effort into creating the right environment and ***nurturing supportive relationships*** with professionals including teachers, often pushing themselves outside their own comfort zone

in order to create opportunities for their child to reach their potential. Kate described a conversation with a school principal,

> I said, 'do you mind me asking why you never opened up an autistic unit?' And he said, 'my honest response is because of fear of being able to cope with these children, fear of not having the ability or the skill set.' I was like ‘well look’, I said, 'fear holds us back from absolutely everything, if we don't ever try, we’ll never know.' And I went home that night, and I sent him an email and I just explained to him about the kids in Rufus's [autism] pre-school and if they don't get opportunities that other children have and if somebody doesn't give them a chance they’re never going to succeed. And I told him a little bit about them and about Rufus and about the mammies and about the journey and how everything is a fight, and it’s very draining and it’s very tiring…he rang me in the August, and he was like, ‘Rufus is an enrolled student, he’s starting in September, so you get first priority.' And I said, 'first priority for what?' And he said, 'I’m opening an autistic unit’.

In appreciation Kate bought the principal a pair of Asics [running shoes] for Christmas. He loved running, and in the card, she wrote,

> Every time your foot literally hits the ground, and you run, I hope you remember every single child that passes through them gates. They begin with you and what you have given to these kids. And never forget that that decision over fear has created like a catalyst of energy for these kids to be something to be recognised and to have a life. So, he rang me saying the Asics weren't necessary, but I think they were.

5.2.4 Occupation as coping and reclaiming

Mothers engaged in meaningful occupational engagement, separate from family and children, for enjoyment and as a form of rejuvenation and reclamation**.** DIY gave Paula an opportunity “to be” and “to think” without over thinking. Similarly, cooking for Tamsin, was a productive use of both hands and mind, “Right amount of mental energy so it is not stressful…But I need to think about it enough that you know I can't focus too much on anything else”. ***Flow, absorption, and identity*** were elements of these meaningful occupations that may have been represented to a lesser extent in occupations of mothering. To selfcare and recharge some mothers read, others walked, gardened, practiced yoga, rummaged in charity shops, attended church, listened to and played music. Sadie sang; commenting “I have a karaoke app on my phone and if I was to sit and sing oh that would be my buzz for the day”. Tess, referencing her weekly choir, said, “Just the joy, just the euphoric feeling when I am leaving. And it’s something I’m doing for myself”. Maeve rushed to get

to her faith group on time, “I literally flung dinner at everybody and ran out the door and it was like a drug, I just had to get there”.

Propelling Heather to develop other interests was the realisation that she “Could only speak about autism…all I was doing was focusing on getting through the day and I wasn't interested in what was going on in the world”. This excluded her from adult conversations outside of those with her husband, so she made a concerted efforts to self-care. Mothers acknowledged additional ***benefits on their wellbeing and personal relationships*** of taking time to engage in self/person-centred, meaningful occupations. Tess noted, “When I do something for myself it has an impact on how I am at home. And I’d definitely like to be calmer at home and not overwhelmed”. Maeve said, “It has improved my marriage an awful lot, made me much more accepting”. Mothers recognised the difference between meaningful doing for/about themselves in comparison to potentially pleasurable mothering related activities. Tamsin compared her interest in cooking for leisure, which was pressure free, to cooking with her children which was often fun but limited in scope. When mothers found an occupation of meaning that centred on them, and when they prioritised this as a legitimate use of their time, often others in the family supported their engagement. Tess stated, “They just know at home I have choir and that’s it…John [husband] knows it’s really important to me”.

The ***passage of time positively influenced mothers doing***. As children aged and fathers gained competence, mothers reclaimed time for themselves or re-engaged with previous interests. Imogen, described re-igniting her passion for water sports, stating,

> Literally it’s now taken eleven years for me to actually go and do something that I wanted to do, and it was amazing. So now that I’ve realised that I can do it and Dermot [her husband] can take over, yes, I’m going to go and look after myself.

Losing, pausing, and changing interests may be common to all motherhood (Horne et al., 2005) but it is likely that these mothers reached a point of re-engagement with activities for the self, later than mothers of non-autistic children.

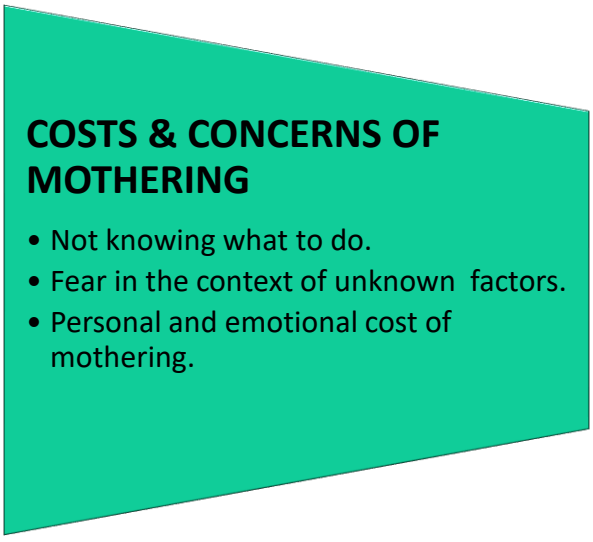
Doing was used as a coping mechanism to help mothers manage their everyday lives. Sadie found writing about Scott for the Domiciliary Care Allowance application to be cathartic in helping her come to terms with his diagnosis. Referring to her leisure interest, Eloise said it “kept me going”. Similarly, Olivia had a space in the house to which she retreated to engage in her hobby. She explained,

> Joseph [her husband] distracts Leon, and I get my little room to myself just for a few minutes. And that enables me to listen [to Leon's questions] for another half an hour. He doesn't mean to be hard work, but God bless him he is.

Alcohol and anti-depressants – the dark side of occupation (Twinely, 2023) – were also mentioned as mechanisms to help mothers cope with mothering. Maeve referred to her habit of drinking a bottle of wine a night when Ruby was in hospital and reverting to similar behaviours to cope with Covid lockdown, "I was quite stressed with the home schooling initially I was eating a lot and drinking a lot as well at nighttime".

Some mothers commented that they ***deliberately disconnected with others*** in order to cope, which Maeve explained as needing "To conserve my energy for where I need it". Tamsin opted out of school communications. Because of her own autism she found their form of communication overwhelming. Imogen needed space to herself to cope with her anger and, when her husband came home from work, would "walk out" her frustrations alone.

5.3 THEME 2: Costs and concerns of mothering



The focus of this theme is on mothering experienced as floundering, worrisome, and requiring sacrifice. In this regard the subthemes within theme 2 are a shadow image of the striving, doing, and adapting; resisting, coping, and reclaiming evident in theme 1. The theme describes how mothers did not always know what was best to do for their child which, among other outcomes,

created opportunities for mothering inadequacy and occupational identity discrepancy. Secondly, theme 2 explains how mothers feared for their child's future growing up in a world that may have little understanding of autism, and little capacity or willingness to accommodate to meet their needs. Finally, the theme identifies how mothering sometimes demanded much sacrifice and created occupational imbalance. The consequence of the active practices described in theme 1, was experienced as losses related to mothers' roles and potential, their imagined child and motherhood, and their sense of self.

5.3.1 Not knowing what to do

Managing behaviour centred on ***knowing the right thing to do*** – the right way to be and respond in the situation. Kate on getting little feedback from Rufus said, "I'm winging it on a prayer and just hoping that it's the right thing and the right job". Sadhbh on managing Alex's school refusal noted, "If we'd pushed him harder and stayed in school maybe things would be worse now, I don't know. But maybe they would be better too, maybe he would be in school if we had done that, I don't know". Jane, speaking about helping Eve with homework, said, "I shouted a lot, and I hated myself because I didn't want to be shouting but I couldn't seem to get through to her". These situations had an impact on mothers' experiences of mothering and their management of these situations was reflected in their understanding of themselves as mothers. Mothers reported not always knowing how to manage their child's behaviour, how best to meet their needs and support their individual development and progress. Nessa, on managing a meltdown when Kai was over stimulated, stated, "I suppose we would try and talk, in the early days we didn't know what we were doing as such or whatever, talk rationally and it was just making things worse. It was just firing him up even more".

Maeve, Tamsin, Nessa, Heather, Tess, Jane, Sadhbh, Olivia, Claire, and Kate all felt there may be ***more they could do, or things they might do differently***. Sadhbh, in relation to moving schools, stated, "I wouldn't say I'm sorry we didn't do it sooner because I don't know if we should've done it at all". Olivia said, "Pretty much every day I just think, oh God I should do that, I should do the other". Kate claimed that "If I went to a treatment seven days a week with Rufus…I would still be like, yeah am I doing enough?". She described occasions when she created activities because she "Felt like I just had to be doing something" to progress Rufus' development. While this demonstrated her commitment to enabling him to reach his potential, it also showed that she coped with mother-guilt by doing for the sake of doing in the absence of knowing what to do

otherwise. Referring to her plans to start Rufus in play therapy, she claimed, “To be honest, part of it is for me to say that I’m doing another thing. Does that make sense?”.

The element of *not knowing* in relation to their mothering decisions and practices led to decreased confidence. In light of their child’s needs and the social expectation of mothers, according to Niamh, self-doubt about being a “good” mother is “magnified about a thousand times when you have a child with additional needs”. Sadie explained, “As a parent of children with additional needs you have more of those situations where you can second guess yourself”. Unfortunately, as Nessa explained, socialising with their children demanded a high level of confidence in one’s mothering and ability to manage situations outside the familiar and the everyday, which, in Nessa’s case, was shaken by past adverse experiences. Because their mothering performance was related to their child’s performance (which was not always positive and often required interaction with outside bodies), being the primary carer exposed mothers to more challenging social interactions with increased ***opportunities for self-doubt*** and questioning of their adequacy as a mother and created discrepancy in their occupational identity.

Some were disappointed that they were not being the mothers they wanted to be. Often mothers were required to respond to problems as they arose – to fire fight. Distracted and busy, Tess said, “You do the only thing you can think of at the time” and found she often lost her patience. The fact that they were living a situation in the moment of its occurrence was considered by mothers to be an invalid explanation for mismanaging it. Even those who were overall happy with their mothering questioned their practices which typically fell short of their pre-motherhood ideals and good mother ideology. The degree, in terms of time and energy, to which mothers engaged in expected activities of mothering, such as nurturing, protecting, and socialising (Ruddick, 1982; 1989/1995), exceeded that which was demanded of mothers with children who did not have autism. This moved their mothering further from the occupational possibilities considered ideal for mothers and had potentially far ***greater adverse consequences*** when they got it wrong. By not acting as broker with outside agencies, their child’s needs may not be addressed, nor environments made supportive. By not choosing the most appropriate schooling, their child might not only not reach their potential, but not survive school. By not preparing and planning ahead, meltdowns and strife may occupy the home. By not mothering their child using an autism friendly approach, their child might struggle to navigate the world. There was a gravity to mothering decisions that did not apply to the same extent to neurotypical mothering.

5.3.2 Fear in the context of unknown factors

Looking to the future was a point of sadness and worry and a daunting prospect for all mothers at some point on their mothering journey. Nessa considered Sam to be "A very sensitive soul which is lovely you don't want him to lose that, at the same time you're afraid for him and want to protect him because it's a hard old world". Similarly, Maeve said, "My fear for him is when he's in school as a teenager and if he's stressed, he stims[10] and when he is in school that might be a problem, he could get bullied in secondary school". Heather stated, "He's going to be an autistic man, and he has to deal with the world, the world has to deal with him…it's very frightening, very frightening. It's awful". Mothers feared that their child would be unemployed, alone, unsocialised, and under-productive. Helen was scared for Isaac's future, imaging one in which he was dialling-in Uber Eats and watching YouTube videos. She said, "It would just break my heart to think of him living in some one bedroomed flat in a pigsty, grossly overweight, depressed, not interacting with anybody".

Although mothers expressed some tentative hope and optimism for the future, it was easier for some not to take a long vision view. Claire admitted, "It's just day by day really for me, it's day by day", while other mothers like Imogen, for whom many issues had stabilised, saw a brighter future, "The last six years has been very fucking hard…But it's seeing the progress and the hard work made the difference, so yes, I do see brighter times ahead". The resolution of challenges was a source of comfort. Jane attributed much of Eve's prior difficulties in school to her ADHD; now medicated, Jane expressed no concern for Eve's future. Myra, whose son Noah, ten years post diagnosis, had developed satisfying friendships, routines, and meaningful occupational engagement, was more optimistic about Noah's transition to adulthood than when he was first diagnosed.

In anticipating their child's future challenges, mothers wanted to arm them with coping mechanisms for resilience and independence, yet contrary to normative assumptions for child development, the level of independence and maturity their child would gain was difficult to predict. Heather wished for Seán, "To be as independent as they can be. [teary] And I don't know will we get there? I don't know". Although on the one hand optimistic about Ethan's future, Imogen also worried about, "How's he going to support himself when I'm gone? How's he going to get a job? How's he going to learn to live a normal life?". Mothers were concerned for their

[10] Stims or stimming (self-stimulatory behaviour) such as hand-flapping is something that autistic individuals may do to self-soothe and reflect an autistic individuals' alternative modes of learning, their method of self-regulation and expression.

children's future happiness and mental health as well as their prospects for independence. Mothers were cognisant of the implications of their child's potential dependence for mothers' own futures. Consequently, several mothers found it ***difficult to see an end point in their mother-child care*** and were aware of the subsequent impact of this on their ability to evolve in their mother identity in keeping with norms of mothering grown-up children. Olivia considered that, "We're going to be dealing with him on a day-to-day basis forever. I just don't see Leon being independent…I think we'll have him until the year dot and some part of that exhausts me even thinking about it". Similarly, Niamh was not oblivious to the implications of having an ever-dependent child, asking, "Will he be able to go out in the world and eke out an existence for himself and if he doesn't then part of that is my life will be very much tied up in that". There was a certain pressure attached to eternal mothering – fear that they may not be able to care for their child indefinitely created impetus to prepare for the future right now. Eloise said, "Hopefully we're all still alive but who knows like? So, I have to make those things now right so that we can have the best for that stage".

Mothers' ***aspirations for their children***, in line with social norms, were for them to have a meaningful future. By and large, these mothers wanted their children to be happy and to give them the skills and opportunity to be so. Claire remarked, "The world isn't going to change for Max, so we're trying to get Max to be comfortable in his own skin…to keep him involved in the community". Likewise, Helen said of Isaac, "He could be productive, work, socialise, he just has to want it, and I just have to coax him in that, or provide whatever support I can to enable him". Some mothers didn't see their child fitting into open employment. Heather saw herself generating opportunities and bringing purposeful occupation to Seán rather than expecting him to seek it out, "Moulding the situation into something for him to make his own little niche in life…coz I don't think it's going to come to him". If Seán liked to fish, she would support him to start a fish farm. Assuming not all mothers may have the capacity with regards to time, inclination, ability, or finances to create such opportunities for their child, if this is what it takes for some children to have a productive future it reflects an unfair expectation of mothers. The fear experienced by the unpredictability of their child's future was exacerbated by the lack of services available to nurture their child's current development, to support their child at critical points across their childhood, and to provide appropriate opportunities for their child's occupational engagement and meaningful role development as an adult.

5.3.3 Personal and emotional cost of mothering

For many, following diagnosis, there was a period of sadness and grief (described by Kate as "no balance…just like feet ungrounded"), which began with the possibility of autism and for most was heightened by the reality of the formal diagnosis. Mothers grieved the child they thought they would have, they grieved the loss of their expected and desired everyday engagement, and they grieved their imagined future for themselves, their family, and their child. Mothers had normative images of what family life should be – "bedtimes", "good food", "reading books"– and as Niamh stated, "all that kind of stuff was very much drilled into me growing up and those family values were actually very strong". Niamh explained, "You're trying to aim for a kind of a perfect model of family life…things don't work quite as you imagined they would". It was possible that ***deviations from typical family life*** could result in a level of annoyance and embarrassment, loss and disappointment. Clare described feeling self-conscious managing Max's public meltdowns, while Kate explained her sense of a lost imagined life,

> I wanted my child to go off and play soccer and win trophies and have a laugh and go to parties and fucking do what kids are meant to do, or what we think they're meant to do. Whereas I think the realisation of that was not going to be my life was very profound.

Mothers' commitment and dedication to their children was demonstrated through their activities and sacrifice. As described by Nessa, "You have to ***put yourself second*** when it comes to your kids…they're so important…you wouldn't do it for anyone else". Mothers made sacrifices on a personal, social, and professional level in excess of those typically made by mothers and in ways that were both explicit and tacit. By taking responsibility and acting as the go-to responder, mothers compromised more of their pre-motherhood selves which had a pervasive impact on their everyday lives (for example, less time for hobbies, friendships, work outside the home), and was experienced as positive and/or negative. They adapted and compromised their career ambitions, their imagined family life, their personal social life, their ways of doing mothering, their spontaneity. This was compounded by assuming the role of the primary carer. For some, this created imbalance and reduced occupational harmony.

Despite efforts to pre-empt issues arising, mothers reported that they needed to react to situations and be ***available to respond*** to their child's challenges as they arose, leading to, as Heather described, a sense of a "lack of control over your life". Paradoxically, this contributed an element of unpredictability to the lives of those mothers who had deliberately routinised and adapted family life. Heather explained, "I just don't know what is going to come around the

corner". Being present and available was important to mothers – as Niamh expressed, "I still feel that I'd somehow be lacking or that I'd let them down if I couldn't be there". Even Claire, whose husband was the weekday primary carer, made concessions to be as available as much as possible for Max by turning down workplace promotions. Mothers placed themselves centrally in their child's care and education. According to Tess, "As a mother you always want to be the one going to the appointments and compiling all the information". Sadie, for instance, felt over-burdened yet admitted, in relation to her children, she wanted professionals to consult her first rather than her child's father.

Reluctance to leave home, was found to prevent families from doing "hundreds of things" (Sadhbh on Ríodha). Maeve was saddened by Ruby's reluctance to leave home which resulted in no extended family holidays, the loss of connection with relatives, and division of the family unit with one parent required to remain home with Ruby. She noted the unfairness of the situation on Ruby's younger brother. In this way, the ***restrictions placed on families' occupational engagement*** had implications extending beyond that of immediate non-participation in focal activities. When the child's occupational engagement was limited or inflexible, family life accommodated with consequent modifications to the occupational engagement of parents impacting their occupational balance and potential for participation. Max's public meltdowns and refusal to play in his housing estate, caused his family to be isolated within their community and obligated his parents to become his playmates. Claire explained, "He'll get [his father] to play a sword fight with him…me and him, we'd play tag, we go into the woods, and we go to a few places and run around". Low moments for these mothers in relation to their children had the potential to be very low. Claire described being outside with Max,

> He was just growling at people all the time, that was quite dark. I didn't understand why he was so upset, I thought we would never be able to interact with other people again…Obviously, there it's just in the moment but I felt this is what our life is going to be like now, we're going to have to be in the woods with no people around us because this is how Max was, you know this is the way it is and that was quite dark.

A primary change in mothers' lives was their compromised relationship with work outside the home. Heather, Eloise, Imogen, Paula, Helen, and Claire had once been ambitious professionals working long hours. With the exception of Claire, all scaled back their work hours. Aspirations for the direction of their ***career had been curtailed*** by first becoming mothers and then by the

circumstances of having an autistic child. Heather described her difficult decision not to return as an "identity" shift,

> For somebody, whose whole life was my career and what I built up and what I'd worked so hard for and then I decided you know what, there's a little person here who needs me more, and that was a big thing.

Many mothers altered their work arrangements to support their mothering as their child's needs became more demanding. Typically, when mothers reduced or left work, they did so to make things manageable for the family as a whole. Eloise claimed that "it was the right thing to do in the sense that I was just here, and I wanted to be here, and he needed me here and I needed to be here, and my husband needed me here". However, creating balance between their various roles was problematic and Sadie found it difficult to give either work or motherhood "the attention it deserves", leading to experiences of occupational imbalance.

Striving to be the mother their child needed, to meet societal expectations of mothers, as well as navigating existing support systems and shaping the existing educational environment to fit their child, was generally perceived as ***exhausting, both emotionally and physically***. Nessa explained, "I just feel sometimes it is always a struggle, always a battle, you are battling for services, you are battling for inclusion, you are battling for this, that and the other and it's just exhausting all the time". There were constant reminders in daily life of their child's differences and challenges. Imogen felt that "Sometimes you just want to just have a day without being reminded. Just leave it. Like have a normal day. Rather than it being in your face all the time". Niamh juggled, "The responsibility for the house and the raising of them and the administration that goes behind having a child with additional needs and the interaction with the education system, the health system, that's another job in itself". Pressure on time and energy led to an increased maternal care burden. As Kate said, "Where do you stop, when do you breathe, when do you sit down and read a book?". An acceptance of being available for their children, resulted in mothers being less inclined to allow time to engage in personally meaningful activities. Heather explained how she might forget to take care of herself, "I've got to that stage a few times where I just kept going until I literally am collapsing". Tess, who had wanted to be "Mother Earth" said,

> In my head I thought I would have been sitting down doing art with them all the time, but I'm not and I don't even want to sometimes [laughing]. Sometimes it is too much of an effort and if I have five minutes I just want to sit there with a cup of coffee and my phone.

Emotional peaks ebbed and flowed as child and ***environmental challenges changed***. Each year, for example, there was a need to inform every new SNA and teacher of how best to meet their child's particular needs, effecting an emotional response in mothers and compounding their exhaustion. Sometimes, particular incidents provoked emotions. Heather spoke about learning to "Roll with the punches". Other times, mothers found everyday life worrying and upsetting. Kate compared her mothering to a "wave", with some "really challenging" days. Even when things were stable, mothers might, unprompted, begin to worry about current or future potential issues. As Sadhbh stated, "I tend to go through patches, it's all good with him, it's fine, sure he's in his new school and he's happy, and then I go, Jesus Christ, what's he going to do about physics?".

Helen, just two months post diagnosis at the time of interview, was reluctant to adjust to a new version of herself as "a nuisance" and was annoyed that the school might perceive her as "this crazy woman…making a mountain out of a molehill". In being wholly focused on doing and being for their child and family, some mothers experienced a ***lost sense of self***. Tess stated, "You never stop and go how is this affecting me or how do I feel about it?"; and according to Niamh, "You lose all sense of yourself in the midst of it all". Mothers described changes to core aspects of their person as the negative impact of accommodating to their child's needs. Tess, who thought of herself as unflappable pre children, said, "Things would get on top of me more…their needs definitely take a toll on me, my calmness, my patience". Mothers lamented the loss or adjustment of aspects of themselves which they had held as fundamental. At times mothers felt vulnerable, lost and alone.

Mothers felt pain for the challenges their child experienced which was tangled up with their sense of personal loss. Jane described an incident with Eve before her diagnosis,

> She started banging her head off the wall and saying that she was stupid…I just remember it being so awful and feeling so horrified…and knowing that she is in so much mental anguish and there was nothing that I could say or do that was making it any better.

Helen was upset when explaining that Isaac "keeps away from people because" he believed he "just irritates them". Heather said Seán, "has no friends, and nobody calls for him". Imogen acknowledged that what she felt watching Ethan play alone was not necessarily a reflection of how he experienced aloneness, "The good thing is he's happy in his own company. But it's just sad for me". Mothers' ***wellbeing was interconnected*** with that of their child's and might be considered co-dependent. Olivia described a particularly good day of Leon's saying, "I feel so much better going to bed tonight because he was happy". Mothers put their child's wellbeing ahead of

their own. Kate returned to work part-time only when she was content that Rufus was being appropriately educated. She commented, “Once he’s all right, I’m all right”. The fact that mothers felt better about themselves when they perceived their child was happy and appropriately supported, may not be unusual for mothers generally. It may be harder to achieve, however, for these mothers, given their child’s challenges in the context of current services (see Theme 3) and demands of obligatory/assumed childhood occupations.

5.4 THEME 3: Interface with society & relationship with occupational justice

The third theme – Interface with others and society and relationship with occupational justice – speaks explicitly to the concept of occupational justice. The relevance of occupational justice in the lives of these mothers was most apparent in their interactions with society and societal structures at a micro to macro level. The theme expounds on the inadequacies of services from mothers’ pursuit of diagnoses through to their use of services and interactions with society. The theme provides accounts of mothers’ experiences of marginalisation and, applying a feminist lens, it describes participants’ perception of societal expectation of mothers and women generally.

Recognising mothering as gendered labour, adds to the understanding of the relevance and reach of occupational justice in the lives of these mothers.

5.4.1 The assessment and diagnosis story

Getting a diagnosis of autism was experienced by Helen as a "bumpy road, ups and downs". Receiving a diagnosis of autism was a poignant turning point and occupational role transition for mothers, even for those who had sought, and were relieved to receive, it for their child. At this juncture in their narratives, participants' mothering formally deviated from mothering neurotypical children. Identifying the need for some form of assessment or intervention was the first stage in the journey towards an autism diagnosis. Due to a lack of clear systemic pathways, most mothers were obliged to fathom the assessment process for themselves which often took time and involved interfacing with professionals in healthcare and education. ***Learning through experience*** was the approach of those who were strangers to the healthcare system, who did not have the professional advantage of Eloise or Sadie (both healthcare professionals), or prior contact with the system on behalf of their other children. Jane explained that it was, "very hard to find out what to do if you don't know anything about it. I mean I went in flipping circles". Sadhbh was frustrated by the system and stated that,

> Alex had an assessment for dyspraxia when he was nine…But nobody at that assessment said do you think we should get him assessed for anything else at that point? And like as a parent you think, well they know everything. If there was something else, they'd point us in the direction of looking into it, wouldn't they? But they don't.

While each mother told their own unique story relating to their personal situation and child, it was also possible to identify commonalities in the lead up to the diagnoses. In the examination of factors precipitating diagnoses, each child's case was grouped according to how the need for an assessment came about (see Table 5.3).

Table 5.3

Recognition for the need for assessment

GROUPING of mother with child – how the need for diagnosis was recognised.
BATTLED TO BE BELIEVED or listened to by professionals – mother drove assessment forward. Heather with Seán. Olivia with Leon.
DEVELOPMENTAL REGRESSION – mother/parents noted regression. Claire with Max – Claire highlighted concerns with public health nurse. Kate with Rufus – Kate highlighted concerns with public health nurse.
CRISIS pre diagnosis – child or parents identified need following crisis. Maeve with Ruby – hospitalised with mental health condition, left school. Myra with Noah – ran away from home and school, threatened self-harm. Sadhbh with Alex – school refusal sitting in wardrobe, identifying as non-binary.
UNEXPECTED AUTISM DIAGNOSIS – healthcare professionals (assessing/treating another condition) recommended autism assessment. Tess with Sam – attending for support with dyspraxia; Tess was surprised by autism and ID diagnoses. Sadie with Scott – attending for ADHD support; Sadie was surprised by autism diagnosis. Jane with Eve – attending for ADHD diagnosis; Jane was surprised by autism diagnosis.
COMPETENT CHILDCARE – childcare staff/educators identified need, recommending assessment. Imogen with Ethan – childminder. Paula with Conor – preschool teacher. Nessa with Kai – afterschool childcare staff. Niamh with Aidan – primary school teacher.
PERVASIVE CHALLENGES – mother recognised challenges to child's daily occupational engagement. Maeve with Joseph – understood autism and system as Ruby already had autism diagnosis. Helen with Isaac – attended CAMHS[11] 5-7y/o, inconclusive diagnosis on discharge; ongoing private psychological support into teens, Helen requested private assessment. Tamsin with Matt – recognised autism in Matt as Tamsin identified as autistic. Eloise with Lucy – developmental delay, later diagnosed with an intellectual disability; Eloise was qualified to work with children with additional needs. Sadhbh with Íarlaith and Ríodha – understood autism and system as eldest child, Alex, already had autism diagnosis.

[11] CAMHS is the Child and Adolescent Mental Health Services treating children with moderate to serve mental health conditions in the community.

In the main, the mother recognised their children's challenges, despite often being unaware that these stemmed from autism. Two mothers – Heather and Olivia – described a ***battle to be believed.*** On raising their concerns over and over with healthcare professionals (Heather) or educators (Olivia), these mothers reported that their opinions were disregarded, and their credibility undermined. On being rebuffed by the school secretary for requesting an appointment with the principal Olivia described,

> I completely lost the plot, I screamed, 'she will see me, she absolutely will see me, you do not get to put economics over my son's welfare, you have patted me on the head, you have sent me off with a flea in my ear for five years now, longer, seven years, I want to see her and I want to see her quickly.' And I went out, sat in the car, and cried my eyes out because I'd been rude.

Both mothers persevered, motivated by a desire to understand their child and the determination to be vindicated. Heather said, "I wasn't going to let them win…I wanted what was best for him, I wanted to figure out what was going on. I wanted to be the best parent". Not being heard or believed was demoralising for these mothers and had an impact on their mental health. Heather explained,

> I got very depressed, and this was very early on when he was very young, and I wasn't getting anywhere, and I wasn't getting any diagnosis…I just was really crying all the time, and I was really beating myself up because no one would listen to me.

Neither mother accepted the professionally informed position on their child, as desired and expected, but battled against the system demonstrating a belief in their own opinion as equally valid.

Claire also fought the healthcare system to fund Max's assessment for autism. Both Max (Claire's son) and Rufus (Kate's son) were placed on a list for an assessment of need by their public health nurses following notable ***developmental regression*** aged 1.5 to 2 years. Despite this similarity, Kate's and Claire's experiences of gaining a diagnosis differed as a function of their trust in the system. Rufus, following a private assessment, was diagnosed in time to enrol in a specialised preschool because Kate had reached out to her social network and quickly gained an understanding of the system. Conversely, Claire, although investing in private therapies for Max, trusted the public healthcare system to operate in a timely manner. She did not reach out to a community of mothers; she was not forewarned to seek a private diagnosis. By not learning how to enter and use the system Max remained on a waiting list for four years, indicating that

diagnoses are accelerated when mothers have funds, social capital, and insight to circumvent this system and seek a private diagnosis.

For some, a ***crisis gave impetus for diagnosis***. Following a breakdown in daily function, the need for assessment was recognised by the community mental health services, the child, or the mother. Myra's son ran away from home and school, threatened to kill himself and was immediately seen by community mental health services (CAMHS) who recommended an autism assessment. Ruby was hospitalised with a mental health condition, withdrew from secondary school for a year, and recognised in herself the characteristics of autism. Finally, Alex refused to attend secondary school and instead sat rocking in a wardrobe; his mother requested an autism assessment with a private therapist.

While some had harrowing experiences, others' journeys to diagnosis were relatively straight forward. The difficulties experienced in firstly, recognising their children's challenges, secondly, finding collaborators to validate their concerns, thirdly, figuring out the assessment process, were bypassed in cases where diagnosticians recognised autistic traits and suggested assessment. Where ***external bodies highlighted their concerns*** and had the capacity to provide diagnoses, though unexpected, (as Jane said, "I didn't see that one coming"), represented the least arduous and most efficient route to assessment. Such diagnoses occurred when children attended clinicians for alternative health concerns (dyspraxia and ID: Sam; ADHD: Scott and Eve) and in these cases external bodies took ownership of the assessment process driving it forward. However, without the capacity to diagnose, recognition of the need for assessment by an external body such as childcare staff or teachers, did not accelerate the journey to diagnosis any more than if the mother had identified this need herself.

Because of the relationship between the health and education systems, delayed (health-owned) assessments potentially jeopardised the application for (education-owned) special needs assistant (SNA) which are greatly strengthened by professional reports and assessments (Department of Education and Skills, 2014). Both Ethan and Max had needs that required support when starting school. Both mothers, Imogen and Claire, experienced ***points of high stress*** when their sons were not diagnosed in time to meet the SNA application deadline. Imogen recalled, "I had a bit of a breakdown. I literally was on the side of road having a massive cry, and I just couldn't cope with how much crap you have to fight for".

The assessment process was made easier by having prior ***understanding of the system***. Sadhbh and Maeve met subsequent children's needs by repeating the process they had previously undergone with their first child. Maeve began using the system as a consumer by requesting additional assessments/resources for one child that had proved necessary for the other. Such consumer use of the system was also seen in Sadie, who was in the unusual role of being a member of an autism diagnostic team. She began the diagnosis journey for Scott with the attitude, "I am the parent, I hold the reins". The length of time and experience to reach diagnosis was dependent, to varying degrees, on multiple factors: the child's presentation, the skill of the diagnostician, the resources within the system, the team's attentiveness to the mother's concerns and the mother's advocacy skills. Understanding the system through prior experience, either personal or professional, created an attitude of confidence that enhanced mothers' ability to use the system as a consumer-of-a-service rather than a mother-of-a-patient.

Factors external to the mother that alleviated some of the trials on the journey to diagnosis included having another child already in the system, having worked in the system, living in certain areas, having personal funds, and applying the advice of other mothers in similar situations. Table 5.4 provides a synopsis of each mothers' account of the assessment to diagnosis journey.

Table 5.4

Mothers' diagnoses stories

Mother with child (child's age at interview)	Age at autism diagnosis	Funder of assessment	Additional diagnoses (age diagnosed)	Narrative related to the application for assessment
Imogen with Ethan (12)	4	Public	ADHD (10)	Spoke with other mothers and applied to health service for assessment. Incorrect version of assessment-measure used. Age 4. Reassessed months later. Results not returned in time for SNA. School funded SNA for junior infants; government funded SNA thereafter.
Maeve with Ruby (17)	16	Public	ADHD (17)	Following hospitalisation at 16, Ruby requested autism assessment from CAMHS. Left school for a year. Private assessments for additional learning needs replicating her brother Joseph's assessment suite.

Maeve with Joseph (10)	9	Private	ADHD (9)	Private assessment following sister Ruby's diagnosis.
Paula with Conor (10)	3	Private	ID (9)	Autism dismissed by private clinician (without Conor present); diagnosed privately months later and referred into the public system at age 3. Global developmental delay diagnosed at age 4. Teacher referred Conor to community team at 5. Supported by SNA.
Tamsin with Matt (8)	8	Private	/	Tamsin, who is autistic, recognised Matt's challenges in school. Sought private diagnosis.
Myra with Noah (17)	7	Public	ADHD (7) Dyslexia (8)	Following incidents of absconding and threat of self-harm assessed and diagnosed by CAMHS within weeks of referral. Attended autism class in mainstream primary school. Integrated in secondary school with long-arm support of SNA.
Nessa with Kai (10)	5	Private	/	Older sister, Zara, using health service for ID. Nessa working in aligned service. Referred to public system age 3 on recommendation of afterschool childcare workers. Private OT assessment recommended assessment for autism.
Sadie with Scott (11)	11	Public	ADHD (8) Sensory processing disorder (6)	Sadie employed in autism diagnostic services. CAMHS recommended autism assessment following a report from Sadie that Scott was struggling with his ADHD.
Heather with Seán (12)	Almost 5	Private	Language disorder (5) ADHD (6) Dyslexia (9)	On waiting list from age 3. Private diagnosis not accepted by public early intervention team who re-administered assessment and found severe language disorder, not autism. Attended additional public service for intervention which did accept diagnosis. Supported by SNA.
Tess with Sam (8)	5	Public	Dyspraxia (4) ID (5)	Autism dismissed by health service team age 4. Diagnosed with dyspraxia. Team revisited and subsequently diagnosed autism and ID following year. Supported by SNA.
Jane with Eve (12)	9	Private	ADHD (9)	Jane spent a year fathoming assessment process for ADHD. During private diagnosis for ADHD, diagnostician recommended assessment for autism also.
Eloise with Lucy (8)	2 4	Private, later public	ID (5)	Private autism diagnosis at 2 on recommendation of friend.

				Referred to public system. Inconclusive assessment of need. Autism diagnosis from health service age 4. Special class in primary school.
Sadhbh with Alex (17)	14	Private	Dyspraxia (9)	Academically gifted. Identified as non-binary following diagnosis. Secondary school refusal (14-15). Supported by SNA. Ultimately left mainstream education at 16.
Sadhbh with Íarlaith (11)	8	Private	/	Dyslexia. Moved primary school. Diagnosed privately following Alex's diagnosis.
Sadhbh with Ríodha (8)	6	Private	/	Moved primary school with brother Íarlaith. Diagnosed privately following Alex's diagnosis.
Olivia with Leon (11)	10	Private	Social communication pragmatic disorder (10) Phonological dyslexia (10)	Olivia raised concerns with preschool personnel and again repeatedly with teachers in primary school. All dismissed concerns. Sought private diagnosis to better understand Leon.
Niamh with Aidan (11)	7	Private	/	Autism concerns raised at 3.5y/o; dismissed by public system age 4. Reassessed and diagnosed age 7 on recommendation of school SENO. Supported by SNA.
Claire with Max (8)	6	Private but funded publicly	Language delay (2) Tiptoe walking	Regressed development at 1.5y/o. Privately funded speech therapy while awaiting assessment. Awaiting assessment age 2 to 6. Private diagnosis of autism (refunded by health service) to meet deadline for SNA application.
Kate with Rufus (7)	2	Private	/	Private diagnosis on recommendation of friend. Rufus attended ABA specialised preschool. Mainstreamed in special class for junior infants. Moved house. Integrated in mainstream classroom with SNA support.
Helen with Isaac (17)	17	Private	Developmental Coordination Disorder (5) Obstructive Defiant Disorder (17) ADHD (17)	Attending CAMHS age 5-7. Diagnosis of autism dismissed. Continued to attend psychologist and OT privately. Sought private assessment at 17.

Early versus later diagnosis was compared in the four teenagers discussed by their mothers. Noah who was diagnosed at seven and received appropriate supports at that time. By 15 years old, Noah was in a band, socialised with friends, sat with the family for daily meals, and was hoping to attend

music college. At the time of interview, the mothering conditions for the three other teens (Ruby, Alex, and Isaac) was more challenging. They each received their diagnoses of level one autism (high functioning/mild) in secondary school (aged 16, 14, and 17 respectively). Ruby duly left school for a year before returning at 17 and applying herself intensely to her studies. She had no extracurricular activities; did not attend family functions; and rarely left the house. Alex had very poor school attendance in secondary school; identified as non-binary in second year; had just one friend; ate meals separately to the family; despite having the support of an SNA, he left mainstream school at 16 and attended alternative schooling sporadically. Meanwhile, Isaac sat alone in class and for lunch, his only social contact was his immediate family. Everyday his mother battled to encourage him to engage in basic activities of daily living. Maeve fretted over Ruby's minimal social life; Sadhbh was worried that Alex would not be supported to reach his academic/professional potential; and Helen was particularly concerned that she had little time to put the right supports in place for Isaac before he becomes an adult and falls yet further behind in society's expectations for his development.

A level one diagnosis of autism in teenage years might extend an assumption of little functional impact yet the implications of autism on the teens in this study (Ruby, Alex, and Isaac) was seriously impactful on their day to day lives, which was compounded by their proximity to transitioning to adulthood. I do not contend that these children needed an earlier diagnosis, rather nuanced and immediate supports when diagnosed as teens. Mothers needed support and guidance, not only to adjust to the diagnoses, but also to make accommodations and advocate for services while their children's fast approaching adulthood placed them under pressure for time.

5.4.2 Inadequate supports and unsympathetic environments

Mothers complained about the availability and quality of services. To varying degrees, many mothers experienced extensive waiting lists, uncoordinated services within the system, unfilled posts, little support, unreasonable deadlines, and incompetent professionals. Macro-level, systemic issues in healthcare, such as waiting lists and low staffing, impacted the speed with which children moved through the assessment process. On receiving the diagnosis, mothers were often very hopeful to receive the correct form of support for their child and ***felt naïve and let down by the system*** when their child was placed on a waiting list for services or no appropriate supports existed. The general unavailability of specialised supports, and lack of composite and rounded provision of services, created crises for some such as Claire whose negative experiences of the

healthcare system in relation to delayed assessment and intervention were exacerbated by her discovery of a dearth of trained physiotherapists to treat Max's tiptoe walking.

An additional system-related factor contributing to the long journey to diagnosis stemmed from ***inconclusive assessment results, misdiagnosis, and the non-diagnosis*** of children. Without formally assessing for autism, in some cases several clinicians dismissed autism, perhaps for good reason, as a likely diagnosis. Unfortunately, this delayed children's entry into the system. Having attended CAMHS from 5-7y/o, Helen explained that Isaac was discharged "with no definitive diagnosis". Unlike Heather and Olivia who pressed for further investigation, Paula, Tess, Helen, and Niamh accepted these conclusions waiting several more months (in Paula's case) or years (10 years in Helen's case) before pressing for their child to be formally assessed for autism. Mothers worried that their child's progress could be impacted by a delayed diagnosis. Olivia described the guilt she felt when Leon was finally diagnosed,

> When she told us that the professional people were wrong, and I thought about the consequences of what I'd done [not advocating more vehemently] …and the torture that I'd already enforced on him [extra schoolwork] was a shocking thing and hard to reconcile. Because as parents we're supposed to advocate for him, and we're supposed to protect him, and we did the opposite and that's an awful thing…I could've shouted louder. I let Leon down.

Niamh, Eloise, and Claire made reference to the geographical inequities existing within structural supports. Eloise's efforts to establish special classes in her local schools concluded that location-based ***discrimination at a structural/meso-level*** was built into the system – in some areas there were services and special classes and in others there were none. Additionally, inequality was apparent with the time it took to get a diagnosis of autism being dependent on the service a child was trying to enter, how and why. As explained in the previous section, operating from within the system (that contained a diagnostician) accelerated a diagnosis of autism while waiting to enter the public system through an assessment of need created delays.

There was a sense of ***doing it alone and desperation*** among some. Kate remembered with sadness "the whole air of being completely unsupported and a struggle and almost feeling like nobody wanted him". Reflecting on the extensive private therapies she had funded for Max, Claire stated, "We're on our own here most of the time". Sadhbh described the period after diagnosis when Alex was struggling to function,

> And he had had a diagnosis at this point, and I'd expected we'd get some help by now. There was nothing. Tusla got back in touch with the autism services and told them school was about to breakdown, could they intervene now? And they [autism services] didn't even respond to that. And I was ringing them going 'can we get some help...we fucking need help?' and there was nothing.

Being listened to, and empathised with, was important but there was also a great need for intervention when mothers were floundering. Tess believed that "without professional help, you can only do so much". Heather, describing her early years with Seán said,

> He was up, down, around about, inside out, the child didn't know what he was doing, he was crawling under tables, he was crawling under mats, crawling under this… he was all over the shop, the poor old thing…And I was like, but I need help, I don't want to hear that that's terrible. You don't need to hear that.

Because mothers were not present in all spaces their child inhabited and could neither witness how their child interacted in these environments nor protect them there, mothers were dependent on the people in the services, including education, to understand, advocate, and care for their child. Helen was upset when she thought about Isaac's isolation in secondary school and the inaction of teaching staff,

> It just broke my heart to know that this little kid is coming under the radar, the teachers didn't know him, they didn't know him because he didn't cause any trouble. He just sat at the back, kept his head down. They saw him eating his lunch on his own every day. And things like that really upset me.

Several mothers encountered difficulties with the education system and its staff. Mothers described incidents of teachers publicly complaining about their children's behaviour in front of other children and parents. Myra explained that the teacher "wasn't taking on the possibility that there was an issue there with Noah…he was just lazy, he was able to do the work, he was just choosing not to do it". Leon was also considered lazy. When ***professionals' attitudes were unsympathetic***, the wellbeing of both mother a child were affected. In encountering a teacher who did not understand his needs, Ethan began urinating on the bathroom walls in school and at home, Noah became a flight risk, and Leon stopped progressing academically. It was possible for the educational environment to create additional challenges for these children. Sadhbh, referring to Ríodha, explained that "He was fighting in the yard, he never fights at home…We would know not to push him that far".

Interactions with professionals in education and healthcare had the power to ***undermine confidence and competence*** as mothers, in turn creating the possibility of occupational identity discrepancy. Olivia stated, "I resent that he was denied that [earlier diagnosis] because people were so busy dissing me. And I am seriously peeved with myself for not having the confidence to stand up and say you are wrong". Even when challenging the system, Claire was cognizant of her lack of training and expertise which exacerbated their feelings of failure.

> Our family time is taken up by trying to fight to get help for Max and give him the best support. We weren't skilled enough, we're parents, we're not psychologists and we're not occupational therapists and we're trying to do all this in the background and sometimes we felt we were failing miserably...it's just taken over a lot of our lives.

Navigating the system, first to understand their child and then to access supports, was hard work and left mothers battle weary, depressed, with shattered confidence and esteem. Meanwhile they continued to struggle to meet their child's needs at home and were directed to parenting courses by way of support. Almost all mothers experienced such ***supports as irrelevant.*** Sadhbh explained,

> On the parenting course they were talking about children not wanting to go to a disco and my child was curled up in a wardrobe not wanting to go to school. It was a different scale of a problem. By second year he was identifying as non-binary as well…there was a lot going on.

In some cases, courses had the potential to further their feelings of inadequacy as mothers. Regardless of the professional's intention in giving her advice, what Heather heard when "told to go on many parenting courses" was "I'm rubbish at my job as a parent".

Given the shortfall in the public system, mothers invested in private therapy at their own expense. Over half of the 20 children described in this study were diagnosed by a private practitioner. Following diagnosis, mothers who had fewer complaints about the health services had typically used private funds on an ongoing basis to pay for therapies. The ***financial cost of having a disability was borne by families*** – Olivia explained they "Maxed out the credit card", while Kate explained that it was a struggle to balance paid employment (to do *for* Rufus) with having time to spend *with* Rufus, "If you don't work then how do you pay for these things? How do you go, okay let's go to play therapy and drop €50 or let's go to OT and drop €100 or let's go to speech and language...". Claire stated that, as a parent you feel part of the problem if you can't afford

interventions, which was a heavy burden to carry. Rather than rely on public services, mothers redirected their efforts towards self-sufficiency. Claire stated,

> Since they told us they could never tell us when they could give us an appointment, that was exactly the wording they used, I just made an assumption and planned, okay we need to make sure that we can cover everything of our child's needs ourselves.

The lack of publicly funded supports discriminated against those with insufficient funds. In relation to education, the possibility of providing appropriate schooling through private funds was unlikely, rendering families fully state dependent. Two groups of mothers noted how the education system was wholly inadequate to support their children. Niamh and Eloise referred to the dearth of special classes in their affluent suburb causing their children to be potentially bussed out of area for senior school. In this regard, the system discriminated against Lucy and Aidan by virtue of their affluence. The second group – Maeve, Sadhbh, and Helen – considered the education system ill-equipped to support and enable their children (diagnosed in their teens with level one (mild) autism) to reach their potential. The education system was ***neither fully resourced in all areas nor equipped with appropriate additional support*** to facilitate full participation of its vulnerable children.

When they did receive services, some mothers commented on ***feeling beholden*** instead of experiencing a sense of entitlement. Although only receiving a partial therapy service, Tess was still grateful when she compared herself to other families on long waiting lists for assessments of need. As Eloise stated,

> When you're feeling that vulnerable and you're at the behest of others, you're at the behest of schools for taking your child…buying presents every two minutes, saying 'oh thank you, thank you, thank you'. Instead of going, 'thank you for doing what you should be doing', which is quite a difficult thing to say to people and then you're feeling quite disempowered.

Mothers were reluctantly propelled into mothering activities that they felt ill-equipped to perform. Their *doing* for their child was not what they wanted for their maternal role and was adversely impacted by inadequate supports and services. Such experiences of occupational injustice were compounded by the impact of the structural environment on mothers' feelings of guilt and failure. Structures that did not support the child's engagement in occupations of

childhood, did not, in turn, support mothering, demonstrating the relational dimension of occupational justice.

5.4.3 Marginalising experiences of mothers

While most considered the diagnosis had utility in communicating needs, not all embraced it as such. Niamh felt disloyal sharing this information on behalf of Aidan, saying "I never knew exactly how it [autism] was going to develop in him and to what extent…I felt like it was betraying him as well and that it wasn't my information to tell". The diagnosis brought the ***potential for labelling and stigmatisation.*** In disclosing the diagnosis there was a fear of "acceptance or rejection" Niamh claimed. Both Niamh and Claire recognised that the benefits of sharing information must outweigh potential harm, and it was difficult for these mothers to predict how their community might receive autism.

Mothers reported a ***lack of understanding and acceptance*** and experiences of rejection and marginalisation. Heather's friends have said, "Oh but sure he'll grow out of it", which to her demonstrated little understanding and was of no help. Jane explained, "Unless you're living it you never really fully understand it, but people could try more to be educated about extra needs for kids". Feeling isolated and different was a sentiment shared by many mothers. Imogen explained,

> Say I'm in a group of people, and we're talking about our children, we don't have the same complaint, we don't have the same challenges. I just keep my mouth shut, there's no point complaining because people will just distance themselves and not care. Not that they don't care but they just can't relate.

Conversely Heather took a different approach, despite also feeling isolated at times. She said, "Every conversation I tell them about Seán but not that I'm looking for any sympathy or anything, I say it because I'm always trying to educate people". On the one hand, by not sharing Imogen isolated herself further, while on the other hand, sharing stories that resonated little with others may have reinforced feelings of difference and aloneness for Heather.

The concept of living a smaller life resonated with several mothers as function of their child's challenges and mothers' inclination to disconnect with those who may not understand their circumstances. Nessa described,

> Our lives changed a lot and became a lot smaller…and maybe you know that was kind of survival rather than putting my child first…I just wasn't able to do or didn't want to do

other things as well. Conserving that energy and that time and that headspace as I say for just getting through the day and being the best parent.

Maeve also ***deliberately distanced*** herself from friends whose lives were "perfect" and "going swimmingly", finding such socialisation a painful reminder of the social milestones her children were not meeting. Heather stated, "The last thing you want to do is go out with a friend unless it is somebody who really understands your situation and a lot of people don't". Imogen noted how "people fall off your radar" the more their mothering paths deviate.

The reduction in mothers' physical and social reach beyond their immediate family was also imposed on them by society. Mothers experienced a ***level of othering***. Eloise explained how sometimes unknowingly people's conversation was exclusionary and marked her and her child as different. Imogen commented that, "Once you've had children with additional needs, people don't want to hear about it". On socialising with others, Imogen said, "I'd have to be worried about his behaviour, or I'd have to leave early, the meltdowns and that type of thing. People stop inviting you when that kind of behaviour happens quite a bit". Maeve noted that when Ruby got sick, "nobody called". Imogen cited the impossibility of hiring a babysitter because the babysitter couldn't cope with Ethan nor Ethan with the babysitter, and several mothers reported that appropriate childcare was difficult to find. With few, to no, offers of help, according to Imogen the "support network gets very, very small" and some mothers (for example, Heather) withdrew because other mothers asked them to keep their child away. Claire commented on how parents can be unthinkingly cruel – publicly inviting most, but not all, children to a birthday party. She stated, "If you are going to invite people and not invite others that's fine but don't come in and start putting your invites over some children's hangers and not others". Helen, hurt by Isaac's exclusion, described parties and playdates as "toxic crap". Kate explained that mothers of children with autism valued invitations. Even if their children would never attend, the gesture was appreciated.

Most mothers found the social experiences of society in relation to their autistic child to be marginalising. By being excluded from contributing to the social fabric of mothering life, they were able to build fewer connections, have less voice in social situations related to mothering, and engage in fewer mothering occupations in relationship with other mothers. This was occupational injustice.

5.4.4 Perception and expectation of mothers and women

Participants valued motherhood, understood its importance to society, described by Jane as "the loadstone", "its foundations". However, overwhelmingly they considered there to be a meso- to macro level ***devaluation of the mothering role***, describing it as invisible in societal consciousness until something within the family went wrong. According to Sadhbh mothering was considered to be "a little bit of an extra thing you do on the side of your job". Tamsin considered motherhood to give an additional, but superficial, status to women yet the important work of mothers in preparing the next generation went unrecognised, unappreciated and uncredited. The relationships between mothers' work and their children's behaviour and performance exposed their mothering to societal comment and criticism. This, in turn, reflected these mothers' worth as mothers. For instance, following Ruby's diagnosis and withdrawal from school, Maeve's friend commented, "There isn't a thing wrong with her, she just needs a kick up the backside and you just need to be firm". Niamh commented, "It's funny but you don't get the credit when things are going well". Mothers were aware that society held an image and expectation of what mothers should do and be, and deviations from this had the potential to make mothers feel "devalued" (Kate).

These mothers felt they needed to push themselves to perform outside their comfort zone to become mothers they had not envisioned being. In this way, their form of mothering resisted normative expectations of the role (which these mothers may themselves have held before becoming mothers of autistic children). The requirement to perform beyond typical role norms was related to the need for mothers to act as conduit between their child and the world and to compensate for inadequate supports – to advocate strongly for services, to support their child's social interactions, to explain their child's behaviours and respond to incidents. The additional mothering activities and alternative mothering demands moved these ***mothers' occupational possibilities*** further from that considered the ideal for mothers in their sociocultural context, reducing their potential for career, leisure time, and social life in comparison to other mothers and their children's fathers. These experiences speak directly to the concept of occupational imbalance and injustice.

Although mothers lived in various circumstances, with and without partners who variously shared the workload and responsibilities of childcare, and each held different wants and needs in terms of relationships and lifestyles, many commented on society's ***unequal expectation of mothers in comparison to fathers***. Their labour was gendered. Mothers were assumed to be the child's

primary carer; expected to “step in” (Imogen). Care work was considered by society to be mothers’ work. Eloise, having taken a career break following her son’s diagnosis, commented that neither society nor her husband expected a father to take leave from his job. Regarding mothers, she said society believes “you’re meant to be a carer”. While this assumption may have stemmed from traditional gender role expectations (Negraia et al., 2018), it potentially informed, not only society’s opinion, but also shaped mothers’ self-beliefs around their own mothering roles and expectations.

Applying a feminist lens, it was apparent that gender differences were evident in the form and time parents spent caring for their family and home and had the potential to cause resentment, which was directed at the system, and/or their circumstances, and/or their spouse. Resentment was observed to arise in instances where: 1. Mothers employment situations were not how they had imagined. This was relevant both for mothers who left their valued careers (Imogen and Eloise), and, for those who, due to the requirement for additional income, were unable to reduce their hours (Tess and Claire); 2. Mothers felt the burden of responsibility to meet the child’s developmental needs and respond to their challenges but received little support/appreciation from their child’s partner. This was evident in the cases of Jane, Sadie, Tess, and occasionally, Paula, Kate, Sadhbh and Niamh. As Kate stated, “If I tried to pass something to him [husband] he’d say, ‘No you do it better’. I don’t want to do it better all the time, maybe I want a fucking break [laughing]”.

Mothers were aware of the ***reliance of society, fathers and children on mothers to cope***, and felt the subsequent pressure to take responsibility and know how to manage situations related to their children. Helen reported, “Like a few minutes ago, you didn't hear this, but my 19-year-old came to the door and said, 'there is no food in this house.' But my husband is downstairs”. Some, not all, fathers continued to *do* according to how they always did – they worked their usual hours, they engaged in their usual hobbies, they addressed their own needs. Fathers did not always take responsibility for their home or child’s daily life. This may have been a function of gendered parenting – the occupational expectations of mothers and fathers – and the fact that mothers accepted the role of primary carer fulfilling the requirement to respond and relieving the father of this obligation. In other words, mothers’ role adoption perpetuated this expectation. Nevertheless, the expectation that these mothers should *do* for others, given that the reality of their situation included a dependent child with additional needs, was an unfair burden and one that created the conditions for occupational injustice.

5.5 THEME 4: Mothers' acceptance and growth

The fourth and final theme represented the positive and constructive learnings in mothers' data. It centred on mothers' acceptance of autism in their lives, their consequent growth, and their requirements for support. Mothers recognised their child's strengths. Heather's understanding of mothers as being "underneath them and around, being there", imparts an impression of protection and availability reflected the tone of acceptance in this theme. Mothers accepted their form of non-normative mothering and developed both as mothers and women as a function of their performance in this role. This demonstrated the potential for occupational identity growth and *becoming* through mothering as a meaningful occupation. The theme also describes the forms of supportive and nurturing environments mothers experienced or desired which in turn laid foundations for mothers to experience occupational justice.

5.5.1 Acceptance of autism

To mother their autistic child, changes of behaviour were required – personal sacrifices and modified ways of mothering – but also a change in attitude and perception, expectation, and aspiration. This then helped mothers ***reach a level of acceptance with their form of mothering***. Kate said,

> I'm like will I ever be alright with all of this? And the honest answer is no I won't be because this is not how I had planned everything. I mightn't be alright with it, but I can accept it…I just sort of embody it and I don't resist it anymore because it causes you pain when you resist.

Eloise described herself as, "the mother I'm supposed to be because this is the way it is". Imogen said, "everything I once had, I don't have but it's not necessarily a bad thing".

Mothers were conflicted in their desire to communicate their child's particular needs while protecting their child's reputation. They found the constant requirement to represent their child through a deficit lens upsetting. Heather said, "You hide their, what is the word, deficiencies, that's a horrible word to say, you hide that from the world". Kate wanted, "People to see him for what he can do as well". While they identified many ways of doing and being that their children found challenging, mothers were also aware of their ***child's strengths*** – some children were particularly talented academically, or very funny, or displayed attributes such as loyalty and perseverance. Paula noted how Conor was "in his element once he's outside in nature, looking around, observing things. He's got a real visual brain". Myra explained that "Noah is a complete natural, he started very, very young playing music. Whatever he puts his hand to he just learns". Nessa believed, "Other kids kind of are attracted to him as such because he has that gentle, non-challenging, he is very gentle". Tess said, "I am always very grateful for the fact that behaviourally he is very easy to manage…he's so good". Olivia marvelled at the Leon's neurodiversity,

> He's an awesome child, but it's like he's been born with overcompensations for the weaknesses that he has. He wants me to read books on how aeroplanes are made, technical books that are mind-blowingly boring, and he can narrate the damn thing after you. But he can't read Jack and Jill went up the hill.

Mothers expressed huge value and regard for their children and were proud of their progress and achievements. Seemingly small achievements were particularly meaningful for these families. Walking into therapy without having a meltdown was a huge achievement for Lucy and consequently for Eloise. Nessa commented that her children, "have those additional challenges and yet they're brilliant". Claire enjoyed Max's cutting humour, saying, "He has no filter at all which we kind of like, actually, which we really like. [laugh] He'll tell you how it is". Sadhbh said, "Mine aren't typical children which is all okay really", while Nessa added, "I just think God what a lovely boy he is".

Despite the challenges, mothers ***enjoyed having children and being mothers***. Sadhbh described her children as "her people"; Tamsin said, "It's nice to be around people who aren't judgemental"; Nessa remarked that, "You come through the fog and just enjoy them for who they are and the craic you have and the love they give you"; Niamh described motherhood as, "a wonderful privileged thing to do, irrespective and I guess having a child with autism just makes it different, but none the less rewarding". Tess advised mothers to, "look at them and admire them and enjoy them". Sadhbh claimed, "I didn't get what was nice about them until we had one…my favourite person in the world gets to live with me for their whole lives". While mothers may have wanted aspects of their lives to be easier, and some of their child's behaviour to be more manageable and in line with norms, they liked their children for who and what they were.

Participants identified the type of mother they perceived themselves to be (listed in Table 5.5). Despite, or perhaps because of, the challenges to their mothering, many described themselves in positive terms.

Table 5.5

Self-perceived descriptors of participants as mothers

Imogen	Supportive, loving, kind
Maeve	Anxious, quiet, inconsistent & disorganised – improving but a lot of work yet to do.
Paula	Thoughtful, patient, honest
Tamsin	Engaged, loving, fun – a better mother than she thought she'd be.
Myra	Funny, strong, caring
Nessa	*Unanswered*
Sadie	Cuddly, loving, emotional
Heather	Loving, determined, hopeful
Tess	Nurturing, loving, strong
Jane	Loving, helpful, striving
Eloise	Loving, impatient, perseveres
Sadhbh	Busy, fair, accepting
Olivia	Serious, strict, conscientious (good food & education). In relation to her first child, she felt she did a good job.

Niamh	Caring, calm, supportive
Claire	Loving, strong, dependable
Kate	Loving, supportive, determined
Helen	Warm, open, affectionate

5.5.2 Becoming through mothering: Changed perspectives and roles

There were aspects of mothering that contributed greatly to mothers' contentment. Niamh synopsised her experience of being a mother, "that sense of just I guess pride and combination of love, it is just a lovely feeling of happiness and warmth that I would struggle to replicate in any other respect". Through mothering the participants found ***contentment, meaning, and purpose.*** Olivia explained, "Because I'd always had a very untenable relationship with being alive, it [motherhood] actually grounded me and made me feel like I do have an existence that's worthwhile". Helen "felt complete" on becoming a mother and Niamh found mothering "really fulfilling in a positive way no matter how hard it was…I see myself in more positive terms than I used to". As well as growing in confidence and self-assurance, Sadie felt "truer" to her nature having become a mother – "It feels like me; it just feels like it's what I was always meant to do". Mothers who had some mental health issues prior to becoming mothers (Olivia, Niamh, Maeve, Tamsin, and Helen) or had other disabilities such as ADHD (Jane), noted there were occasions when these issues were exacerbated by motherhood. However, overall, for these mothers, motherhood had a curative effect where mothers' focus on their children reorientated their perspective. Becoming a mother to an autistic child with ADHD, helped Jane to recognise "how much stronger I am than I thought I was…it's shown me who I am I suppose, who I wanted to be and who I have become".

Meeting normative expectations for family life was not easy. Mothering children with additional needs changed the how, what, and where of family life. Referring to family activities, Sadie commented, "People go 'oh look at this lovely rainbow we all painted together'. I'm like seriously one of us would have been put through the window if we tried to do that". Their ***mothering focus and norms for doing were different*** to other families without an autistic child. Initially Maeve found herself comparing her family with those of other mothers in her friendship group. However, following her children's diagnoses, her focus shifted to learning how to best mother her children which she felt was at odds with other mothers' concerns. Heather noted how, "It's annoying you know when society is telling you 'You should be doing all these things to be a good parent' and ours is a completely different path". This felt difference demonstrated how the occupational possibilities for mothering (that which is considered ideal by normative standards) were at odds

with that which was available to these mothers and families. Having a child with additional needs gave mothers' new perspective and alternative priorities. As Niamh said,

> I'm not going to fret about all the other peripheral stuff that people get their knickers in a twist about…That you kind of go, really if that's all you have to be worrying about, you should just take a deep breath and move on.

Helen's attitude was "this kid is great and if you're not going to accept him, I don't care, it's not important to me".

Personal growth in confidence, strength and assertion following efforts to advocate for their child were noted by Heather, Sadie, Claire, Jane and Kate. Heather claimed that "You think when you become a mother it's going to be beautiful and wonderful but when they don't work out that way it can have a very positive effect…I'm not a pushover anymore. I learned the hard way". Kate had begun to question her deference to healthcare professionals-as-experts on her son and recognised, in relation to his needs, her knowledge and understanding of Rufus was a form of capital, claiming "In the last year I've really taken that power back on board to be able to say I can do this as good as anybody else". Recognising their own strength, several mothers reconstructed their occupational identities and adopted new subject positions as capable mothers relative to service-led discourses on autism. As Claire's confidence as a mother to Alex grew, her sense of "embarrassment" reduced. She explained, "We were out in the park, and it was like, oh my God he's growling at that man, what are people going to think? Now I couldn't be bothered".

Mothering outside the neurotypical domain provided the basis for learning and personal development. Engagement in this form of mothering (non-normative mothering) afforded mothers an opportunity to explore and practice skills, experience success and accomplishment through doing, and in this way its capacity to serve as a mechanism for mothers' development was evident. Myra and Heather spoke about their roles as go-to resources recommended by parents and teachers for advice and information on autism. Such purpose provided status and opportunity for personal development. Given her knowledge of autism, the principal in Seán's school asked Heather to project manage the creation of a sensory space within the school – a task she found energising. The impact of advocating for Noah and advising others had a ***pervasive impact*** on Myra's self-confidence. Where once she shied from ordering a takeaway meal, she was now empowered to confront teachers on behalf of her son. Similarly, Paula developed resilience through mothering that transferred to managing tricky situations outside the home, stating, "Even at work I think to myself, come on look at what you deal with at home, and you generally cope

with it". Being a mother to an autistic child resulted in unplanned occupational engagement (for example, Imogen retrained into a new career) which opened up new opportunities for alternative engagement (as Imogen explained, "now again I am repurposing"). This in turn supported positive personal growth and, when experienced as meaningful, had power to enable becoming through engagement.

Mothers recognised how their experiences had altered the way they viewed others, particularly those with disabilities. Maeve identified changes in herself, stating she was a "different mother now to before"; she had become "less judgemental, and a bit more open, a bit softer". Likewise, Claire felt she was more compassionate and understanding of disabilities having become a mother of an autistic child. Being a part of an alternative system of healthcare and on the fringes of mainstream education, expanded mothers' understanding and perspective, as Helen explained, **"**You learn stuff about yourself, and you are learning stuff about your child, and you are learning stuff about the system and society, and it can be fascinating, and it can be overwhelming, and it can be exhausting". According to Kate, autistic children "Teach us so much patience, so much empathy. It's hard, of course it is, but they ***make you a better person***".

5.5.3 Supportive environments and services

Several mothers (including some who also reported unequal care burden and expectation) felt their mothering efforts were valued by their partners. Helen noted how she appreciated her husband saying that her son was lucky to have her champion his case, and even more so because he had been one of the people who had dismissed her concerns about Isaac. Similarly, Tamsin's husband said that motherhood had been the "making of her". Eloise's husband bought her flowers weekly as a sign of his gratitude for her commitment to Lucy. Mothers needed ***appreciation and reassurance*** that they were doing things right. Although this often came from the child's father, they also drew encouragement from positive interactions with those outside the nuclear family. Heather relayed, "Somebody said a lovely thing to me yesterday, that 'he has a lovely nature', and it meant so much to me", demonstrating the supportive impact of small societal-level gestures. The additional effort and accommodation required to function in daily life was made easier when the parents pulled together on a united front. Claire claimed, "It's really important that this team at home works well for everybody because it's hard, it's hard". Olivia referring to her husband stated, "What makes it happen is Joseph [father] for sure. If it wasn't right with Joseph everything else would fall over". Heather commented,

> At the end of the day, I do it because I love my children and my husband and I would do anything for them, they're my family, they're number one for me… I know I'm number one in their lives.

Home for some was a refuge. Tess and Sadhbh, who did not find their children's behaviour challenging, described their contentment within this environment. "If I'm in my own little bubble [home] I'm happy out" (Tess). **"**Everybody is fine at home, like Alex can eat in his room…we can accommodate him, and adjust to what everybody needs, and we do but the world doesn't do any of that" (Sadhbh). Additionally, occupation within the home environment had the ***power to hold the family together*** as well as divide or impose upon it. When children developed a new skill or capacity it had the potential to open up a new avenue of opportunities for the whole family. In this way, successes in *doing* laid the foundations for improved functioning within the home which led to opportunities for togetherness, depending on the family. Tess described a family holiday in her boss's holiday house that had,

> A shed full of bikes, and Sam was the only one who couldn't cycle. So, we got a trailer for Sam, which was grand, but I just thought wouldn't it be so wonderful if we could all cycle together. And then over lockdown, and since the cycling courses, he took off and I was like, oh my God this summer is going to be amazing.

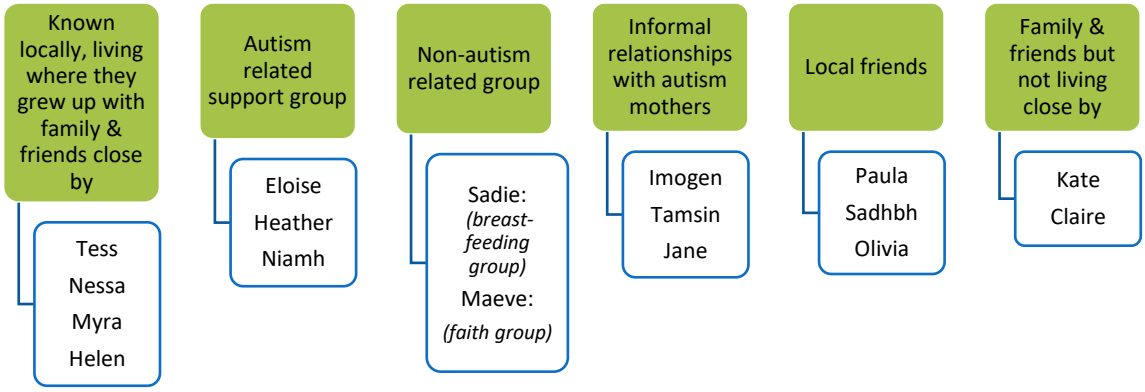
Most mothers gave examples of instances when, external to the immediate family, ***supports were useful and appropriate*** to their situation. Such support came from extended family and friends but also from a healthcare provider or educator. Good support varied from informational (for example, Tess's psychiatrist explained the potential usefulness of a diagnosis to access educational supports) and practical (for example, Olivia's public health nurse washed up her dishes on her visits) to emotional (for example, Eloise phoned friends in the parent support group whom she knew experienced similar challenges). Advice was sometimes sensitively delivered. Written rather than verbal information was given to Maeve, which she felt showed a sensitivity to the age difference between her and a young occupational therapist. This literature, she credited, helped her to better support Ruby's decision to leave school. Each of these forms of support enhanced mothering and were variably available depending on transactions between the child, services, personal support network, mother, and environment in which she lived.

All mothers were a part of some community and had a ***form of support outside their child's father*** some of which had grown because of their association with autism (see Figure 5.3). For several

mothers, in particular Claire and Olivia, their spouses were their main support and confidant; Sadhbh reported not to need additional support when not interfacing with structures outside the home. In addition to her spouse, Seán's school were a major source of support and affirmation for Heather who reassured her that she was "doing the right job, and they do say that a lot and that's lovely to hear".

Figure 5.3

Principal source of support (excluding child's father)



Mothers such as Eloise, Heather, Imogen, Jane, Myra, Kate, and Niamh each formed friendships with other mothers of autistic children creating their own community of mothers that, not only tolerated, but appreciated their children. Being mothers of an autistic child enabled these mothers to do mothering and relate to other mothers in a way that would be unavailable to them otherwise and in turn provided new possibilities for their form of mothering. Whereas hitherto their mothering was on the fringes of neurotypical parenting, from their position as autism mothers and mother advocates, these mothers entered or created a community of like-minded parents with similar vested interests and ***found a space in which to wholly belong as a mother***. Peer support, friendships and connections with other people whose children had similar needs were identified by Niamh and Eloise as reasons to participate in autism-related support groups. Heather wholly embraced her identity as an autism mother. On attending autism conferences, she stated, "I love going to them because I find my tribe, my mothers, I love them, and I hear the experts, I go to see them, I mean they are my heroes, I'm like a, they're like pop stars to me".

By offering acceptance and championing their case it was possible for a professional to compensate for service inadequacies, reinforcing the importance of ***services investing in relationship building***. Claire, Heather, and Eloise referred to the exceptional principals in their children's schools, who went out of their way to accommodate their children. Supportive environments were those in which mothers felt accepted, connected, and understood; built networks of likeminded individuals; services were inclusive and reassuring; communication was open; professionals listened and never dismissed; interactions were authentic and empathetic. Mothers appreciated working in partnership with services, and many commented on the reassurance they drew from being part of a relatable community of parents with autistic children or having other autistic children in the class.

Mothers described ***supportive conditions*** related to healthcare, education, and society in general, and which may also go towards promoting occupational justice. An ideal system of healthcare was one in which mothers' concerns were acknowledged and taken seriously; mothers were given direction and information; children entered services in a timely manner; services identified needs and provided expert professional intervention liaising with other contexts in which the child lived to create seamless and holistic family-centred support. In this scenario, the education system was supported by interdisciplinary professionals, had the understanding, attitude, and capacity to accommodate and support children to reach their potential and flourish. An ideal society would accept autistic behaviours and ways of being/doing as part of everyday life. Imogen expressed a desire to integrate autistic children's "behaviour and their attitude, their intellect in society…that would be amazing". She just was not sure when or how that might happen.

5.6 Conclusion

This chapter addressed the study's central research question through its analysis of 17 mothers' lived experiences of mothering autistic children attending mainstream school. The four themes that were identified spoke to the lived experiences of mothering while also acknowledging the relevance of study's foundational concepts and underpinning theory in these mothers' lives.

Mothers demonstrated heightened activity and emotional energy in striving to understand their child and services, in anticipating and accommodating their child's needs, in interacting with professionals, and in worrying for the future. They gained an understanding of their child's needs, recognising both their challenges and strengths, through their child's occupational engagement

within their varied environments and often in relation to others. Mothering adaptations pressed on mothers' time, values, and finances, however, many showed considered and resourceful mothering and developed ways of doing mothering that differed to mothers of neurotypical children. Mothers loved their children and aspired for their children's futures despite finding mothering often exhausting.

Mothers' active *doing* of mothering was reported alongside accounts of loss, worry, and sacrifice that impacted their experience of *being* a mother and created occupational identity discrepancy. In adapting mothering to meet the needs of the child, mothers often resisted normative expectations which, in turn, moved them further from the occupational possibilities of mothering non-autistic children. The demands on mothering were compounded by the adoption of the role of primary carer and their need to be available to respond to their child, exposing mothers to more challenging parenting situations. Irrespective of fathers' gestures of gratitude, in the main, the balance of care rested with the mother. Gender role expectations were responded to by most mothers with role adoption creating further role expectations.

Engagement in mothering occupations, which was often made more demanding by interactions with the outside world, had the power to undermine mothers' confidence, increasing their reliance on guidance from professional services and decreasing the opportunity for experiences of competency through occupational engagement. The co-dependence of mothers' performance on their child resulted in a poorer fit between these mothers and the demands of the environment and occupation. Although mothers developed their own mothering occupations that fit their situations and definition of mothering, many mothers were excluded from normative mothering and the routine activities of childhood. A lack of societal understanding or appropriate supports in many cases resulted in experiences of occupational marginalisation and the possibility of mothers experiencing occupational alienation.

Navigating the diagnostic assessment process was made easier if their child was already a healthcare service-user, professionals were supportive, and/or mothers reached out to a community of mothers/parents of autistic children. The challenges of assessment and grief of diagnosis experienced by some were not mitigated post diagnosis as few supports were available to meet children's needs. Mothering without adequate state support, such as the insufficient provision of professional services and adjustment of normative services (for example, schooling), was unfair on many levels. The financial burden of managing a disability was borne by parents and

the responsibility of interpreting and meeting their child's needs was consigned to mothers. The alternative forms of mothering required by autistic children, together with the possibility of children's enduring dependency, demanded responsive, nuanced, and readily accessible services to support both child and mother. These structural inadequacies contributed to the establishment of conditions for occupational injustice.

The gendered expectations, attitudes, and reliance of society regarding the role of mothers to care and accommodate, placed constraints and obligations on mothers' occupational engagement. This was exacerbated by many fathers' disinclination to share responsibility for care. Career, social, and leisure activities were seen to be compromised for almost all mothers. Smaller lives and loss of friendships reduced the nature and extent of their occupational engagement further. Mothers were over-engaged in care work leading to occupational imbalance and some were deprived of forms of diverse engagement that could enrich their lives. With more minimal time and opportunity for non-mothering occupational engagement, stemming from attitudes and structures, mothers experienced occupational injustice.

Conversely, particularly when mothers were proactive on behalf of their child, mothering occupations could also be empowering. As a function of the lifestyle changes made to support their child, some mothers created opportunities for alternative occupational engagement, such as career retraining and advocacy. The mother-advocate forged a new role and position in society with associated purposeful activities that brought the mother meaning, the opportunity to interact with others in similar circumstances and develop a sense of *belonging* through mothering. Despite many challenges, mothers also grew and developed both as mothers and women as a function of performing in their non-normative mothering role. In this way, occupational engagement had the capacity to support mothers reach towards alternative ways of *being* and *becoming*.

The following chapter provides a richer and deeper understanding of mothers' lived experiences by applying the framework of doing-being-belonging-becoming through occupation to the biographical narratives of four mothers. These mothers were selected as gold star cases and subjected to full BINM analysis.

Chapter Six

Findings: Learning from the BNIM gold star cases

The stories we tell about ourselves are never neutral but are shaped and structured to create an impression (Nicholls, 2024).

6.1 Introduction

In this chapter, mothering an autistic child, as a lived experience and occupational identity, is explored within the narratives of four gold star BNIM case studies. Where the previous chapter provided a broad overview of findings, this chapter focuses on the nuances within selected cases. It addresses both research questions by providing a richer understanding of the impact of sociohistorical contexts on the lived experience of mothering, and a deeper dive into mothers' efforts to retain/develop agency while interacting with society as mothers of autistic children, relating this, as relevant, to their experiences of occupational injustice. Taking a feminist lens to the interpretation of cases, connections between experiences of occupational injustice and issues such as gender power relations in families and social norm expectations, where evident, are emphasised. Although this chapter presents case accounts under themes particular to each gold star case, efforts are made to align these with Wilcock's synthesis of occupation as encompassing doing-being-belonging-becoming thereby highlighting the centrality of occupation in their lives. A summary of each case's BDA (biographical data analysis) and TFA (teller flow analysis), which formed the basis of the interpretation presented here, is presented in Appendix 16. These provide additional detail of the mothers' lives and narratives.

6.2 Imogen

Autism mothering was central to her position as a mother and strongly present in her narrative.

The centrality of autism mothering (Douglas, 2013) resulted in significant, conscious changes to Imogen's occupational engagement, in part due to the occupational injustices she experienced and lack of support. However, at the time of interview, Imogen was also at a point of revising her

everyday occupational engagement having acquired stability within the family domain and mastery in mothering.

The most fitting theme of self-presentation from Imogen's narrative was that of *responsible sister/daughter/mother* who accepted the role of carer and the task of supporting her families to function. The biographical data analysis of her objective lived-life described a linear pathway in which Imogen met the typical social and educational milestones expected of her class, culture, gender and nationality but encountered atypical events enroute. The diagnosis of her son, Ethan, marked a deviation from her career pathway for several years, but the disruption was potentially temporary. Imogen's told-story narrated her experiences of the events around Ethan's diagnosis, its impact on the trajectory of her adult life; her experiences of society, services and lack of support; and her commitment to care, endure and survive. A summary of Imogen's biographical data analysis (BDA) and teller flow analysis (TFA) are provided in Appendix 16.

6.2.1 Evolution of being – The capable carer

Born abroad, Imogen's position as a carer developed early, with roots in her "challenging childhood". She considered herself "forced into" the caring role to protect her sister from her father's challenging behaviour and alcoholism, and credited her experience as family "mediator" for preparing her later to meet her son's needs. Although Imogen considered herself "raised to care", the form of care she provided as an adult to her second family differed in terms of responsibility and sacrifice.

Motherhood emerged as all-consuming, although this was not Imogen's initial expectation of the role. Imogen was ambitious in her career and the higher earner in the family. As the extent of Ethan's needs became more apparent, Imogen altered the pattern and number of hours of paid employment, until eventually leaving her job entirely. To fulfil her role as carer she "needed to change everything", including her career. She reverted to the role of fulltime carer within four years of Ethan's diagnosis (at age four). Although she commented that this was "not [what] I wanted for my life", her response to her families' needs demonstrated a dedication to caring and to caring well which may reflect an assimilation of the pervasive societal expectation that a woman should care (Chiaraluce, 2018; Miller, 2005). Additionally, Imogen's self-perception as loyal and capable may have increased her sense of obligation and further contributed to her adoption of the fulltime carer role as an autism mother.

Imogen perceived herself as the best person to address Ethan's needs. She, above everyone else, had "the comfort and connection with him" and could "better manage" his challenging behaviour. Her account of attending every possible autism-related course was testament to her effort to become informed and maintain this connection. In shifting her focus from her career, she committed similar drive and determination to upskilling as an autism mother. Imogen did not present herself as self-sacrificing rather she understood how she must make changes in the interest of her son. She made herself always available and present to negotiate on behalf of Ethan and wholly adapted their family mores and activities to support his needs and enhance his development.

6.2.2 Structural environment impacts on capacity to do mothering

Through highlighting the challenges Ethan was experiencing, his preschool teachers marked the beginning of a transition from mothering to autism mothering for Imogen. "Sick" with worry for Ethan, Imogen turned to other autism mothers for advice and quickly took steps to have him assessed for autism. The administration of the incorrect version of the assessment measure by the diagnostician in the public system resulted in the need for reassessment. The consequent lost time in entering the system and failure to meet the special needs assistant (SNA) application deadline was described by Imogen as putting "the nail in the coffin". Frustration, and pressure to fix the situation, contributed to an anxiety attack,

> I was driving so I had to pull over. I had the kids in the car, just had literally almost, like lay down, I sat on the pavement and nearly had to lay down on the grass just to kind of calm myself.

Imogen's episode on the roadside was the culmination of experiences with, 1. Her experience of the system of support as incompetent and while also, 2. Experiencing grief and anxiety towards this new perspective on her child given his confirmed diagnosis. All this was within the context of personal issues including little family support, a parttime career, her mother's very recent death and her floundering father whom she felt needed her immediate help. She commented, "You just get so overwhelmed with everything you're dealing with. You're fighting all the time and nobody's helping you". While at this point, her reality was focused on, "Fucking, he needs help, somebody help him", she emerged from this period understanding the limitations of the system, having drawn on all resources (trusting her own "gut"; reaching out to her social network of friends, the school principal, and her employer; privately funding Ethan's required therapies) and dedicating herself to the job of caring for her son.

6.2.3 Developing an autism mothering identity through doing, being, becoming

In becoming a mother, Imogen developed a new dominant identity, “You are who you are in the background, but you are a mother first”, that changed her perspective and consequent occupational engagement. Her “Children come first, before myself, before my husband, before anything”. Becoming a mother of an autistic child intensified the adaptation required to Imogen’s occupational engagement, sense of self, and world perspectives. To accommodate Ethan’s needs Imogen made the effortful change to become routine-driven and supress her more characteristically spontaneous “rocker” self (for example, she had married following a three-month relationship and emigrated shortly after this). She slowly withdrew from her career and instead minded other children after school to provide socialisation opportunities for Ethan. Unable to find a sitter, she rarely socialised. Much of her everyday expression of who she was as a woman was replaced with engagement in alternative activities and occupations related to caring for her son and family.

Imogen considered herself to be a responsive mother, driven to parent differently to her own parents. While, on the one hand, she wanted to shield her children from experiencing anything like the challenging circumstances of her own childhood, on the other hand, there were aspects of her childhood that she wanted to recreate. She said,

> You have ideas, you know, you think of your own childhood and your friends and playing, and stuff and you think that's what your children are going to be like. And that's what you want for your children, but it doesn't always happen that way.

This speaks to the grief felt at the loss of her imagined family but also to an acceptance of her current situation.

Changes in Imogen’s perspective of certain events were shaped by the life being lived and mothering an autistic child. For instance, the meaning of Imogen’s effort to do “everything right” during pregnancy changed following Ethan’s diagnosis to “It didn't make a difference because he's still going to have the genetics challenge”. Likewise, Imogen’s hurt at Ethan’s exclusion from playdates and sadness at witnessing his isolation at children’s parties was reduced with the realisation that Ethan was content and did not seek friends. Changing her expectations, having space between events with time to reflect on the meaning of his diagnosis, and becoming accustomed to her son’s ways, contributed to her changed perspectives over time.

Interactions with services acted as constant reminders “that your child has extra needs. It's like sometimes you just want to just have a day without being reminded”. The permanency of autism overwhelmed Imogen and she feared for the unknown of Ethan’s future. Additionally, the relentlessness of meeting his needs on a daily basis was exhausting and was exacerbated by taking on the position of responsibility for managing these. While she considered her maternal instinct to be superior to “father-care”, she expressed annoyance at her husband’s attitude that she would “always take care of everything”. Imogen knew herself capable, took on this role and did it well, but desired more sharing of the load and accountability. Gender role injustice, as well as an absorption of the societal expectations that mothers can and will care, was evident in the family leading to experiences of occupational injustice (such as over-work, imbalance, and possible occupational alienation).

Being an autism mother silenced and isolated Imogen in everyday interactions with mothers of children who did not have autism, while it gave her voice when she found appropriate occasions, such as speaking at school events to increase societal understanding of autism. As a consequence of varied experiences with teachers, Imogen adopted the role of mediator, much like she did in her first family, and acted as broker between Ethan and others. When working as a team, Imogen and school were in a co-dependent relationship. Instead of simply being a keen and interested mother she actively guided and prepared Ethan’s teachers to best work with him. Imogen described how Ethan’s school-related anxiety resulted in incidences of high stress for Imogen – once he tried to kill himself by jumping in front of the school bus, and at another time, he “actually started to wee on the wall in the bathroom”. Because her own wellbeing was dependent on society’s fragile relationship with Ethan, Imogen’s mothering identity was broader and more complex than that of normative mothering. Yet coping with adverse circumstances through making changes to her daily routines and occupations, proactively advocating and forward planning, Imogen’s occupational identity as a capable autism mother was reinforced.

6.2.4 Not only a carer

Imogen described herself as driven and understood herself as capable. She noted how she was valued by her employer “He really tried everything because he didn't want to lose me”. Leaving her job was not an easy decision. As well as feeling loyal to her employer, her career reinforced her sense of competence and occupational identity. In relation to her paid worker role she stated, “You feel like you're an adult human being aside from the fact that you're a mother”. Although leaving her job appeased her “mother-guilt” and enabled Imogen to be available fulltime for

Ethan, she also complained about the societal expectation that connected mothers with caring activities. Imogen's perception of the decision to leave work was complex and evidently influenced by society and her upbringing not just her family's needs. Hegemonic and gendered attitudes contributed to Imogen's experiences of occupational injustice. However, despite resenting her stay-at-home caring role, she did not contest it. By, instead, operating within its confines she demonstrated how challenging it is for these mothers to move beyond normative gendered roles, particularly when a child needs additional care.

Imogen recognised that her life was now offering some opportunity for her to reclaim aspects of her former self and that this was related to the increased manageability of her son's behaviour and his improved engagement with school. This may be considered a new phase in the history of her life. Possibilities for autonomy and a level of independence from the family were beginning to emerge as Imogen retrained and developed alternative career opportunities that fit with family life; aspired to re-engage with previous hobbies and to relocate the family to the countryside. Her present perspective saw the possibility of aligning aspects of her former being and future doing, while also allowing her to remain faithful to re-imagined ways of living that supported her family.

6.2.5 Conclusion to Imogen's case account

Imogen's perception of the problem was that she has been required to care for others all her life, first to protect her sister from her father's difficult behaviour and, then to support her son. Underlying this perception was the belief that caring for Ethan was made more difficult by the lack of formal and informal support for both her and him as well as poor understanding of and empathy towards autism by people generally. Presenting herself as a *carer-coper, fighter-fixer* was a consequence of what she believed was expected of her as a mother and family member and her self-understanding as one who is capable.

A central issue within this case was that Imogen accepted responsibility for caring and managing family problems. In addition, she had a vision of what motherhood should be and what mothers should do. Imogen's response to the problem (responsibility taking and upskilling, acting as buffer), resulted in a high interrelationship and interdependence between her wellbeing and Ethan's interactions with the world. She made sacrifices by hugely altering her daily routines and practices, her occupational engagement, and her perception of self as an individual and occupational being. Her effort to care and cope with situations gave rise to more ease and predictability in Ethan's engagement with school and society and her motivation to change her

career resulted in more promise for her own productive occupational engagement in the future. Despite her experience of occupational injustice – operating on the periphery of normative motherhood and receiving little by way of publicly funded therapeutic support – Imogen made things work across time due to her concerted efforts on behalf of Ethan, while simultaneously acting towards changing her own potential for autonomous occupational engagement.

6.3 Maeve

Mothering an autistic child became central to her narrative across time.

Both Maeve's children – daughter Ruby and son Joseph – had diagnoses of autism and ADHD. Regardless of this similarity, Maeve had very different relationships with both children. The complexity of the role of mother was reflected in Maeve's varied adjustment to mothering either child. The influence of personal and contextual factors, as well as the importance of engagement in selfcare occupations, were evident in how they shaped Maeve's doing of motherhood. This section explores Maeve's account of her mothering, the circumstances of her mothering, her supporting occupational engagement and the relevance of occupational justice in her life. A summary of Maeve's biographical data analysis (BDA) and teller flow analysis (TFA) are provided in Appendix 16.

6.3.1 Flourishing in doing; floundering in being – Mothering as activity and role

A surface level examination of Maeve's lived-life as a mother, up to the point of her daughter's hospitalisation (aged 15), described engagement in mothering practices typical of her class and culture. Maeve's friends considered her most competent in mothering. However, Maeve recalled struggling on becoming a mother and having great difficulty meeting Ruby's needs. She described scenes of handing the baby to her husband and running to the bathroom, crying and "vomiting down the toilet". Maeve admitted to not openly articulating, either to others or herself, the full extent of her feelings at the time but continued to be challenged by the experience of mothering as Ruby grew. She recalled,

> Sometimes it felt like breaking in a horse, her will was so strong…And I was quite shattered, my confidence was quite shattered, and I found it very difficult to bond with

> her I suppose, and I couldn't seem to do anything right…it never really developed as such, a bond, there was always a little bit of distance between us.

Several factors contributed to Maeve's struggle to mother Ruby, which were compounded by the fact that she found her difficult to settle as a baby, difficult to manage as a young child and difficult to bond with generally. Before becoming pregnant Maeve was "having a great old time" and described the pregnancy as "a bit of a shock". Growing up with an alcoholic father (similar to Imogen), she reported living in some poverty and having little by way of a childhood. The eldest of seven siblings, she was given much responsibility at an early age, often being required to stay home from school to housekeep and care for family. Pregnancy and motherhood signalled potential loss of freedom and independence and a return to the obligations of family and home. With the benefit of hindsight, Maeve described her reaction to her unplanned pregnancy, "I didn't want to be pregnant, but I was 34 years old, and I needed to grow up. I needed to grow up and get less selfish and get a bit of responsibility".

Maeve's childhood and professional background provided her with considerable experience tending to the practical needs of infants. High expectations of her abilities and incredulity at her struggle, possibly contributed to her resistance, conscious or otherwise, to acknowledge that she was finding, what she thought should be effortless, difficult. Yet by not fully voicing her struggles and seemingly coping, she presented an outer self that was managing/*doing* motherhood well which was at odds with her *being*.

An additional factor contributing to Maeve's difficulties mothering Ruby as she grew was related to her lack of spousal support, practical as well as emotional. Discordant aspects of Maeve and David's parenting exacerbated Maeve's struggle for competence (and occupational identity) in her role. Maeve explained that Ruby "would've gone to him a lot of the time and he would've overruled the decisions I'd made", and "I did row back and I doubted myself…David would've said to me a few times in front of Ruby then, he'd give me a look as if to say you have crossed a line, you've been too harsh". The gender power relations of David's position-taking in battles between Maeve and Ruby may have created a *them versus me* undertone to her mothering practices and ultimately done nothing to strengthen the brittle bond between mother and daughter.

In contrast, Joseph's birth, when Ruby was seven, marked a change in Maeve's self-perception as a mother. Where Ruby had undermined her confidence as a mother, her son reaffirmed her humanity and normalcy and aligned her with societal expectations of mothers.

> I just fell in love with him straight away and it was just lovely to have that rush of love that I didn't have for Ruby because I always felt that I was a cold person. As a result, I felt there was something abnormal about me but to be able to feel that for another human being was amazing really.

Personal and contextual factors, such as an increase in David's availability to support childcare, temperament differences between the babies, and enhanced mothering confidence through having past experience with a first child, contributed to the varying relationships Maeve formed with either child. She commented that, as an infant, "I seemed to be able to give him what he needed", and, on maternity leave, spending "the whole time laughing, just laughing. It was just a lovely time".

6.3.2 Crisis igniting change in doing and being

As she entered her teens, Ruby "fought everyone and everything" and had, what Maeve called, "a lot of power in the house". She recalled, "She kind of took over the sitting room in our house". Despite the ongoing challenges of mothering Ruby, Maeve sought personal lifestyle balance – using the gym and socialising with friends. As an occupational being, she engaged in activities in a well-worn, expected and practiced fashion. When Ruby was hospitalised with a mental health condition, Maeve was encouraged to visit daily which she found both traumatic and humiliating. "Many a night I would go to visit her on my way to work and she would be really abusive…I would have to go to work, and I would just be holding in the tears going in the door". Prior to hospitalisation Ruby had become "Completely out of control. She'd fire food at us, she'd fire glasses at us, she destroyed the house, she put holes in the wall because she wasn't getting what she wanted". At this point Maeve reconnected with her faith group which became her principal selfcare activity.

Both parents were unified in their management of Ruby's illness. Its life-threatening nature took precedence over subordinate matters such as Joseph's school behaviour which was also causing concern at that time. In the early months of Ruby's life, Maeve had floundered when mothering alone but was unable to recognise her own need for mental health support. However, when her child's needs, rather than her own, reached a point where she felt ill-equipped to manage, she immediately pursued and applied the advice of Ruby's healthcare professionals, demonstrating a

concern for her child, beyond which she had extended to herself. Maeve's continued dedication to Ruby, despite her abusive response showed concern, focused care and a measure of love which was something Maeve consistently underestimated in her relationship with her daughter.

Ruby returned from hospital "humbled" – "it was like all that anger, all the frustration seemed to just fizzle out". It was the beginning of a new and more "pleasant" phase of their lives together, "everything was burnt to the ground, and we just had to rebuild it"; "It's like she had to go through it all so, even though it was an awful time I really feel it had to happen...to burn out whatever".

During Ruby's acute illness, the requirement for changed parenting and the development of coping mechanisms became absolute. On Ruby's discharge from hospital, Maeve reframed her priorities and in so doing reconsidered her time use and the activities that were most meaningful to her. Describing her daily life, she said,

> For me since Ruby got sick and the diagnosis, really my life has got quite small, I go to work, and I come home, and I look after the family. I don't really have a lot of time for...I suppose if I am going to meet somebody socially…it is somebody that is special to me. I rarely do.

Instead of being activity-orientated and aiming for personal occupational balance, as she done in earlier times, following this crisis she concentrated on meeting her children's needs, worshiping her God, and in turn found contentment in herself as a work in progress.

6.3.3 Diagnoses reframing perspectives on doing mothering

Following discharge, Ruby was diagnosed, at her own instigation, with autism and later ADHD. Sometime after this, Joseph, her brother, received the same diagnoses. Ruby's diagnoses assisted in the reassessment of Maeve's perception of her daughter, the reconstruction of their relationship, the growth of new ways of interacting and a rationale for alternative mothering. Following discharge Ruby, now 16, expressed a desire to leave school which, pre-hospitalisation, was unlikely to have been entertained by her parents. Maeve and David's adherence to the professional advice to "back off and let Ruby make her own decision" was evidence of their trust in professional opinion, and ironically offered Ruby more power and control over her own life – the very thing Maeve had felt was her daughter's "undoing" pre-hospitalisation. At this point Maeve altered her schedule to work weekends only, so either parent might be available for Ruby at all times.

Maeve also applied her learning from her experience of one child to the other, making her navigation of the health system more seamless. Ruby, having already entered the system on account of her original mental health condition, had ready access to autism diagnosticians on her discharge. Subsequently, Maeve recognised similar autistic traits in Joseph and sought a private diagnosis. When private practitioners recommended additional assessments for Joseph (both children also have ADHD), Maeve mirrored this advice requesting the same assessments for Ruby, showing a capacity to straddle public and private systems with consumer-led usage.

Changing well-worn patterns of interaction required a conscious effort to relate differently to Ruby and Maeve made considerable effort to act on her changed perspective of her daughter. Her parenting was less overtly controlling – she referred to "planting seeds" by way of making subtle suggestions – as she sought out ways to provide maternal guidance in a form that was acceptable to her daughter. Maeve spoke kindly of Ruby, "we have a much softer relationship with her now", despite believing that she continued to hold a lot of power in the house, Maeve said "she knows, and she laughs about it, and there is a kindness to her that wasn't there". The alteration in their relationship resulted in "probably the best three years of her life with us" which was a positivity that likely encouraged more effort towards change.

Although she held herself accountable for the initial poor mother-daughter relationship, Maeve expressed no regret over lost time with Ruby. She did not engage in self-flagellation but had a forward-looking orientation that focused on how to do things differently in future. This may have been helped by Ruby's diagnoses which, in some way, validated Maeve's experience of her daughter as a child with needs that Maeve might not have been presumed to meet without professional support. So, although she believed herself culpable for the angst that was between them ("I never accepted her"), it was, she may have perceived, also not wholly her fault. Following the diagnoses of both her children, Maeve dedicated herself to their welfare, managing their ADHD medications, interceding with health and education professionals, making personal accommodations to her career, leisure, and social life. The meaning she drew from mothering Ruby increased, while her engagement in occupations for personal enjoyment decreased. Nevertheless, she felt she had grown as a person – not despite her children but because of them. As Maeve's life has got "smaller", it also got easier and potentially more contented, if not somewhat imbalanced.

Maeve continued to have a vision for how she thought Ruby would best find happiness in line with conventional norms related to socialising and developing independence. Ruby's return to school after a year and a half at home was seen as a positive outcome of trusting Ruby to make her own decisions and may have reinforced Maeve's trust in fate and faith. However, Maeve's concern for Ruby's lack of independence, zealous commitment to study, and reluctance to socialise, despite Ruby's assurance of her happiness, demonstrated her difficulty in shedding normative ideas about how children best grow and how mothers best nurture.

6.3.4 Spiritual occupational engagement: Responding to and creating change

The most significant coping strategy Maeve employed was to reconnect with her faith group. Under the guidance of this group, Maeve undertook what she called a self-scrutiny exercise which occurred as all parties were emerging from crisis and had the timely effect of preparing Maeve to make behavioural and perspectival changes, and modify her being and doing to become changed as a mother. Through this scrutiny, she reportedly recognised her tendency towards "control", her need to have things her "own way" and how her lack of acceptance of Ruby contributed to their fractious relationship. Maeve explained, "I couldn't love her, and I couldn't accept her and never did. That was my problem not Ruby's". The requirement for change was instigated by Ruby's illness but given direction, firstly by Maeve's faith group self-scrutiny and, secondly by Ruby's autism diagnosis. Maeve's revised perspective of the past provided an alternative understanding of events and demonstrate her tendency to accept responsibility in the present for the aspects of life that, at the time, were not flourishing.

6.3.5 Conclusion to Maeve's case account

Maeve's story is of ***a crisis made good.*** Maeve's form of mothering worked well for Joseph to whom she was very attached and whose needs she instinctively met. Various interacting factors related to person, time and context resulted in her mothering not fitting Ruby's needs. Ruby's hospitalisation was a superordinate event that created space to reconfigure relationships and ways of mothering. Maeve's increased self-awareness, developed through her faith group self-scrutiny, gave rise to a revised perspective of herself, her past and significant others, and prompted changes to her practices. In this way, meaningful occupational engagement acted as a mechanism for positive change. To change mothering perceptions, practices and routines, required Maeve to relinquish other occupations. While this may be perceived as occupationally unjust, Maeve's retention of her one selfcare occupation (her faith group involvement) sustained

her and she did not bemoan the loss of additional leisure pursuits nor any lack of support from structures either within or outside the family.

Maeve's narrative was rich in self-responsibilisation with the burden of change and reform predominantly placed on her by her. Gender had influence on her story in her recognition of her need for spousal support but again she accepted some responsibility for not voicing her needs and took heart in the transformed parenting brought about by their shared management of crisis. The focus on family dynamics, mother-father-daughter relationships, moved the narrative inward looking. Maeve's professed culpability for mother-daughter relationship difficulties, together with her inward-looking orientation, the family's financial capacity to pay for private assessments, her consumer use of healthcare, and the adequacy of her personal and occupational changes in enhancing her mothering, seemed to make occupational justice less relevant to this narrative. Nevertheless, I contend that occupational justice had relevance given Maeve's over-work managing her children's additional needs, her increased reliance on alcohol to cope (noted in Chapter Five) and reduced time to socialise, her voiced discontent with being unable to take family holidays and with working weekends.

The trajectory of Maeve's story was of an arc that peaked with her newfound life of fun and freedom before motherhood, dipped with the birth of her daughter, rose with the birth of her son, dipped as her children's difficulties became apparent, reaching its lowest trough with her daughter's illness till steadily rising again as mother and daughter adapted and changed. The pattern to this narrative is the common story of ***there's no easy way*** (Rawling, 2022). Maeve's life had ups and downs but the story concluded on a hopeful incline. This account of Maeve's life as a mother examined her being and becoming through her participation and response to challenges and disruptions. It recognised the impact of external conditions – people, timing, histories – in contributing to these peaks and troughs. A lack of relevance of justice orientated theory was evident when the mother perceives herself primarily accountable for circumstances taking responsibility for mothering to change and thrive. Yet I contend that occupational justices were present in this narrative primarily due to this fact – that an unquestioned neoliberal self-responsibilisation was the necessary primary response to the situation.

6.4 Eloise

Autism gave direction to the form of mothering enacted and so was central to the narrative.

From the point in time that Eloise made plans to have a child, she experienced a series of setbacks and challenges. Although maintaining an image of herself as capable and industrious, following the birth of her only child, Lucy, and her later diagnosis of autism and an intellectual disability, Eloise orchestrated her daily life, including her productive occupations, around her care. Despite considerable adversity, Eloise continuously moved forward making efforts, often at considerable expense to her own health, to turn situations around. Her relationship with *doing*, work ethic and sense of self as highly capable underpinned her form of non-normative mothering. A summary of Eloise's biographical data analysis (BDA) and teller flow analysis (TFA) are provided in Appendix 16.

6.4.1 *Being* and occupational identity

Eloise had a clear image of who she was, and this was directly related to all that she did and had achieved. She spoke very confidently about her skills and capability – "I am sitting here going I should really be the CEO of something". Generally, Eloise put herself forward for leadership positions. This may be related to her sense of personal capability, confidence in her own voice and approach, and perceived obligation to fight for justice. She argued that she tended to, "always do something about something", never leaving "any stone unturned", and she didn't "just take no for an answer". She filled her diary with work-like activities, even minimising her own health issues to prioritise autism campaign work. She demonstrated repeatedly throughout her life narrative a strong work ethic, a tendency to follow through on commitments and an inclination towards managing, directing, and responsibility-taking. Eloise chose to live a life rich in forward-looking, goal orientated *doing*, which shaped, and was central to, her occupational identity.

Eloise made personal concessions to become and be a mother. She redirected her career (taking voluntary redundancy) to facilitate IVF and altered her career further to maintain her family. Lucy's diagnosis resulted in her retraining into a less demanding role that was more supportive of her family's needs. Eloise commented that she tended to be a person that others came to with problems or for support rather than vice versa, thus it was likely that she projected an image of capability to the outside world which reflected her self-perception. Following her voluntary redundancy from a senior role, which she perceived as a setback in her career, and despite moving

forward with two additional degrees and changing career direction twice, Eloise had not reached the level of senior management which she had achieved prior to starting a family and that which her husband had reached (minus additional degrees). Yet since this period, through her scholarly achievements and formal advocacy/activism, Eloise had shown and known herself to be practical, capable, responsible, tenacious, and unafraid to speak out against perceived injustice.

6.4.2 The centrality of *doing* to Eloise's life as mother

Busyness and constant *doing* permeated Eloise's narrative. She tended towards productive activities typically engaging in two in parallel. For instance, Eloise independently self-financed her full-time bachelor's degree by working full-time. On subsequent occasions, as she experienced disruptions to her employment, she made productive use of any consequent freed time engaging in goal directed activities such as taking a master's degree. She explained that "I have always kept going and I do things about 300 times more than everybody else". On sick leave, while concurrently dealing with her own serious health issues, she ran an advocacy campaign. Additionally, she did all this while giving private tuition on a part-time basis. Eloise's adaptation to her role as "primary carer" was mothering by formal advocacy/activism which demanded engagement at a macro level with policy and politics. Her parallel occupations were predominantly productive, rewarded, and had status.

Doing underscored Eloise's approach to managing difficulties and she believed that her life had presented her with many challenges. Speaking about their efforts to start a family through IVF, Eloise concluded that, "My husband's career wasn't affected but mine was" and noted, "but it's difficult because I'm more qualified". This reflected gender based systemic discrimination, an inequality in opportunity for the would-be mother, and occupational injustice. Similarly, she, and not her husband, took carer's leave following Lucy's diagnosis. For Eloise *doing* may have become her habitual way of coping with issues. This, coupled with her tendency to take responsibility, resulted in time filled with activity and commitments, allowing little space and time to address her own health needs, even while on sick leave. Eloise recognised that she was overly engaged (*over-doing*). She did not address her need for diverse occupation nor give herself time to heal.

Central in her narrative was her effort to fight adversity. She battled for education rights for autistic children. Eloise admitted to some weariness commenting that, "We are going to be fighting all our lives now… when does the fight get too much". Yet she also stated that, "Every time I start saying I am not going to do much more, I'm going to take a break…then something else

happens". Eloise had given life to an advocacy campaign and may have found relinquishing control to be difficult, particularly when the alternative endeavour required that she prioritise herself in her *doing*, i.e., her health, and recognise that goal-directed application and productivity may be of less importance.

6.4.3 *Doing* as a mechanism for change: The campaign

Eloise led an ambitious advocacy campaign to establish special classes in mainstream schools in her affluent suburb and considered this her primary form of mothering. She was very confident in her approach to activism, explaining that, "I'm not out with the megaphone, 'when do we want it, we want it now'. Because actually, even though parents have done that, it doesn't actually achieve anything". Her approach was to quietly but doggedly assemble the facts and approach the right audiences, namely decision makers in government. She and her group spoke the language of politicians, which she recognised, but did not credit as stemming from personal privilege. This was activism using class-based tactics to combat the inverse discrimination Eloise argued was at play. Firstly, schools in her affluent area did not want to enrol children with additional needs, hence the dearth of special classes. Secondly, her area was not perceived to represent a needy population, consequently their right to classes were not prioritised.

While Eloise might have relied on statistics to make her objective case for special classes at a government level, she was, herself, motivated by and responded to how the problem was experienced at the level of the person. She relayed how one of her tutees had referred to a child with a disability taking "the chromosome bus".

> So, the bus comes in and collects Johnny, Johnny goes out of the estate, mammy is delighted, Johnny comes back, and nobody knows Johnny. So, I don't want that for my child, nobody else's child is doing it here, they are all going to their local school.

Eloise experienced the pull and tug of wanting to actualise through formal paid employment, understanding herself to be most capable, but also needing to care for her daughter, her family and her health-needs and so was reluctant to reignite her career ambitions. She explained, "It's quite difficult for me personally because here I am, very able and I haven't really been able to make that shine do you know what I mean?" and "But do I really want, do you want the stresses and the strains of that?". Her campaign work propelled her into a managerial role requiring her to organise and chair large public meetings and represent her group to government officials. This may have compensated for a lack of opportunity to reach her employment potential and

counteracted the occupational injustice inherent in the disruption of her career. By altering her career to accommodate her family's needs, Eloise aimed to "be here for my child"; by leading the campaign she kept "something professional for myself" so that her *doing* was balanced and provided opportunity for meaning and fulfilment.

6.4.4 *Belonging* through *doing*

Eloise joined the school's parents' association to network "because otherwise I'd know nobody" She commented,

> I suppose the greatest isolation I have felt is, as the mother of a child, of an autistic child, as she's got older and at the [school] gate nobody inviting your child for playdates. Em. Nobody really bothered, I don't mean that in a bad way, but you are not part of anything then.

Additionally, her efforts to avoid her daughter's public "meltdowns" and personal embarrassment ("so you're mortified a lot of the time", "you're standing out like a sore thumb with your child", "other people don't understand"), acted to further isolate her, explaining that she tended, "not to go places because, oh I couldn't be bothered bringing her out, I'll just keep going the same route, it's much easier". Eloise understood fully why she and Lucy might be excluded concluding that "people want the norm", "we all want normality, don't we?" Eloise's sense of isolation as a mother was compounded by experiences of exclusion, the implications of which extended beyond the immediate social experience to create an absence of a sense of belonging within the community.

Despite a consciousness of her difference, Eloise also perceived her difference positively. She singled herself out as having different interests, capabilities and application to other mothers in her area, "I could never really enjoy, 'Oh let's have a playdate and let's meet up', you know, let's all talk about how fabulous we all are and all that kind of crap", and, as having a different focus to parents in her affluent locality who were determined to have their children attend certain schools and compared their children's accomplishments. A favourable by-product of her campaign was the social support it provided through connecting parents of autistic children. Eloise said,

> The good thing is we have met these parents so at least we can all, it is a kind of peer support because our children are all around the same age. Initially when I started off this campaign, I thought I was the only person in the area, and it turns out there are three kids in our estate with the same level with no places to go.

Through *doing* (her campaign work) she found belonging. While her campaign provided an opportunity for alternative occupational engagement, how it was peopled was also fundamental to creating her sense of community. With reference to her fellow campaigners, Eloise reported, "a lot of us have very similar backgrounds so that has been great to have that so we can ring each other up and have an old moan because the other one will understand". Commonality of experience with regards to their children was reportedly important, but so too was their personal history, social class, educational/ professional standing. For this reason, what Eloise did, how she did it and with whom, were each essential facets of her occupational identity and of the meaning she yielded from such occupational engagement.

6.4.5 Conclusion to Eloise's case account

The concept of occupational justice was very evident in how it curtailed Lucy's engagement in education – with no special class available to her as she entered senior primary school, she was denied the opportunity to participate in one of children's primary occupations (education) in her locality. The education system and everyday normative *doings* pushed Lucy, and by association Eloise, to the edges of the community resulting in experiences of marginalisation. Despite the potential for life on the periphery to be isolating and disengaged, through her advocacy campaign, Eloise turned what might have been a quiet, in-home way of living, into a life with influence in the public sphere, engaging directly and actively with meso- and macro level structures. On a micro level, the campaign created a social support network of like-minded parents with common experiences and backgrounds, building a sense of community belonging through purposeful occupation. The campaign extended the Eloise's caring activities into a role that was less like a traditional mothering role and more akin to a professional career (Traustadottir, 1991). It spoke to Eloise's skills and sense of self, providing her with a dynamic productive role, that may have partly compensated for the sacrifice of her career and the missed opportunity for a fulfilling professional life.

Despite the advantageous impact and by-products of Eloise's activism, her life story may also be examined in relation to evident gender and occupational injustices. Gender was seen to inform opportunities, with Eloise's career potential being compromised several times in her efforts to create and maintain her family, in a way that her husband's career was not. Additionally, her choice to work part-time (on Lucy's birth) and in a less demanding role (following Lucy's diagnosis) reflected normative expectations of mothers (Miller, 2011), especially those with children with additional needs (Bourke-Taylor et al., 2010), which are perpetuated by society. Eloise's busyness

and inclination to take responsibility to support the family's function reflected a neoliberal agenda of self-responsibilisation (Trnka & Trundle, 2014) that compensated for inadequate structural supports. Purposeful and determined, goal directed occupational engagement represented Eloise's approach to addressing needs. *Doing* was central to Eloise's narrative. However, her preferred *doing* (activism) might be seen as both a foe – dominated her time and priorities reducing her occupational balance and time to heal – and a friend – supported her occupational identity, provided meaning, and enabled her to participate as a collective in inciting systemic change.

Many parents in Eloise's locality have funds for private therapy and complementary services for their children, hence recognised to be an advantaged group. However, they were dependent on the system to provide special classes to support their children's education, whom without this facility were in danger of experiencing occupational injustice. This community was experiencing disadvantage that reasonable wealth could not resolve. In this instance, macro level intervention was required to solve a community problem demonstrating that inadequate resources can create conditions of occupational injustice even for the affluent (wealthy children) once they have a vulnerability and additional need (in this case, autism).

6.5 Sadhbh

Mothering autistic children was central to her narrative and strongly influenced who she was as a mother.

Sadhbh was a mother to five children, three of whom had autism. Although she had not planned to have children, on becoming a mother to her first child she embraced this as her central purpose. Her narrative was a love letter to her own mother whose mothering shaped her own. Sadhbh's mothering demonstrated understanding of her children's needs and ability to accommodate within the home environment. Her frustrations were wholly directed at the structures which she believed were inadequate to support her children to reach their potential. A summary of Sadhbh's biographical data analysis (BDA) and teller flow analysis (TFA) are provided in Appendix 16.

6.5.1 *Being* mothered influences *doing* mothering

It would be difficult to understand Sadhbh as a mother without also considering her experience of being mothered. As an only-child to a single mother in 1980's Ireland, Sadhbh had one-to-one adult attention and a familiarity with an unconventional family makeup. Through analysing stories within Sadhbh's life narrative, it was apparent that she was given autonomy and control over her own decision making consistently and early. At 12 years old Sadhbh chose, and was facilitated, to remain living in her hometown staying with family friends while her mother relocated for work, and again, empowered to reconsider this decision when, several months later, she relocated to live with her mother. There was no evidence to suggest that Sadhbh, as a child or teen, responded to the demands of this, or future, home relocations in anger, resentment, or distress. This may have been because she was given space and time to independently reach decisions. Rather than command, her mother made suggestions, "everything was consulted". Consequently, Sadhbh had little need to assert her independence through opposition. Included in decision making, trusted to understand her own needs, Sadhbh may have gained a sense of herself as autonomous and agentic from early in life.

The mother-daughter relationship was neither dictatorial nor particularly authoritative, instead may be viewed as reciprocal, underscored with respect for each other's position and preference. Sadhbh knew she was her mother's priority, "I always came first…I always got that I was the centre of her world". Sadhbh considered her opinion valued and her position in the family to be of equivalent standing to her mother's, "If she had salmon, I had salmon. She didn't have salmon while I had fish fingers". Similarly, Sadhbh "wanted to give my children that status as well"; "I knew how important I was, and I suppose I just transferred that directly to this child…kind of an extension of myself".

Sadhbh experienced what she considered to be *best* mothering and emulated her mother's mothering. Although this created a high bar to reach and maintain this also highlighted an advantage to having a positive mothering role model for mothering to be learned and imitated. Echoing her mother's mothering, Sadhbh described instances of listening to her children and respecting their autonomy whilst demonstrating cognizance of their level of maturity. Before responding to her second son, Íarlaith's, desire to move school, they "talked about it for a couple of months" to help her decipher whether she was "listening to a child who is right or am I listening to a child who is making a decision when he is nine?". Sadhbh was attentive to her eldest son's desire to leave school and tried to accommodate his school refusal without becoming

authoritative – with the help of social services, she organised for him (Alex) to attend school for select classes; when the school were unable to accommodate Alex fully, Sadhbh found him a home tutor, and then an alternative school. In many ways her orientation towards accommodation rather than authoritarianism reflected how she herself was mothered.

6.5.2 Alternative doing found preferable

On an intellectual and practical level Sadhbh was decidedly against becoming a mother. On finding she was pregnant, aged 22, she "cried for the whole day…I suppose it was a shock more than anything else, I didn't want children". Some of the anxiety she felt towards impending motherhood may be explained in relation to her circumstances (a student beginning her second fulltime bachelor's degree). However, Sadhbh's feelings towards becoming a mother were contradictorily manifested. She was determined to mother well and immediately began reading books on pregnancy and parenting, reflecting the approach to *doing* she had observed in her mother growing up, while at the same time, she did not welcome her pregnancy nor disclose her pregnancy to her mother, who unfortunately learned of it via a third party.

Referring to how her mother had worked hard to meet their needs, Sadhbh explained, "I wanted to do all that". Her choices for occupational engagement were in keeping with the mothering ideals developed through her childhood experiences of being mothered. Referring to her first degree she said, "Okay, I've no job out of this, what am I going to do? How am I going to pay for this child going to school and swimming lessons and everything?". Sadhbh showed personal responsibility on becoming a mother, choosing to do a professional course (second degree) with immediate prospects of employment and extending it across three years (rather than as a year and a half accelerated course) to make it manageable with an infant.

Sadhbh transformed the circumstance of her unplanned pregnancy into something positive and expanded it to create a household of children, which was in direct contrast to her only-child status growing up and at odds with her former commitment to childlessness. This demonstrated her willingness to learn through the experience of a happy accident that shaped who she became (a mother) and what she proceeded to do (mothering) in her life. The nature of her mothering demanded an all-consuming and sustained change in daily activities and shift in occupational identity and role. The meaning of this occupation may have contributed to the abandonment of her earlier ideals. In relation to motherhood, Sadhbh said, "Once I got it, I got it, but before I got it, it just didn't make any sense. It's not logical at all to have children, is it?". Her description of

motherhood as “winning” may account for the dearth of reference, either positive or negative, to her husband as co-parent – she embraced the role irrespective of support. Motherhood created a new emotion/feeling way of being that overrode Sadhbh’s reported tendency towards rationalisation. Describing her feelings towards her children, she said, “It’s like a hug or something, it’s a very in your chest kind of a feeling…it feels very biological to me...it’s not in my head”.

With her own mother’s death when Sadhbh was 27 years old, only she remained of her first family. As her original two-person family decreased in size, Sadhbh expanded her second family. Having a home filled with family members was found to be preferable to having her independence and greater freedom to do as she pleased. Conscious of the loneliness of being an only child with no living parent, Sadhbh was keen to nurture a bond between her five children, “They have each other…they can look after each other and help each other when they are stuck”. Being alone in her first family may have enhanced her enjoyment of having a large second family and may have given particular meaning to motherhood, “They’re my people. I suppose when I don't have siblings [voice trailed off].” Having her first child at 22 meant that her adulthood was shaped by motherhood. Sadhbh described her relationship with mothering as being,

> A huge part of me, of who I am, d’you know, it has changed me entirely…I think sometimes I didn't learn to be me before I had children, so me is mothering, me is minding everybody…there’s not a lot of other space.

While she was given opportunity to assert her autonomy as child, teen, and student, she had little time to know herself as an independent adult outside being a mother. Yet she did not mourn a life lost or resent the loss of a potential life, commenting, “I don't think I’ve lost me, if that makes sense, but I think it’s because I was so young…like I went from the drinking phase into the being a parent phase...I don’t know what I’m missing”. If motherhood was her role and children the primary focus of her life, then it makes sense to have many children to give life much purpose, meaning, and identity.

6.5.3 *Doing* mothering across micro and meso- systems

Busy and committed to caring for her family, Sadhbh modified her career (from full- to part-time work). Following her first encounter with breastfeeding she trained to be a breastfeeding counsellor. When Alex was diagnosed with autism, Sadhbh took a higher diploma in autism. She liked to know wholly how to do what she needed to do. In this regard she somewhat mimicked her mother.

> What I find with my mum is that I am really proud of the other things that she did… she had her career, and she did lots of other things… it wasn't just all about me she was setting an example in other areas.

Sadhbh realised at Alex's autism assessment that all five of her children met the criteria. This, potentially overwhelming insight into a future of guaranteed additional needs and challenges, was not defined negatively by Sadhbh, "Mine aren't typical children which is all okay really", nor did it present as a stressor within in the home domain. Her attitude was that their autism-type traits were part of who they were and what was "amazing", though hard work, about them.

Sadhbh developed her own way of doing mothering. She was accepting and accommodating of her children's ways and reinterpreted their behaviours. She regarded her third son, Ríodha, as stubborn, explaining that, "He would punch somebody out of frustration if they're in his space…and I think that just comes across as he's just misbehaving". At home they prevented situations escalating and becoming violent. She had a similar understanding of her children's food preferences, "I would just say he doesn't like onions, it's not rigid, he just doesn't like them. Everyone has things they don't like, don't they?". Sadhbh permitted Alex to routinely take his dinner apart from the family, "He can cook for himself when we're all gone to bed and that's generally what he does". Sadhbh told a story of losing a child at a fair and another of a child jumping into the penguin enclosure at the zoo. "So, we turned around and we only had four children left. Feck. It happens so often that we don't actually panic, we're like, he's probably fine, he just goes somewhere". Her stated reaction to her children's idiosyncrasies and various needs described a mothering style that was slow to panic, effortful in understanding her children's behaviours and needs, and amenable to adjusting family mores. Sadhbh was not naïve about the impact of autism on family life, commenting, "Our children's difficulties have dominated every part of parenting for us", nor was she unaware of the range of possible challenges that may lie ahead. However, her perception of her children, and accommodation of their behavioural needs, without a compulsion to conform to societal expectations of how families should operate, may have contributed to Sadhbh's ability to seemingly cope well at home.

Operating outside society, within their micro-community of home, diagnoses were unimportant. However, diagnoses are more essential in interactions with meso-environments given their role in applications for additional educational accommodations (Ryan & Runswick-Cole, 2008). Sadhbh had highlighted Alex's challenges years before he was diagnosed – "I was asking but nobody else was listening to me" and she was angry that the assessment process needed to be initiated and

driven forward by the parent. She valued education and was aware of the inadequacy of school supports to sustain Alex in an educational environment in which he could flourish. In this regard, Sadhbh demonstrated a consciousness of the occupational injustices that her children were experiencing. Both Alex and Ríodha were "exceptionally able" academically, yet their needs were not being met. "They should be thriving; they're entitled to do really well".

Sadhbh wanted structures in place to support her children's development in the world – ways of engaging her children in education that would work with their individual ways of being and enhance their school functioning. She described an under-resourced and consequently reactive education system, which allowed difficulties to escalate instead of proactively assessing individual needs and developing services, both educational and social, accordingly, stating, "If you fail miserably at school and you school refuse, somebody will write a letter to somebody, they'll do nothing and then we'll pull you out of school and then your family can figure it out". Her anger was directed at macro level politics that have, at a theoretical level, designed adequate systems – "nothing new is needed" – but have failed to enact their plans – "how it looks on paper is quite good, but it's just not actually happening. They need to wake up". "The assessment of need needs to actually fucking happen. The Educational Act has to be fully enacted".

6.5.4 Conclusion to Sadhbh's case account

The legacy of Sadhbh's mother's mothering, the self-understanding and autonomy it may have nurtured in Sadhbh, was evident throughout her life narrative. Sadhbh was trained to think for herself. Despite living through adverse events, her decisions, or at least those she shared, demonstrated self-reliance, self-confidence, and responsibility. While having little time to explore life as an independent adult, growing up as an only child she had much time on her own and freedom to choose her activities without the obligation of sibling compromise. Building a large family, in contrast, offered a different way of *being* and *doing*. The meaning Sadhbh found in mothering located her, unapologetically and without resentment, within a traditional gender role of carer. As suggested by Takševa (2018) motherhood was a site of her empowerment and she seldom mentioned her husband's contribution to the family.

Being a child of a single mother in 1980's rural Ireland suggested an unorthodox family life. This, coupled with her lack of interest in having children, may have positioned her not to have conventional family ideals/aspirations for when she did raise a family, thus making it easier to accept her children and family as they were. Sadhbh's attitude towards her children was

unconditionally accepting and her perspective towards their diagnoses was neuro-affirmative. Being taught to confidently express her opinions and make decisions from a young age may have equipped Sadhbh with an understanding of her capabilities, enabling her to cope with her children's additional needs within the home environment. She adjusted her mothering to accommodate her children, thus *doing* mothering her own way.

However, beyond their home life, support for her children was required in their interface with societal structures (schools) and obligations (to be educated). Sadhbh deemed support services to be inadequate and the education system to be ill-equipped to meet her children's needs. The resultant injustices inflamed an emotional, heart-born response in Sadhbh that aligned inversely with the positive emotional experience she reported of motherhood. By not being enabled to flourish in their lives, her children experienced occupational injustice. Sadhbh's narrative exemplified how her perspective had the power to positively shape her experience of life events. Yet, it was possible for this power to be diminished by the structures within society (education and health systems) which, when not established to provide the required support, impacted on occupational engagement (i.e. disrupted schooling).

6.6 Chapter summary

This chapter presented the case interpretation of four gold star cases. The multifaceted BNIM analysis enabled a broad interpretation of the cases which was given additional meaning and depth by examining initial case histories using a feminist lens that made gender roles and social norms an issue for occupational justice. The application of Wilcock's perspective on occupation as encompassing doing-being-belonging-becoming provided coherence to the structure of cases without losing the particularities of each account. Occupation was held central throughout. Although representing the lived experience of mothering, each case was distinctly different and demonstrated the importance of exploring the interaction between the mother and her occupational engagement within the context of her past life, focal others, current supports, and wider societal and cultural expectations.

While Chapters Five and Six have addressed both research questions broadly, the following chapter takes a closer look at the gold star cases in relation to research objective two focusing primarily on mothering identities as occupational beings.

Chapter Seven

Findings: BNIM cross-case analysis

7.1 Introduction

The central concepts presented in this chapter for comparison between the gold star cases were arrived at following an examination of the *doing-being-becoming-belonging* of mothering presented in the previous chapter. A core strength of BNIM in this study was the insight it offered into the construction and reconstruction of the self as mother in the telling of their stories. This chapter is a deep dive into the gold star cases' mothering identities as occupational beings and their adaptation of mothering across time. It connects directly with research objective two (i.e. mothering as a mechanism for agency, belonging, becoming, and occupational identity construction). By gaining a deeper understanding of the interaction between mother-agency and temporal/sociocultural factors through unpicking the construction and disruption of the mothering (occupational) identity and examining their mothering (occupational) adaptation, the chapter aspires to explain how mothers became the mothers they were. This is achieved by moving forward and back between participants, referencing their circumstances and backgrounds to provide context, and by attending to the nuances within their narratives.

7.2 Occupational identity as mother of an autistic child

In recent years, there has been a shift from looking at motherhood as only a biological endpoint to thinking about motherhood as an identity, examining how mothering is done, and exploring motherhood as a subjective experience. This is, Tabatabai (2020, p.112) claims, a "narrative turn" within the study of motherhood and one with the potential to contribute to an understanding beyond that of a universal experience grounded in biology. It is possible to identify varied versions of the centralising concept – mothering – being played out in the BNIM cases. Narratives give power to deconstruct and reconstruct selves (Austin & Carpenter, 2008; Casey et al., 2016; Smith & Sparkes, 2006). The mothers in the current study constructed their occupational identity as mothers through their storied accounts of their mothering experiences. Each mother differed in their understanding and enactment of motherhood relative to their contexts and circumstances and yet, due to the requirements of the mother role and their child's interaction with societal systems, each had much in common in terms of what they did. Although there is no one mothering

identity (VanderKaay, 2016) and many occupations contribute to the construction of occupational identities (Laliberte-Rudman, 2002), through examination of their lived experiences mothering identity can be better understood (VanderKaay, 2016).

Hansson et al. (2022) analysed the concept of occupational identity (OI) finding that the empirical literature primarily explored aspects of OI in relation to its construction, disruption and discrepancy. In explaining these aspects of OI, they drew on Wilcock's conceptualisation of occupation as doing-being-belonging-becoming. In this section I have used Hansson et al.'s conceptual analysis, to understand the OI of the four gold star cases, referring to their doing-being-belonging-becoming in accordance with Hansson et al. as well as drawing on other authors to make more sense of particularities.

7.2 1 OI and competence

Occupations enable individuals to develop and express their identities and in so doing they build life stories. The ordering of life events, allows their meaning to be derived in relation to events that have gone before (Christiansen, 1999). The mothers in this cross-case analysis constructed mothering identities related to self-perceptions of competence already established through previous interactions and engagement. Their understood occupational competence was then used by these mothers to help them understand new occupational demands and to reconstruct their occupational identities.

Approaching caregiving in a similar way to how other occupations were undertaken in the past is found to maintain a sense of consistency in identity (Laliberte-Rudman, 2002). Similarly, in their exploration of mothers in recovery, Martin et al. (2011) report that a perception of the self in the past influences present-self and future *becoming*. Phelan and Kinsella (2014) reiterate similar findings. In the current study, the influence of the past OI on the present sense of self as an occupational being and an imagined future life was seen in the life stories of each mother. In the case of Imogen, she reported strong organisational and managerial skills in her professional life pre-children, stating, "I loved working. I was always like driven. I always wanted to do this, this and this and move up the ladder…I mean, I enjoy it, but it's not for me anymore. So". Imogen responded to a meaningful crisis by upskilling as a carer until she was managing family life successfully and upskilled again to reshape a vision for future family life that provided her with a selfhood beyond mothering. The fact that Eloise and Imogen knew themselves to be capable

carers generally, helped them cope with their child's diagnosis, shaped their actions thereafter, and illustrated a relational and temporal dimension to the construction of occupational identity.

For mothers of autistic children, whose mothering competence is challenged by multiple factors such as their child, society, and services, this relationship between OI and occupational competence could be problematic for their mothering identity construction. Interactions with services on behalf of Ethan had initially challenged Imogen's occupational competence; her later success in regaining competence and developing a strong autism mothering OI was evidenced by the time and space she had created for occupational transformation (career retraining). Imogen was very confident in her ability to learn and practice a form of mothering that met Ethan's needs. Eloise was confident and competent in her organisational skills to mother through activism. Sadhbh was very clear that she had no problems parenting within the home domain – "We can accommodate him, and adjust to what everybody needs, and we do but the world doesn't do any of that", reflected her high parental-self efficacy[12] despite potential occupational injustices in interactions with systems and structures. These mothers did not express feelings of inadequacy as mothers. According to Bandura (1995) the most effective way to create strong efficacy beliefs is through experiences of mastery. Maeve's narrative, on the other hand, expressed a dearth of mothering mastery experiences. She did not want to become a mother and felt emotionally overwhelmed on doing so; she found Ruby challenging, and was very under-confident in her mothering ability, stating, "I really did have to back down most of the time and that is what it felt like". Confidence in role fulfilment, coupled with its meaningfulness, is considered to be integral to OI (Hansson et al., 2022). As the conditions around her parenting changed with Ruby's illness and subsequent diagnosis, Maeve established a new way of mothering Ruby and was gaining confidence in, and more meaning from, the role. However, Maeve considered herself a work in progress commenting, "I've made lots of mistakes, I'm still making mistakes, but I think I'm getting a little bit better…I still have an awful lot to learn".

7.2.2 OI construction

OI construction describes the building of connections between *being* and *doing* across time; and the expression and construction of the self through *doing* (Hansson et al., 2022). The life stories

[12] Parenting self-efficacy is the term used to describe a "parent's belief in his or her ability to influence the child and his or her environment to foster the child's development and success" (Ardelt & Eccles, 2001, p.945), Ardelt, M., & Eccles, J. S. (2001). Effects of mothers' parental efficacy beliefs and promotive parenting strategies on inner-city youth. *Journal of Family issues, 22*(8), 944-972. in other words, their belief in their ability to successfully parent.

of Sadhbh, Eloise and Imogen began with OI construction. Imogen perceived herself as a capable carer since childhood – her *doing* reinforced her self-perception (*being*) through the activities she engaged in to protect her younger sister from her father's alcoholism and family disharmony, claiming, "It's almost like an anxiety thing, it's almost like you have to look after everyone else around you to keep them safe because that's how I was raised". Likewise, Eloise's perception of her personal capacity (*being*) was formed early, aligned with her commitment to life roles and her ability to make things happen (*doing*). For example, she described her busy schedule of working while studying.

> When I was doing my degree, I was working all the time…so I would be cycling off down to X and everywhere, no car. A lot to be very grateful for. I think people have to acknowledge that too, but I have worked very hard for all the stuff.

Stories from Sadhbh's childhood described her OI construction in terms of *being* and *doing* related to demonstrations of agency, evidenced when she decided, age 12, not to move house with her mother. Additionally, this OI construction was strongly connected to the mothering she received from her own mother (*belonging*) which developed in her a sense of being valued as an individual.

Christiansen (1999) claims that, as we perceive ourselves becoming more like the person we want to be, our life satisfaction increases. Being a mother was Sadhbh's principal OI and her many children reinforced this construction. Unlike Maeve, she made healthy adaptation to her mother role and desired OI. Her confidence in her ability to mother within the home environment may have acted as a buffer for her mothering OI in her more recent interactions with professional services that potentially threatened her mothering identity outside the home. In creating the conditions for occupational injustice, adverse experiences of structures experienced by Imogen, Sadhbh, and Eloise, may also have impacted their sense of mothering competence had they not had prior experiences of mastery nor an inclination towards the self-responsibilisation of Maeve. Although Alex was unsettled in school at the time of interview, like Eloise and Imogen, Sadhbh's told-story revealed a strong OI as a mother, notable in her comment, "I don't know what we could have done differently to make it work differently. The school would need to change, not us".

7.2.3 OI discrepancy

Maeve's telling of her life story began with occupational discrepancy with her unplanned pregnancy initiating a conflict between past and present self. OI discrepancy is explained as a disconnect between perceived role fulfilment and actual role fulfilment; disparity between what a person desired to be and do with the actuality of their situation; incompatibility between a past

and present self (Hansson et al., 2022). There was discrepancy in what Maeve was and desired as an adult occupational being (independent and free) and what she perceived she needed to do and become as a mother. The experience of losing one's occupational identity is closely tied to a sense of a devalued self with more intense feelings of loss being related to a stronger perception of diminished self-worth (Martin-Saez & James, 2021). Horne et al. (2005) notes that the process of becoming a mother results in a significant and permanent change in occupational identity. Identity continuity, that aligns the past, present and future self is important for wellbeing and a sense of coherence (Martin-Saez & James, 2021) and Maeve grappled for a sense of occupational identity continuity in knowing herself as before.

While Maeve performed the actions of her role as mother, from her accounts of mothering Ruby, it might be suggested that she found embracing motherhood as her occupational identity challenging. This prompts consideration of the idea that doing the tasks of a role automatically confers a societally assumed occupational identity of that role, regardless of an individual's preference for the role. Sadhbh's transition to motherhood, despite being unplanned, did not create conflict or disruption in her OI because she embraced the change which highlights the importance of meaning in OI transformation. Sadhbh's *being* and *doing* aligned as a mother. According to feminist and philosopher Simone de Beauvoir (1949), the child can be regarded as anything from a burden to a gift depending on the mother's economic or sentimental considerations. As de Beauvoir (1949, p.546) claims, the experience of motherhood varies considerably depending on the conditions in which it takes place, "in revolt, resignation, satisfaction or enthusiasm". We see this resoundingly in the case of Maeve. Her underlying fear of loss of subjectivity, or self as an occupational being, created by maternity, and her resignation to the condition of motherhood, were not helpful in mothering her first child.

Maeve's continued OI discrepancy as a mother to Ruby was compounded by a lack of support from her husband. According to Unruh et al. (2002) there is an interaction between OI, the environment and aspects of the person. Kielhofner (2008) also refers to the environment enabling and limiting the development and expression of OI. The notable improvement in Maeve's experience of mothering, and her belief in her competence, occurred when Maeve changed her mothering style (personal factor), Ruby adjusted her interactions and behaviours within the home and Maeve and her husband supported each other in their parenting (social environmental factors). Maeve, in developing her OI as a mother, with the support of her spouse and church, reinforces the claim that construction of OI is an active process requiring person-environment

interaction (Laliberte-Rudman, 2002). Unruh et al. (2002) claims that the meaningfulness of an individual's OI influences their occupational performance. As the meaning of motherhood changed for Maeve so too did her performance in the role. To Hansson et al. (2022) this represents OI in construction and demonstrates how OI is a dynamic concept (Phelan & Kinsella, 2014), being constructed and reconstructed in response to internal and external factors.

Eloise too described a period of OI discrepancy when she took voluntary redundancy before becoming a mother. She stated that her professional behaviour at this time was not characteristic of who she knew herself to be, demonstrating a disconnect between her past and present OI.

> So, to be in a position where kind of married with trying to have a child, losing parents and then I also had a problem with my neck and stuff, it was very upsetting for me because it wasn't really the true me at the time. So, I suppose life gets in the way sometimes. And in life getting in the way then I had to make huge decisions. So, I decided to take redundancy from that role.

Later, Lucy's diagnosis likely created some discrepancy between Eloise's past *doing* and expectation for future occupational engagement, but this was not the focus of Eloise's told-story. In the main, Eloise's OI and self-perception as a capable doer, reinforced by her over-engagement, remained consistent. Both mother and child experienced a level of occupational deprivation and marginalisation (no playdates, no parties, restricted family time in public places). Like Imogen who became a childminder to increase Ethan's social contact, Eloise developed an occupational repertoire (establishing a community of parents in similar situations) to manage occupational injustices, and this in turn reshaped her mother identity.

7.2.4 OI reconstruction

Laliberte-Rudman (2002) claims that engagement in occupations could lead to opportunities for growth and reconstruction of identity. In the current study, engagement in occupation is recognised to have this power however, growth was not inevitable without ready adaptation and judicious engagement in occupations that supported the individual's competence-development in the role in question. For example, in their own way, Imogen, Sadhbh, and Eloise worked hard to develop a sense of competence and effectiveness in mothering by engaging in occupations (courses, advocacy etc.) related to their mothering and modifying their homelife. However, by merely engaging in mothering occupations with Ruby, Maeve did not experience growth and reconstruction. Unhealthy adaptation can occur when people do not perceive themselves progressing towards their desired identities (Christiansen, 1999). By rethinking her mothering, restricting her social life, and gaining familial and service support, Maeve was able to reconstruct

her occupational identity through occupation. Therefore, doing the right things with the right perspective in the right context is important for growth and reconstruction.

To reap rewards through occupational engagement, including those that shape identity positively, control over the occupation is found to be important (Laliberte-Rudman, 2002). Across time Eloise and Imogen had both created mothering roles in which they felt in control. Sadhbh, on the other hand, was experiencing some lack of control over mothering in relation to systems outside the home. Ironically, Maeve was in the process of gaining more control over mothering by "Just letting go of trying to control and make Ruby do what I thought she needed to do, just be", thus gaining more positive rewards from her occupational engagement and reconstructing her OI as a competent mother.

7.2 5 OI and choice

In relation to choice and OI, Christiansen (1999, p.550) claims that "When we exercise choice, we are expressing our selfhood and unique identities". As motherhood is a function of social convention (Pollard & Sakellariou, 2012), it is bounded in its possibilities for autonomy and choice. According to Maher (2005), mothers' choices within the mothering identity can be further constrained by responsibility and over-work. The assumption that individuals have autonomous occupational choice disregards situational factors that create conditions around obligation and duty which in turn impact on occupational engagement and role fulfilment (Cote & Levine, 2002). It is possible that the value that Western culture holds for individual autonomy and occupational choice (Laliberte-Rudman & Dennhardt, 2008) may have contributed to Maeve's disappointment in becoming a mother in light of her childhood experiences caring for siblings and house, and perception of motherhood as one with little freedom, much obligation and very little occupational choice. The over-burden and obligation evident in mothering autistic children (Asmare et al., 2023; Bozkurt et al., 2019; Fowler & O'Connor, 2021; Mohammad et al., 2022; Padilla-Petry & Saladrigas-Tuà, 2022; Patel et al., 2022; Rasoulpoor et al., 2023; Soytaç et al., 2022; Vilanova et al., 2022), particularly in relation to structures outside the home, increases the expected labour and responsibility of mothering and were seen to restrict choices for subjectivity and the occupational engagement of each of these mothers across their productive, social and domestic lives.

7.2.6 OI disruption

Crises before their child's diagnoses challenged both Maeve and Imogen creating conditions for OI disruption. Neither mother was able to *do* mothering and *be* as before. When OI is disrupted and challenged by circumstances some resolution of issues is important before OI can be successfully reconstructed (Unruh et al., 2002). Finding new ways of *doing* are strategies used to reconstruct occupational identities (Hansson et al., 2022). Although Imogen was overwhelmed by circumstances around Ethan's diagnosis which tested her occupational competency, with effortful doing (attending training courses, adapting family life) she reconstructed her OI as an autism mother. Her approach to crisis management and OI reconstruction was in keeping with how she approached other crises – by stepping up to meet the challenge.

7.2.7 OI as gendered

Motherhood, like gender, is actively performed (Butler, 1990) within a cultural milieu that influences how the role is conceived, enacted, and received. According to McGrath (2017), hegemonic practices become rooted in specific contexts, evolving over time and across cultures. They reflect the dominant assumptions and fixed ideals of what is considered natural or normal. Although ideals change across time within any given culture, those of the dominant forces pervade and are assimilated unseen and unquestioned into everyday occupational performance and practice. Extending this to motherhood, certain ideologies existing in the social milieu were seen to influence these mothers' doing-being-belonging-becoming through occupation, in turn influencing their occupational identity (OI). Despite changing expectations of women and mothers across the years, the current study showed that all gold star cases felt the continued presumption that they should and would carry the load of childcare and domestic activities.

Gender exercises a formative influence on what women do and on their occupational patterning (Pierce, 2003). If women construct and contest their femininity within the confines of the categories they inhabit (McGrath, 2017), motherhood, with its assumed norms, must place further limits on their opportunities for engagement restricting agency in being and doing and problematising the possibilities for belonging and becoming. These mothers were constrained by their own definition and construction of motherhood as well as external factors including social norms. Their gendered subjectivity influenced their negotiation of the mother identity. Although Imogen and Eloise complained of unfavourable expectations of the mother in comparison to the father, their gendered subjectivity led them to accept and expect to perform the typical activities of mothering, despite family conditions that made this difficult. Even Maeve, who reportedly did

not accept her child, accepted the mother role and the active performance of mothering activities aligned, in as much as possible, with gendered social norms.

7.3 Mothering adaptation

Parental agency refers to the proactive role and activities parents adopt in promoting their child's development (Moyano, 2013). Kuhn and Carter (2006) note that autism knowledge is positively related to maternal agency for mothers of autistic children. All four gold star cases were active in their management of their children's lives and promotion of their development, reflecting a high level of maternal agency. Sadhbh reflected on the value of having knowledge and being informed, "I always figure I can do my best if I know more". These mothers increased their knowledge on autism and, in doing so, their ability to act as agents for their children. Each advocated strongly for their child within the health and education arenas. Moyano (2013) found maternal agency to be significantly higher than that of fathers and unrelated to the age of the child or parental education. These findings were relevant in the current study across the gold star cases and other mothers. Mothers managed and promoted their children's lives and acted as their advocates irrespective of the child's age and, by their accounts, to a higher degree than the child's father. The maternal role in carrying the greater care burden in comparison to the father for their child at home, in school, and in healthcare is well established (Padilla-Petry & Saladrigas-Tuà, 2022; Kim et al, 2021; Fowler & O'Connor, 2021). The gold star cases were found to accept, if not embrace and relish, the tasks and obligations that traditionally fall within the mothering role.

Belief in their ability to successfully parent – their parental self-efficacy – was reflected in Sadhbh's, Imogen's, and Eloise's confidence to develop their own versions of mothering. Coping and adaptation is related to numerous individual parental characteristics (Schwartz, 2001) with each mother doing mothering in their own way. By orchestrating their occupational engagement to support their child's engagement, stepping in to ensure their child received the right kind of services that supported their childhood roles and development, mothers were seen to be agentic and to actively problem solve. Their occupational engagement may be viewed as a way of coping with and managing a diagnosis that supports further occupational adaptation.

Ruddick's (1989/1995) assertion that motherhood is concerned with ensuring a child's survival/preservation, growth/development, and sociability can be teased from that which represented the non-normative mothering of Eloise. Eloise described her version of mothering as:

> Going for a walk with her, so the very basic things for me, that is when I have a chance to be her mother, otherwise she's not... Like I am much more Lucy's advocate than her mother I feel a lot of the time because she's not really giving me much back…motherhood for me is spending time, those moments that are very precious for any parent.

Although she expressed a level of disconnect with Lucy and held tight to the mother as warrior[13] identity, mothering for Eloise also embodied the mundane and everyday mothering activities that suggest nurturing and require co-occupation (*doing* together). Similarly, Imogen commented that the everyday and nurturing mothering activities, "Making sure they know they're loved, singing Baa Baa Black Sheep every single flipping night to an eleven-year-old, that type of thing [laugh]", represented mothering to her; while for Maeve it was "moments of connection when you can laugh", and for Sadhbh,

> …just chatting in the car, somebody sitting in the front seat and whatever crops up in conversation is really what it is all about. I mean for me as a child that is what I remember most with my mum is sitting in the car. And I'd have my arms up. I would have my seatbelt half off, I'd imagine, and I would put them around the bar in the head rest and my two elbows around it and we just chatted about whatever. So I suppose when that is one of my strongest memories I think our kids are going to remember whatever we chatted about in the car, talking about when I was younger or talking about my mother or them asking me questions about school or how I coped with this…we put on music and we sing really loud as well...so once they get a little bit older, they can sit in the front and it is magic, it is lovely. Knowing what is going on in their lives and in their heads.

'Revising dreams and future planning' is identified by Lutz et al. (2012, p.211) as coping responses to experiences of 'disappointment and sacrifice' (p.210) brought about by mothering an autistic child. Certainly Imogen, Eloise, and Maeve had revised their imagined careers and social engagement. However, Sadhbh was an anomaly in relation to Lutz et al.'s model. Although she worked part-time and no longer rowed, or mountain climbed, she did not feel she had given up any part of herself, her aspirations, or her imagined future on becoming a mother of autistic children, claiming, "Me is mothering, me is minding everybody, me is those things…there isn't a me that's missing". While Eloise's and Imogen's roles as autism mothers were well established and Maeve's adaptation to autism mothering was in its infancy, Sadhbh did not report making any deliberate adaptations to her style of mothering following the diagnoses of three of her children.

[13] Mother as warrior, referred to by VanderKaay (2016), describes the mother who battles to accommodate her child's needs.

Her home accommodated to her children's needs regardless of diagnoses. Pakenham et al. (2004) explains that making sense of and finding benefits to having an autistic child and reframing behaviours as positives are important processes that are integral to parenting these children. Sadhbh excelled in this regard believing their behaviours not a problem if it were not for the world and its systems.

Adaptation is considered a journey across time (Lutz et al, 2012). In the current study, adaptation was not linear nor were responses universal or stressors wholly resolved. In this study, following the typical upheaval brought about by the diagnosis and subsequent efforts to access appropriate educational and health supports, mothers tended to enter a more settled phase of parenting and family life. Such adaptation is considered typical (Green, 2001). At such time, mothers understand the systems, their child's needs, the implication for supports during times of transition, and can anticipate the requirement for their intervention with services. Imogen (six years post diagnosis) versus Sadhbh (two years post diagnosis) are a case in point – following a period of learning and fighting, Imogen understood when and how to act to best support Ethan. Conversely, Sadhbh, through Alex, was in the midst of flux, coming to the realisation that the education system was inadequately served to support Alex appropriately. As children progressed through the education system, transitions required mothers to rethink their child's needs in the context of new educational environments. Eloise prepared for Lucy's transition to senior primary school by contacting the principal and requesting a school tour. Ongoing mothering adaptation was made more difficult by resistant systems and services, which speaks to the relevance of occupational justice in these mothers' lives. Eloise's request for a school tour was denied. She also referred to discrimination in affluent areas where parents support their children's education, "It is harder sometimes in areas like this where difference is very difficult because they [schools] are not used to it". She complained that despite her representation of the need for a special class in Lucy's new school, "If the principal doesn't want it, it doesn't happen" and he opposed it.

Although they may not have imagined having an autistic child, each mothered according to what worked best for their child and family, made sacrifices and worked hard to ensure their children were supported in their development. Maeve claimed, "As a mother my priority are my children. I suppose they're my mission". Pakenham et al.'s (2004) study of parents (majority mothers) of autistic children found that making meaning of their situations was related to adaptive coping processes. Imogen stated, "Everything I had [before children] I don't have but it is not necessarily a bad thing, just a different way of looking at it". An important step in adaptation is parental re-

imaging or re-idealising the child (Londero et al., 2021). Sadhbh described motherhood as "More of a feeling than a thinking thing…I'm winning…I'm playing a different game". These mothers' capacity to adapt to mothering an autistic child and derive meaning from their role, may have been related to reimagining their child and was certainly facilitated by doing what was needed to be done to love and care for their children because they were their children. Being the mother provides purpose and strength for these women to do for their children despite difficulties related to the child, mother, system, or support, illustrating the connectedness between maternal *doing* and *being* (Del Fabro Smith et al., 2011).

In creating their own versions of motherhood each mother made efforts to develop a way of doing things that would enhance their family's and child's functioning. Many mothering occupations with or on behalf of the child were non-normative. Fundamental adaptation to the mother role was required including the development of alternative strategies to meet the children's needs (for example, changing careers (Imogen); supporting a child to leave school at 16 (Maeve)), and engagement with systems atypical in normative motherhood (for example, meeting with politicians to develop special classes (Eloise); collaborating with child protection agencies to develop an educational support package (Sadhbh)). Adaptation is important as, through it, people begin to recognise themselves and become equipped to meet the demands of their new realities (Roiz & Figueiredo, 2023). Adaptation to mothering an autistic child in this study required modification to the nature of normative mothering and to the extent to which mothering occupations were performed. This in turn resonates with Kielhofner's (2008) assertion that occupational adaptation requires readjustment of a person's OI and competence.

7.4 Conclusion

From this cross-case analysis, it is apparent that embracing motherhood is a first step to constructing a healthy mothering identity. The transition to motherhood and, in particular, to that of mothering an autistic child, is made easier if the mother lets go of aspects of her personhood and prior occupations, at least initially. Therefore, on one level the concept of choice had less relevance to these mothers' occupational identity; choice within their OI was restricted if they were to adapt to the demands and expectations of mothering an autistic child.

Mothers' present sense of occupational competence was related to the self-perception and OI they built upon throughout their life and shaped what they knew themselves capable of achieving

in the future. In this way, past OI supported competence in the present. Similarly, high occupational competence and performance of mothering across systems buffered the OI in a system in which mothering performance was faltering. Mothers' perspectives were important to the establishment of a heathy OI. However, despite occupational competence, the unpredictability brought by their child's interaction with the world and inadequate structural supports potentially threatened mothers' future sense of OI coherence and wellbeing.

These mothers worked hard to be informed and to understand the systems in which they must operate for their child to best function in the world. Notwithstanding the importance of the mother's perspective in supporting adaptation to this new OI, services and systems took time to understand and to navigate. Parental self-efficacy was evidenced by mothers' achievements for their child but also by the quality of the mother-child relationship. Belief in their mothering competence and parental self-efficacy was reduced by poor relationships and by circumstances in which mothering had less impact and mothers had less control.

Mothers were required to adopt alternative mothering which caused a shift in their mothering identity and placed alternative demands on their occupational competence. Their mothering was represented by mundane and extraordinary occupations, and most were in some way adapted. Irrespective of their adjustment to the idea of autism, and in spite of the reduced choice for alternative occupational engagement, mothering remained hugely meaningful for each mother and their dominant OI. Consequently, they continued to adapt to changing circumstances, respond to their child's developing needs, and act as conduit between child and the outside world. The additional obligations, workloads and challenges mothers experienced was seen to impact their mothering OI, contribute to their experiences of occupational injustice, yet they persevered – adapting, advocating, caring – because this is understood to be their purpose as mothers.

The following chapter further discusses the themes and topics developed through the analysis of findings in Chapters Five, Six, and Seven. Drawing on the literature, and in relation to the objectives of this study, it expands understanding of mothers' experiences of occupational injustice, problematising mothering, while also attending to mothering as an occupation with possibility for growth and becoming.

Chapter Eight

Discussion: A feminist and occupational justice understanding of mothering an autistic child

8.1 Introduction

The following chapter integrates findings from the three findings chapters (Chapter Five: the reflexive thematic analysis, Chapter Six: BNIM cases, and Chapter Seven: cross-case analysis) with the literature. Mothers' lived experiences of mothering autistic children are understood in relation to the key occupational concepts presented in Chapter Two. In line with research objectives three and four, this chapter brings the centrality of occupational justice in these mothers' lives to the fore. Objective three focused on exploring the relevance of occupational justice in the lives of these mothers including their micro-macro level supports and challenges, while objective four aimed to explore how these mothering experiences might expand an understanding of the concept of occupational justice. Applying a feminist lens to the discussion of findings, this chapter relates the understanding of mothering presented in Chapters Two and Three to the lives of the mothers in the current study. Feminism is used to highlight deeply entrenched ways of thinking and being that influence the doing of mothering and which contribute both negatively and positively to mothers' lived experiences.

The chapter is divided into two main sections. The first (section 8.2) draws out the conditions pertaining to occupational justice that were evident in all 17 mothers' narratives. It describes their additional care burden and occupational imbalance; mothering as gendered labour; their experiences of marginalisation; and their negotiation of structural supports. The second section (8.3) in the chapter explores factors, both internal and external to mothers, that may be indirectly related to occupational justice but that problematise mothering. Mothering is also conceptualised as an occupation with possibility and as site for growth and becoming. To this end, this section presents ideas that may meet the diverse needs of these mothers and build a more occupationally just society.

8.2 Creating conditions for occupational (in)justice

The conditions that support or hinder occupational justice, evident in the current study, are discussed in this section linking this chapter directly to the research questions – mothers' lived experiences and the relevance of occupational justice in their lives.

8.2.1 Burden and balance

Across studies it is generally understood that mothers of autistic children carry a high care burden (Asmare et al., 2023; Bozkurt et al., 2019; Fowler & O'Connor, 2021; Mohammad et al., 2022; Padilla-Petry & Saladrigas-Tuà, 2022; Patel et al., 2022; Rasoulpoor et al., 2023; Soytaç et al., 2022; Vilanova et al., 2022). Mothering an autistic child is considered a broad role that invades most aspects of mothers' lives (Dash et al., 2023). Mothers, as opposed to fathers, typically carry the burden of family functioning (Kim et al, 2021; Fowler & O'Connor, 2021) and take a disproportionate responsibility for care, as well as educational and therapeutic decisions (Padilla-Petry & Saladrigas-Tuà, 2022). As suggested in Chapter Three, excessive *doing,* busyness, and burden are known to create conditions of occupational imbalance for these mothers (Hodgetts et al., 2014; Rizk et al., 2011). Balance in the current study is understood to manifest in relation to the practice and experience of motherhood within a given sociocultural context. It is of particular concern in this study given its relationship with occupational imbalance, which, when the result of external factors, is an outcome of occupational injustice. To frame imbalance as a function of doing-being-belonging-becoming through occupation, I conceptualise it as mothers' struggles and successes at: 1. Balancing their various demands on their doing – doing for their child, family, self, and more, 2. Balancing the active demands of mothering with their values and emotional experience of mothering (being), 3. Balancing personal meaning in mothering with their desire to meet social expectations for their engagement (belonging), 4. Balancing their priorities for mothering activities relative to participation in other meaningful participation and relative to their aspirations for future participation (becoming).

Matuska and Christiansen's (2008) construction of a model of lifestyle balance focuses on meaning through delineating five biological and psychological dimensions necessary to achieve balance and wellbeing in life. An aspect important to lifestyle balance is the perceived satisfaction of occupational needs within each dimension. By synthesising related literature, Stein et al. (2011) validate the Model of Lifestyle Balance by applying it to parenting autistic children. For these parents it is possible to buffer, or alternatively increase the risk for stress, in the dimension of

biological health and safety needs by balancing, or not, occupations in relation to the remaining four dimensions. In mapping Matuska and Christiansen's model to the current study's findings and considering outcomes as occupational injustices, the dimensions were found to be interconnected. This study reinforces Stein et al.'s conclusion that imbalance in the other four dimensions can result in reduced wellbeing at the level of health and safety needs. See Table 8.1 for full explanation.

Table 8.1

Application of Matuska & Christiansen's Model of Lifestyle Balance

Application of Matuska & Christiansen's Model of Lifestyle Balance				
Five dimensions required for lifestyle balance	*Stein's application to parents of* autistic *children*	***Application of model to findings within current study***		
		Creating conditions for occupational BALANCE	***Creating conditions for occupational IMBALANCE***	***Recognition as an OCCUPATIONAL INJUSTICE***
1 Embracing rewarding and self-affirming relationships	Caring for child can alter parent's social supports and relationships with friends, family & others.	Through connecting with other mothers of autistic children; leaning on family for support/childcare. Creating socially supportive education/health environments.	Through being excluded by others or self-excluding from normative mothering and familial activities. A lack of understanding and support from family & friends. Battles with schools and healthcare services.	Occupational marginalisation & alienation within the informal social environment. Unsupportive system (macro-meso-micro) supports.
2 Feeling interested, engaged, challenged, and competent	Parents may have particular challenges managing behaviours, fostering development, providing appropriate care & services, feeling engaged with their child. These may lead to	Through advocacy activities with education and healthcare. Through successful negotiation of child-related crises.	Through lack of regard of & support to mother from professionals. Through experiencing failure in securing services or appropriate educational provision, in negotiating crises.	Lack of available, accessible and supportive service provision to support child, mother, family leading to feelings of incompetence, guilt & shame in mothering role that negatively impact engagement in mothering.

	feelings of incompetence in parenting role.	Through attendance at useful mothering courses/services that enhance parental efficacy. Through effective autism related research.		
3 Creating meaning and a positive personal identity	For some, parenting can increase life satisfaction but many experience 'loss of self' and struggle to maintain individual identity.	Through parental efficacy endeavours and meaningful 'me' time. Through adjusting perception of child, aligning expectations for personal engagement with experiences of mothering.	Through endeavours to maintain pre-mother identity that cannot be supported by demands of current role and environment. Through disengagement with occupations of personal meaning beyond mothering.	Occupational alienation, imbalance and perhaps deprivation when engagement lacks diversity, choice and personal meaning.
4 Organising time and energy to meet important personal goals and personal renewal	Parents' lives are often dominated by the needs of their child, leaving parents with little time for other personally meaningful occupations.	Through selfcare, planning time, adapting activities and routines, altering standards and expectations to fit contextual demands.	Through hectic school and therapy schedules, lack of support to manage everyday activities and social life.	Occupational imbalance and alienation. Deficient practical (macro-meso-micro) system support.
5 Meeting biological, health, and safety needs	Parents are at increased risk for stress, anxiety, depressive feelings, poor sleep quality and quantity, decreased daily mood, and decreased perceived wellbeing.	Through becoming informed about autism, attending behaviour management/parenting courses, prioritising & engaging in selfcare activities.	Through worrying about the present & future, not experiencing control over their environment, not experiencing mothering competence, not being supported by spouse or family, feeling misrepresented by roles and activities.	Indirectly leads to the above occupational injustices.

Mothers of autistic children were represented in Chapter Two as having additional demands in relation to *doing*, with consequences for their daily lives and relationships (Bobadillo, 2024). Hoogsteen and Woodgate (2013) describe chaotic, disruptive days and burnout that impact mothers' ability to satisfy many dimensions of a balanced lifestyle particularly relative to organising their time and energy (dimension 4) and managing stress. In line with the literature, many mothers in the current study described time pressures, worry, and a life that involved the accommodation of normative activities that was concentrated on supporting their children and family. Juggling multiple roles (Safe, et al., 2012), struggling to meet the demands of childcare and pressure to "keep it all rolling" (Hodgetts, et al., 2014, p.88), justifying taking time for themselves (Safe, et al., 2012), assuming the many responsibilities to care for others (Anderson, et al., 2020; Bobadillo, 2024; McGuire, et al., 2004) and to meet others' needs (McAuliffe, et al., 2019), both in the literature and in the current study, resulted in career and leisure sacrifices (Blanche, et al., 2015; Hodgetts, et al., 2014), loss of friends (Altiere & von Kluge, 2009), lifestyle imbalance (McGuire, et al., 2004; Safe, et al. 2012), deterioration of personal wellbeing (McAuliffe, 2019), frustration and exhaustion (McAuliffe, et al., 2019; Shattnawi, et al., 2021).

Contributing to mothers' burden, busyness, and occupational imbalance is the individual and societal conceptions of caring (Bobadillo, 2024). These mothers spend significantly more time in childcare than mothers without autistic children (Behina et al., 2017). In keeping with the literature, most mothers in the current study identified as the primary carer (Blanche et al., 2015; Chiaraluce, 2018; Nealy et al., 2012). Maximally using autism services is recommended by Hines et al. (2014) by way of sharing the care burden and enhancing balance. As discussed in section 8.2.4, this was problematic for mothers in the current study given the dearth of local services. Feminist and human rights activist, Waring (2017), urges that attention be paid to over-occupation that results in a lack of time for occupations to enhance quality of life and to the consideration of the conditions under which unpaid carers work that may violate their human rights, such as little time for rest and access to support. Imogen, Niamh, Maeve, Sadie, Tess, Jane, and Helen each referred to the additional burden of caring for the whole family and household with inadequate sharing of the load from their spouse. Bi et al. (2022) recommend improved division of labour in the home, namely practical assistance in household matters from spouse and extended family. Reconsidering the ownership of practices that share the care burden and responsibility could create supportive conditions conducive to occupational balance and wellbeing.

Matuska and Christiansen (2009) suggest that structuring daily routines to address the needs of the family is essential for achieving life balance. Pentland and McColl (2008), on the other hand, emphasise living in harmony with one's personal values as central to the development of a sense of balance and a key contributor to wellbeing. Taken together, these authors highlight the importance of aligning daily activities with both family responsibilities and personal values to create a balanced life. In the current study and the literature, mothers expressed their values through the prioritisation of their child's wellbeing (Kim et al., 2018) and in their need to be available for their child (Bobadilla, 2024; Hoogsteen & Woodgate, 2013). Although aligned with their mothering values, this reduced their discretionary time and energy for occupations focused on the mother. Personal projects and social lives of parents are abandoned as parents adapt their lives to attend to their child's needs (Padilla-Petry & Saladrigas-Tuà, 2022). Consequently, it is likely that mothers are not meeting dimensions of the Model of Lifestyle Balance presented in Table 8.1 (*Creating meaning and a positive personal identity,* and, *Feeling interested, engaged, challenged, and competent),* which contributes to generalised experiences of occupational injustice, including that of occupational imbalance. McGuire et al. (2004) report social and leisure participation difficulties of these mothers. In the current study mothers, commented on the difficulty of taking time to themselves (me-time) given the demands of their various roles and their need to resolve their children's support issues.

Some mothers (for example, Heather, Imogen, Paula, Tess, and Jane) recognised the need to make more time to create occupational balance and a sense of wellbeing. McAuliffe et al (2019, p.72) describe the requirement for mothers to integrate "me-time" activities into their daily routines, satisfying their need within the Model of Lifestyle Balance with regards to *Organising time and energy to meet important personal goals and personal renewal*. While taking time for oneself is considered a healthy coping strategy that should be promoted among mothers of autistic children supporting them to fulfil their mothering role (Kuhaneck et al., 2010), Rizk et al. (2011) warn that increasing the leisure demands for mothers, who already carry high caregiving burdens, may exacerbate feelings of exhaustion. Without personal meaning attributed to leisure/me-time activities, the cost of engaging in an activity, in terms of applying additional pressure on time-poor mothers of autistic children, can outweigh its benefits (Rizk et al., 2011). Me-time, for mothers in the current study, when meaningful to the extent of being perceived as essential to their weekly function, such as participation for Tess in choir and Maeve in church, contributed to occupational balance. As described in Chapter Five, many mothers in the current study had re-evaluated their perspective on life, and occupational engagement in discretionary time was often seen as an

opportunity to reclaim a sense of themselves. Depending on the personal meaning attached to the occupation, not all lost leisure or sacrificed social occupations were perceived negatively by mothers in the current study. Some mothers readily shed association with other mothers whose attitudes no longer reflected their own, demonstrating *becoming* through creating new occupational balance.

That said, compounding perceptions of occupational imbalance in the current study may be the incongruence of their mothering experiences with those of their peers which in turn reduced opportunities for *belonging* through mothering. Congruence between occupations and the values of family and community (Yazdani, 2018) are shown to influence perceived occupational balance. These mothers were operating outside the normative mothering ideology of their social group (Wada et al., 2010); their participation in the typical activities of women and mothers of their life stage were restricted (Backman, 2004) which may contribute to their perception of imbalance and experiences of marginalisation.

The Model of Lifestyle Balance (Table 8.1) stresses the importance of: *Embracing rewarding and self-affirming relationships*. In keeping with this, Wagman and Hakansson (2019) refer to the interpersonal aspect of occupational balance. This plays out positively when support is provided to mothers (Santoso et al., 2015), conversely, mothers' endeavours to meet the needs of others can demonstrate a negative impact of interpersonal relations on their occupational balance (Hodgetts et al., 2014). According to Ford (2018), if the mother functions as the ground on which the rest of the family build their subjectivity, she has no support for herself. To balance their caring obligations, authors emphasise the importance of emotional, rather than practical support, from spouses (Bobadilla, 2024; Woodgate et al., 2008). The development of Maeve's mothering concurs with the need for emotional support. Although the challenge of mothering Ruby increased with her hospitalisation, by no longer being undermined by her husband, Maeve's confidence in mothering saw an improvement. Khanna et al. (2011) note that coping with care giving challenges as a collective unit could have beneficial effects on caregiver health status. Social experiences within the family can serve as either a protective or risk factor, depending on the level of family support (Gray, 2002a, 2006; Ilias et al., 2018). Spousal support is considered essential for mothers in managing their daily lives caring for autistic children (Ilias et al., 2018; McAuliffe et al., 2022) and may go towards compensating for the low levels of other support that is typical for this population (Bromley et al., 2004).

Dash et al. (2023) propose that occupational balance as described in the literature is a privilege that is not attainable for everyone. As explained in Chapter Three, mothers of autistic children engage predominantly in obligatory occupations rather than in occupations of choice (Hodgetts et al., 2014; Rizk et al., 2011). It may be that expectations of occupational balance require revision. However, this becomes an occupational justice issue when, in relation to experiences of occupational balance, these mothers are surviving but not thriving in their role. A feminist analysis of mothering autistic children recognises that practices are embedded in structures that uphold neoliberalist ideals of individual responsibility with the onus of such responsibility placed on mothers (Dash, et al., 2023). Aspirations towards autonomy and individualism have no value in mothering (DiQuinzio, 1993), particularly mothering autistic children. Imbalance stemming from structural and attitudinal conditions, that can be alleviated by sharing of responsibilities and reducing the care burden, I suggest, can and should be addressed.

Liu et al. (2023) stress that the complexity of human-environment transaction that occurs during occupational engagement is overlooked by the focus on individualism and agency in most understandings of balance, including the Matuska-Christiansen model. In occupational balance discourses, shifting emphasis from the individual's behaviour and preferences to encompass the importance of the human-environment transaction has resonance for mothering in several respects, not least given its interdependence in families, and with schools and communities. Meso-level mothering experiences in the current study were contingent on their interactions with teachers and healthcare professionals to create occupational harmony and perceived balance. Furthermore, I contend that the Model of Lifestyle Balance ignored human-environment interaction related to gender and other factors that are socially constructed but contribute to shaping behaviours and preferences at an individual level and in creating lifestyle imbalance. The role of mothering as gendered labour requires consideration in the creation of occupational injustices.

8.2.2 Gendered labour

The gendered labour of caring for an autistic child laid foundations for mothers to experience occupational injustice. Because, in most families, mothers are the default carers (Baker & Drapela, 2010; Chiaraluce, 2018; Mello et al., 2019), by taking the primary responsibility for their children, devoting more time to caring through partly or wholly stepping away from other activities, mothers contribute to the expectation that this is their role. Valanova et al (2022), explaining the case of mothers in Brazil, claim that while there is social pressure on mothers to take up the

primary carer role, additionally mothers identify with this role and therefore are more inclined to forego their own interests for the benefit of their family. Frye (2016) describes the activities and responsibilities of fatherhood as very different to those of the mother – most work fulltime (Potter, 2017) and few are involved in the child's therapy (Frye, 2016). Mothers' caring occupations are many and varied while fathers are limited (Dash et al., 2023). Mothers in the current study were aware that society expected of them a different form of parenting than it did of fathers. Although mothers were thought of as the primary carers, only some of the mothers in the current study thought this was an unfair burden relative to fathers; most thought it was an unfair burden because of the impact it had on other aspects of their lives and because their parenting was judged and unsupported. Mothers commented on the traditional expectations placed on mothers in Ireland and the gendered parenting that assumed that mothers will be the first responders to their child's difficulties. A redistribution of parental roles may ease the care burden (Asmare et al., 2023) but modification to mothers' own perceptions of maternal care and responsibility may also create more occupational justice.

In the current study, the gender inequality evident in mothers' experiences of caring for their autistic child and was, for most, in some way related to the familial decision for mothers to increase their in-home hours by reducing their hours of paid employment and thus becoming more available for care and domestic duties. While mothers' careers are known to be disproportionally affected in comparison to fathers' work (Baker & Drapela, 2010; Brewer et al., 2018; Cidav et al., 2012; Gray, 1997), the relationship between mothers and their paid employment in the current study was nuanced. Prior to becoming mothers, they held a range of jobs with varied responsibilities. In response to either becoming mothers or receiving their child's diagnosis, most changed their working hours or form of work. They did so for varying periods of time, with mixed justification, and in the context of their individual familial circumstances and child's needs. Mothers tend to reduce their working hours or leave their job to cope with the additional time demand that is typical of caring for an autistic child (Behnia et al., 2017), to decrease non-parental care, to manage therapy schedules (Hodgetts et al., 2014; Houser et al., 2014; Smith-Young et al., 2020) and to facilitate their multiple roles as advocator, teacher, therapist (Hoogsteen & Woodgate, 2013). Similarly, in the current study, some mothers (Tess, Kate, and Eloise) temporarily left their jobs for a year to establish their child's therapy schedule while others (Myra and Imogen) stepped away from paid work entirely and for several years, before rethinking their career options. Conversely, despite a desire to reduce their working hours, Tess and Claire retained their full-time hours in order to fund additional therapies.

Hartley et al. (2014) refer to the division of labour in caring for autistic children as partial *role specialisation* with mothers adopting more care tasks and fathers participating more in paid employment. The term *role specialisation* may disguise the reality of familial care arrangements and the fact that many mothers, who change their employment profile in response to their child's diagnosis, make an *obligated* choice (Baker & Drapela, 2010) due to the inflexibility of the male-model of workplace organisation (Scott, 2018) and incompatibility of prioritising the needs of their employer and their child (Schmidt et al., 2023). From a feminist perspective, this demonstrates unequal opportunities for the parent shouldering the burden of care, who traditionally and typically, in Ireland (Cronin, 2023) and elsewhere (Scott, 2018), is the mother. It generates difficulties in the development and maintenance of a career and creates conditions for occupational injustice.

In this, and other studies (Dash et al., 2023), mothers engaged in the activities of motherhood as a gendered role. In doing so they gave of themselves partly because their role lacked free choice. The obligated choices these mothers made was conditioned by a society, of which they were a part, and represented motherhood as a patriarchal concept that assumed mothers do for others (Rich, 1976). As suggested in Chapter Three, there is an unquestioned assumption that women take up occupations related to care and nurture (Nussbaumer et al., 2024) and are socialised to do so (Floyd, 2023). Women are held responsible for the wellbeing of others (Floyd, 2023). They have always taken care of everyone else (Ford, 2018) and this is most especially true of mothers (Ryan & Rundwick-Cole, 2019). Although Nussbaum (2000) believes value has emerged from mothers' altruism and demonstration of care and love, caring in general is more often experienced as challenging (Waring, 2017). Since childcare and domestic activities have come to be understood as women's work, they have represented undervalued and unpaid toil (Gregory, 2023). Although recognised as playing an essential role in society, mothering is typically taken for granted (Larson, 2000). As noted previously (section 3.3), a principal reason for feminists' discomfort with motherhood is its potential to reinforce biological determinism underscoring gender differences (O'Reilly, 2019a; White, 2010). Feminists assert that mothering, through the patriarchal lens, limits women's agency, selfhood, and authority (Green, 2019; O'Reilly, 2019b). However, Maher (2005) suggests that mothering should be acknowledged as labour and recognised as occupation that forms the basis for subjectivity. I contend that the problem does not lie in mothering or in caring but in the assumption that mothers will care, care in a way that meets certain standards (Arendell, 2000; Baker, 2007; Williamson et al., 2023), and in providing mothers with no other real choice.

Choice in occupational engagement is related to occupational justice (CAOT, 2016), particularly that of occupational marginalisation (Stadnyk et al., 2010).

In addition to practical efforts to care and orchestrate family life to meet the needs of their autistic child, Floyd (2023) describes how mothers actively manage their own feelings to create a particular emotional environment for the benefit of others. This, she refers to as *emotional labour.* The mothers in the current study were engaged in emotional labour, sometimes appeasing authorities while at other times contesting this position in an effort to create a nurturing environment for their child. Despite the vast and varied number of mothering activities, mothering is often conflated with caring (Dash et al., 2023). Caring is linked to essential moral virtues including empathy, responsiveness, a readiness to prioritise others' interests over one's own, as well as the capacity to problem solve how the needs of others should be met (Nussbaum, 2000). It is conceptualised as supporting, understanding, accepting, and providing (Bobadilla, 2024). Caring, as evidenced in the current study, is a skilled, challenging, but also a potentially fulfilling, role. For most of the mothers in this study, because they cared, they endeavoured to nurture and protect their child through engaging in occupations that may not have reflected their chosen way to live or even mother. Consequently, amalgamating the perspectives of both Nussbaum and Floyd, I suggest, mothers' capacity to engage in emotional labour may be recognised as both the magic and menace of motherhood.

8.2.3 Marginalisation and inclusion

Dominant discourses on motherhood and family influence mothering an autistic child and affect, not only mothers' ideals around motherhood and family, but also their experiences of social inclusion (Chiaraluce, 2018). A diagnosis of autism can result in changes in the social life of families and in reframing the family identity (Farrugia, 2009). The greatest burden expressed by most mothers in the current study related to that which Papadopoulos (2021) referred to as social and emotional burdens. Marginalisation (see Table 8.1) was a prevalent outcome of the occupational injustices experienced by mothers in the current study. Many mothers are actively excluded from normative mothering occupations (DeGrace, 2004; Fowler & O'Connor, 2021; Larson, 2010; McAuliffe, 2019; Moorthy et al., 2023; Safe et al., 2012), and arguably have their experiences silenced (Baker, 2007). Social isolation and aloneness in this population are common (Byrne et al., 2018; Lancastle et al., 2022; Lilley et al., 2020) and are irrespective of society's affluence (Woodgate et al., 2008) – a finding that resonates with the experiences of mothers such as Eloise in the current study. Mothers in this study were actively excluded when their child was not invited

to parties (for example, Helen), on playdates (for example, Kate), or onto teams (for example, Niamh); and mothers were conscious of their difference when they had little to contribute to discussions on normative childhood occupational participation (for example, Imogen). Padilla-Petry and Saladrigas-Tuà (2022) describe the difficulty in responding to social reactions to autistic children that either communicate judgement or indifference. Although being ignored creates parental feelings of aloneness and isolation (Padilla-Petry & Saladrigas-Tuà, 2022), this was preferable to many mothers in the current study as opposed to being stared at in shops, parks, and even schools.

Exclusion of these mothers from normative mothering activities, and their resultant marginalisation, reduces society's exposure to alternative forms of mothering that might serve to expand society's appreciation of diversity and its merits. Society, through daily occupations such as schooling and recreational activities, can exclude individuals not only based on social norms but also on perceived threats to the dominant groups within the social collective (Fransen et al., 2015). *Other-as-perceived-threat* was evidenced when other mothers did not want their child to socialise with Max, Ethan, and Isaac. Kate and Eloise described school principals who were reluctant to establish special classes for fear that the school would not cope with challenging behaviours, or its reputation would be impacted. Exclusion, based on perceived threats to the dominant group, has varying impacts on the child. It affects their opportunity to participate socially, infringing on their right to participate in local mainstream schooling, and consistently it impacts mothers' doing-being-belonging-becoming through mothering, creating conditions for occupational injustice.

Across time, mothers' feelings of exclusion negatively affect their sense of self and are compounded by the aggregate impact of the "looks of disgust" or "bad mother stares" (Chiaraluce, 2018, p.2894). Similarly, the everyday activities in doing mothering in the current study, impacted mothers' occupational identity and sense of being a mother. Claire's orchestration of family leisure time in an isolated forest was reminiscent of mothers in Vilanova et al.'s study (2022) who avoided leisure activities that required social interaction. Socially mothers felt isolated from normative mothering and some had actively excluded themselves from social events for various reasons – they struggled to secure babysitters; their children refused to socialise; it was too effortful to bring their child places; they found their child's behaviours too difficult to manage in public. Social events can trigger feelings of anxiety and fear, leading mothers, like Claire, to avoid such situations, negatively impacting their confidence (Moorthy et al., 2023).

In keeping with the literature (Lilley et al., 2020; Moorthy et al., 2023; Papadopoulos, 2021; Shattnawi et al., 2021) describing experiences of stigma, mothers in the current study, particularly those whose children had public meltdowns, had experienced embarrassment which deterred some from spending undue time in public with their child, further excluding them from the activities of everyday mothering. The current study's mothers self-excluded when they did not attend events or when their focus at the school gate was unambiguously anti-social to ensure a meltdown-free exit. They spoke directly to their difficulty connecting with other parents due to feelings of shame and embarrassment, of being judged by others on account of their child's behaviour, and/or of sharing little common ground as mothers in relation to children. These mothers' sense of isolation and difficulty "fitting in" is compounded by negative societal perception (Kuhlthau et al., 2014, p.1345). In turn experiences of stigma are found to increase feelings of disconnection from other families (Byrne et al., 2018; Kuhlthau et al. 2014; Lilley et al., 2023; Woodgate et al., 2008) and can give rise to feelings of shame (Bai et al., 2024). While the factors creating the conditions for stigma and shame may be external, and so of particular relevance to occupational justice, mothers are also seen to internalise their stigma and cope through self-imposed isolation and avoidance of social situations (Furrukh & Anjum, 2020; Shattnawi et al., 2021), demonstrating how both external conditions and personal factors serve to isolate mothers of autistic children.

Mothers in the current study operationalised their felt-difference through creating, what several mothers described, as "smaller lives" and by so doing reduced their social reach and had fewer opportunities for pleasurable occupational participation and experiences of belonging. The more restricted their social worlds, the less opportunity they had to actively engage with others in diverse ways and expand their occupational identity (OI). While information-based support (usually given by professionals) relies on contact frequency for mothers to feel supported, emotional and instrumental support (usually given by family and friends) is related to network size (Bi et al., 2022) **–** size matters, given that maternal anxiety is higher when their social support networks are smaller (Barker et al., 2011). The current study found that exclusion from normative occupations restricted some mothers' creation of a support network outside that of extended family or other families with autistic children. At times of occupational disruption such as receiving the diagnosis, social isolation can compound occupational identity (OI) loss (Martin-Saez & James, 2021). The relationality of OI highlights the public nature of OI construction and the detrimental impact of occupational marginalisation to these mothers' OI.

Perceived inadequate social support is a major predictor of mental health in this population (Bi et al., 2022; Boyd, 2002), negatively affecting stress and family socialisation (Bishop et al., 2007). Conversely, social support is significantly related to mothers' positivity and enjoyment of life (Al-Kandari et al., 2017; Cetinbakis, et al., 2018) and a reduction in negative maternal outcomes (Ekas et al., 2010). Informal supports, for example family and friends, online communities, and parent groups with shared concerns, provide mothers with relevant information-based support (Chiaraluce, 2018) and act as protective factors against maternal stress (Ekas et al., 2010; Ilias et al., 2018; Plant & Sanders, 2007), (though the literature on this is not wholly consistent – Nahar et al., 2022). Most mothers in the current study reached out to others experiencing similar concerns and living similar mothering lives, indicating the importance of empathy in providing social support. Padilla-Petry and Saladrigas-Tuà (2022) note how parents got more support from other parents of autistic children than from family or friends. I contend this may indicate that empathy is enhanced when those empathising are close to the issue – an important consideration for the concept of inclusion.

For many in the current study (for example, Imogen, Eloise, Heather, Maeve, Helen, Sadie, Jane, Sadhbh, and Olivia), a normative mother network was not valorised. Tribal marginalisation was witnessed amongst some mothers, who were on the edge of society at school and in extracurricular activities but, through contact with other families in similar situations, were immersed in an alternative form of social participation from which they gained a sense of community. Support from autism networks assists mothers in reorientating their perception of their child and contributes to a sense of belonging (Chiaraluce, 2018). The purpose and belonging Heather gained from attendance at autism conferences contributed to the reimaging of occupational possibilities for herself, her son, and their future given their affiliation with an alternative community with alternative ideals for mothering. This was in keeping with Chiaraluce's finding that, with the right type of community support, what is perceived as a loss can be transformed into a gain and provide a framework for mothers to reconfigure the self and family (Chiaraluce, 2018). It also reinforced that to belong as mothers was facilitated by identifying with autism mothering and connecting with the people involved. In contrasting Heather and Eloise with Claire, it was evident, that without active engagement in autism-related social networks, mothers may gain a level of information-based support from professionals but were unlikely to build a related community. Belonging and becoming are not neutral or passive extensions of doing but are negotiated within a given sociocultural and temporal context at individual and collective levels

(McGrath, 2017). The belonging through mothering witnessed in this study required active engagement, motivation to connect, and a reciprocity based on a common focus and interest.

8.2.4 Systemic and structural support

The experience of the diagnostic process and therapeutic interventions was, in this study, a central facet in understanding the lived experience of mothering an autistic child. Chiaraluce (2018) refers to the diagnosis as the primary narrative disruption when family meaning and coherence are lost. In keeping with the literature (Crane et al., 2016; Howlin & Moore, 1997; Siklos & Kerns, 2007), all mothers in the current study had strong memories of the diagnostic process including how the diagnosis was imparted; while, in many cases, disruption to the family had been taking place for many years before the diagnosis, it formalised the mother's and child's deviation from the normative path and triggered the mother's search for services and supports. The autism diagnostic process is known to be stressful and lengthy (Braiden et al., 2010; Brookman-Frazee et al., 2012; Keenan et al., 2010; Siklos & Kerns, 2007; Smith-Young et al., 2020) with the barriers to achieving a diagnosis relating to affordability, availability, and geographic accessibility (Lilley et al., 2023) creating conditions for occupational injustice. Delays in gaining diagnoses and access to services are common (Crane et al., 2016; Keenan et al., 2010; Shattnawi et al., 2021; Zuckerman et al., 2014) and the length of this delay correlates with parental dissatisfaction with the process (Crane et al., 2016). In the current study the stress of delayed diagnoses was heightened where time pressures on children's eligibility for necessary educational supports existed and was also more intense when mothers' interactions with professionals were negative. Once mothers express concerns and professional help is sought, some mothers, both in the literature (Schwartz, 2001; Smith-Young et al, 2020; Zuckerman et al., 2014) and in the current study, had their concerns dismissed by educational and healthcare staff. This led to acts of resistance as mothers in this study battled to have their concerns taken seriously; it created stress and uncharacteristic *doing* and *being* on behalf of mothers.

A delay-free diagnostic journey in the current study was more likely possible when mothers employed private practitioners, or, when recommendations for assessment came from diagnosticians/ healthcare team whom children already attended. Learning from the experiences of other mothers who were skilled system navigators proved important to gaining a diagnosis without extensive delay. Fowler and O'Connor (2021) similarly note the importance of reciprocity between mothers, which, they comment, is typical of female ethics of communal care. Given that misdiagnosis and late diagnosis can impact children's access and use of therapeutic services, in

turn compounding difficulties (Braiden et al., 2010; Johnson et al., 2020), this reliance on personal contacts, other mothers, and/or finances to resource private diagnosticians was unfair to mothers and their child and led to experiences of occupational injustice. Waiting for a diagnosis added to mothers' stress and worry for their child. Mothering was negatively impacted and unsupported by the system and for a protracted length of time. Some, like Claire, were rudderless without direction on how to prioritise Max's therapy needs; others, such as Olivia, were tested on an interpersonal level as they interceded for their child with education staff pre-diagnosis. Crane et al (2016) recommend that the diagnostic process is made easier. In Ireland, with the launch of the government's Autism Innovation Strategy and establishment of the HSE Service Improvement Programme for the Autistic Community, it is hoped that the improved diagnostic processes and capacity may go some way to moderating the stress in accessing diagnostic services, reducing mothers' need to challenge professional opinion, and increasing the speed with which children can avail of therapeutic and other supports.

Mothers and childcare staff/educators are found to be key figures in the identification of developmental concerns in the literature (Braiden et al., 2010; McConkey et al., 2008) and in the current study. However, the delay in mothers expressing their concerns to healthcare staff, together with the delay in gaining a diagnosis, can result in children's delayed access to therapeutic supports (Crane et al., 2016). Relying on mothers' ability to recognise concerning behaviours (Johnson et al., 2020) and appreciate how these are best assessed and addressed, required, in the current study, a level of operational knowledge of the health services, in advance of mother and child entering the system. This was an unfair ask of mothers and exacerbated their feelings of frustration and inadequacy. Smith-Young et al. (2020) describe the period in which parents express their concerns and pursue diagnostic evaluation as *watchful waiting*. In contrast, as described in Chapter Five, the route to gaining a diagnosis, for many in the current study, was considered to involve active rather than passive engagement, with mothers seeking to understand their child, the assessment, and the intervention processes, making contact with services, reacting to crises, and discussing their concerns with professionals in education and health. I suggest that the heightened level of activity and worry at the pre-diagnostic stage may be circumvented by the provision of more diagnostic services, the sensitive engagement with mothers to highlight concerns for children's unmet additional needs, and responsive interactions with mothers who have their own concerns about non-normative child behaviour.

In keeping with the literature (Smith-Young et al., 2020) and regardless of their initial reaction, the diagnosis was perceived by this study's mothers as a pathway to securing interventions and support. Unfortunately, most mothers experienced services and tailored supports as lacking or inaccessible in healthcare, education, or both, and expressed frustration, anger, and disappointment. Keenan et al.'s (2010) sample of Irish and Northern Irish parents (92% were mothers) concurs with this, claiming that, not only is the diagnostic procedure distressing and difficult to understand, but the process also lacks clear post-diagnosis support and advice. Following a diagnosis parents are often left not knowing what to do next (Bai et al., 2024; Zuckerman et al., 2014). The lack of public sector service provision in the current study was a prime contributor to the experience of dissatisfaction, exacerbated mothers' concern for their child's future, and increased the likelihood of children and mothers experiencing occupational injustice. Having little access to public supports considered both essential to their child's development and, in several cases, to the viability of their child's attendance at mainstream school, was unfair on children and, by extension, on their mothers who were unsupported in their mothering role and had little control over, or means to guarantee, their child's welfare.

Studies have identified several factors contributing to parental dissatisfaction at different stages of accessing services for children (Corcoran et al., 2015; Stanford et al., 2020). While mothers have mixed experiences with healthcare professionals, some positive, more negative (Braiden et al., 2010; Fowler & O'Connor, 2021), in the main, delays in receiving diagnoses and long periods on waiting lists for services (Brookman-Frazee et al., 2012; Corcoran et al., 2015; Crane et al., 2016; Lilley et al., 2023; Smith-Young et al., 2020; Swinth et al., 2015), fragmented and inefficient services with poor information sharing (Dillenburger et al., 2010), frustration with professionals' behaviour in both education and healthcare (Corcoran et al., 2015; Dillenburger et al., 2010; Osborne & Reed, 2008; Swinth et al., 2015), and disregard of parents' concerns and perspectives (Corcoran et al., 2015; Smith-Young et al., 2020), are the principal concerns noted in parental reports of service use. Issues with the quality and accessibility of autism services are known to increase the care burden on families (Shattnawi et al., 2021) and act as a primary factor affecting parental adjustment (Bai et al., 2024). Mothers in the current study echoed these experiences reflecting the nature of health and education supports for autism in Ireland. Many had stories of lengthy waiting lists to access diagnostic and therapy services, of unhelpful professionals, of location dependent supports and services, of a dearth of special classes in mainstream schools, of the consequences of untimely diagnosis in preventing access to educational supports, of miscommunication and incompetence, and of non-existent supports and unsuitable childcare and

education. It is hoped that the implementation of the Autism Innovation Strategy will improve service availability, access, and delivery.

Studies in Corcoran et al.'s meta synthesis on the lived experiences of US parents of autistic children refer to the subjective experiences of trying to understand and navigate service options as overwhelming and of efforts to coordinate and attend meetings and therapy sessions as exhausting. Negative experiences of using, or waiting to use services, were considered disempowering and reinforced the current study's mothers' vulnerability to inadequate social structures which added to the challenges of non-normative mothering. Stanford et al. (2020) identify aspects of good practice in autism care that are relevant in the context of the current study. Mothers value empathetic and personable practitioners who also are competent and focused on meaningful outcomes; they appreciate services that are resource-rich, adaptable, accessed easily, and timely so that their child benefits from early intervention (Stanford et al., 2020). The heightened awareness of the neurodiversity movement in Ireland at macro levels has prompted services to align with a neurodiversity affirmative approach (Government of Ireland, 2024; Kavanagh et al., 2025) with the potential to enhance mothers' experiences of service use.

In contexts where there are pressures on public services, seeking the support of private professionals can be preferable (Keenan et al., 2010; Smith-Young et al., 2020). Parents using private services, in Smith-Young et al.'s study, report a consumer-led experience that offers regularity and predictability (Smith-Young et al., 2020). Mothers in the current study also found private services to be an accessible alternative to long waiting lists for public services, although certain supports, such as special classes, were not possible to establish even with funds. The literature refers to the cost of private therapies and families taking on debt to pay for such supports (Myers et al., 2009; Smith-Young et al., 2020). Mothers such as Claire, Kate, and Olivia, in the current study, commented on the financial burden of paying for evaluations and therapies. Within the Irish context, families across one year are found to spend an average of €948 per child on private therapeutic interventions and assessment with some spending up to €14,400 (Roddy & O'Neill, 2019). Such input situates parents as essential to meeting their child's needs and becomes a question of injustice for child and family if the parents do not have the financial means. However, no mother in the study regretted such spend. This demonstrated the deep commitment of mothers to their children; their adoption of the role of protector, nurturer, and trainer (Ruddick, 1989/1995). Olivia commented that it was her duty, and not the responsibility of others, to nurture Leon's development reflecting the reallocation of responsibility for children's

development from state to individual family, and mothers'/parents'/families' acceptance of the neoliberal ideals of independence and responsibilisation.

Referring to Ireland, Bacik (2007) claims that, for a society that has placed such emphasis on the family, the state is doing little to support them and less to demonstrate they value the work that goes into caring for them. The current study found that relying on the public system to provide timely services for children was problematic. To use services like consumers, mothers needed service-experience (to work in the sector or to have other autistic children), contacts (to reach out and take advice from other mothers), money (for private services), or all three. Being available to their children is a great responsibility (Anderson et al., 2020) for which mothers need adequate support. Consumer-led usage was evident in the case of Sadie who had insider knowledge of the autism assessment within the healthcare system. In line with Irish literature (Byrne et al., 2018), an understanding of the system took some time to develop for other mothers. To be able to use services, both public and private, on a needs-basis, mothers required both knowledge and funds. This clearly discriminates against those who have neither and is unjust. Referring to McGrath's (2017) concept of occupational friction, which describes the struggle between what is potentially versus practically possible, that which was potentially possible in the current study reflected, on one level, the normative world aspirations of these mothers, their imagined mothering. On another level, it represented the real possibilities within mothering their autistic child if given the right child, family, and maternal support. Identifying and accessing such appropriate supports, that may not yet exist in the Irish context for children such as Alex and Isaac, led to experiences of occupational injustice and also problematised mothering.

Neurodiverse affirming service provision supports acceptance of autism, promotes community inclusion, and its philosophy underpins several Irish autism organisations and charities (for example, AsIAm, Neurodiversity Ireland). Neuro-affirmative practices aim to relieve the stress autistic individuals and their families often experience when in receipt of services (Izuno-Garcia et al., 2023), and that which was experienced by most mothers in the current study. Although only some mothers (for example, Jane, Imogen, and Heather) referred to the concept of neurodivergence, and many referred to the need for the increased accessibility to existing services, the emphasis placed on the development of appropriate supports might indicate a need to consider a neuro-affirmative approach.

8.3 Mothering as problem and possibility

The following section explains how mothering can be perceived and experienced in such a way as to make it problematic, or alternatively recognised as holding opportunities and possibilities for mothers, largely depending on mothers' frame of reference and social norms. By considering factors that are indirectly related to conditions that support both occupational justice and injustice, such as the conceptualisation of motherhood and mothering identity, this section expands understanding of the relevance and utility of occupational justice in the context of these mothers' lives. It contributes further to answering research objectives 3 and 4.

8.3.1 Problematising mothering autistic children

Mothering an autistic child presents additional caring roles and responsibilities that can differ to those of a neurotypical child (Safe at al., 2012). In the case of mothers in this study, intensive mothering, if one had resources and capacity, was perceived a necessity due to the lack of structural and social supports. As explained in Chapter Three, the intensive mothering ideology, described by Hays (1996), assumes women are the primary carers who devote a great deal of time, energy, financial and other resources to mothering. It is underscored by an appreciation that children are precious, and that motherhood is sacred. The propensity of our society towards intensive mothering influences how society understands the way motherhood should rightfully be practiced (Arendell, 1999; Williamson et al., 2023). The *good mother* adheres to the canons of intensive mothering by being child-centred, self-sacrificing, and time-devoting (O'Reilly, 2019b; Randles, 2021). *Good* mother ideology, when applied to mothers of children with disabilities, additionally requires that mothers do not work outside the home, have the capacity and willingness to remain the child's primary carer for the child's whole life and manage their family life and mothering practices in such a way that it will have the appearance of normalcy (Brock, 2014). Mothers in the current study were not wholly complicit with this good mother ideology. Although almost all identified as primary carers and most modified their employment, their aim was to meet their child's needs rather than create the appearance of normalcy and all feared the future not only for their child but also for themselves.

Organisations and services such as schools understand the mothering role and purpose relative to an accepted standard conceptualisation of motherhood (Chiaraluce, 2018; Gupta & Garber, 2017), developed over time and influenced by dominant socio-cultural values. A singular conceptualisation of motherhood was problematic for mothers in the current study who were unable to inhabit their category as expected. The absence of a role model of a mother to an autistic

child, which was true for all mothers in the current study, is the equivalent to 'parenting without a developmental roadmap' (Greenspan, 1998, p.57) as cited by Ryan and Runswick-Cole (2008, p.203). Autistic children's non-normative participation and mothers' own intense relationships with services and supports, as noted in Chapter Three, reinforce mothering difference, decreasing their capacity to live by normative expectations. Dominant parenting approaches and values are less useful (Ryan & Runswick-Cole, 2008) rendering the development of a good mother (according to the ideology) under these conditions more difficult. Mothering autistic children is typically non-normative which positions it beyond the bounds of the good mother concept. Structural, child-related, and practical factors created conditions in which the current study's mothering diverged from the ideology's norms, as the mothers worked to negotiate and reframe what it meant for them to be a good mother.

Mothering for those in the current study involved changes to their ideas of mothering, their mothering occupations, and their mothering identities. These mothers experienced levels of loss concerning an imagined family and child relations; loss with regards to normative mothering and social group membership. According to Chiaraluce (2018), losses and changes at a meso-level, related to interactions with the local community, peer socialisation and friendships, marital relations, and employment, interact with the micro-level mother to influence their everyday participation. Chapter Three explained that the juxtaposition between mothering ideals and the reality of their lived experiences (Laney et al., 2015) can alter mothering behaviours in an effort to uphold ideals (Williamson et al., 2023). Such experiences were exacerbated for mothers in the current study whose realities were non-normative. Eloise, Kate, Claire, Sadie, Heather, and Imogen referred to their mothering as being ill-aligned with the normative activities of everyday mothering due to their child's diverse needs. Mothers experienced tension based on comparisons between their personal reality of mothering versus their imagined motherhood. Within the struggle between what was potentially versus practically possible, in the current study that which was practically possible was controlled by the structural and social conditions in which mothers lived. However, given the impact of these conditions on the mothers at a micro-level, overcoming these mothering losses and disruptions required a renegotiation of an OI beyond how mothers originally understood mothering and families and a reconciliation with mothering in an alternative form.

Mothers of autistic children often go to greater lengths than mothers of neurotypical children to meet both the needs of their children and the societal requirements for motherhood (Dembosky

et al., 2023). On becoming mothers of autistic children, these mothers strove, at personal cost, to mother against normative ideals and inadequate supports. Normative motherhood was problematic and tested their occupational nature and imagination. Developing alternative mothering practices, such as acting as therapist in home programmes, learning how to use systems to their child's advantage, and anticipating educational difficulties and proactively problem solving, demonstrated mothering responsivity to their child and ingenuity. Their mothering was varied, active, and reflected multiple roles. Increases to both the quality and quantity of these mothers' activities are expected (Woodgate et al., 2008) and speaks to Randles's notion of *inventive mothering* (2021, p.36). Paradoxically, despite their investment in intensive-inventive mothering, such mothering was not in keeping with the expectations of intensive mothering. Inventive and proactive mothering was not perceived by mothers in this study as valorised by society. As suggested in Chapter Three, dominant societal forces reflect an expected way to live (Gupta & Garber, 2017), marginalising others, such as these mothers, who have no choice but to live non-normative lives (Dembosky et al., 2023; Gupta & Garber, 2017).

Mothers became, not the mothers they imagined they would be, but the mothers they needed to be for their children. This required much adaptation to self, to mothering activities, and to family life. To mother effectively in the current study, both the mundane and significant activities were adapted to fit their contexts. Graham (1982) described mothers as copers who handle the pressures of their lives effectively and calmly, meeting their responsibilities by sacrificing their time, health and social life. This resonated with mothers in the current study. When their focus is on responsibility-sacrifice-coping certain possibilities for action, orientated around personal wellbeing, must be structured outside their role capacity, time, and energy. Maternity is further complicated by the relationship between the occupations of motherhood and the normative occupations of childhood. The dependency of child on mother tightens the bind between eithers' occupations. Pregnancy is cited as a form of enmeshed femininity with 'motherandchild' contained as one (Bracken, 2016, p.104). Similarly, understanding maternity as enmeshed assists the production of a patriarchal construction of the maternal as contrasted to the individuality of a subject. I suggest that society's not seeing a mother as a woman with personal subjectivity and OI outside motherhood, facilitates the reliance on mothers to cope and the devaluation of what they do.

Dominant constructions that underpin mothering children with disabilities need to be challenged (Runswick-Cole & Ryan, 2019). Ryan and Runswick-Cole (2008, p.199) explain that these mothers

operate within “oppressive mothering ideologies and disabling environments”, and their skills and contributions are undervalued. The extended period of caregiving typical of these mothers, coupled with the additional supports required, makes their mothering experiences qualitatively different to those mothering neurotypical children (Joosten & Safe, 2014; Lilley et al., 2023). Challenges to mothers’ role adaptation and function produce occupational performance issues relative to mothering (Roiz et al., 2023) and test the creation of a stable and coherent occupational identity (OI). Mothers often feel judged for their children’s failures but seldom congratulated for contributing to their successes despite developing special competencies in mothering children with additional or alternative needs (Ryan & Runswick-Cole, 2008). The non-normative mothering and positionality of mothers of autistic children may diminish their power generally and reduce their capacity to influence societal values. Despite their role as fervent advocates for their children, using their voices for the benefit of their children only contributes to the perception of mothers as selfless carers and may reduce their capacity to influence social perception to claim mothering rights to occupational justice.

Mothering under non-normative conditions places additional demands on mothers mothering in a normative world. I suggest, in line with Randles (2021), that aligning childrearing practices of mothers of autistic children with that of normative mothering perpetuates inequalities by obscuring the complexity of these mothers’ practices and underplaying their efforts in light of limited public support. By comparing these mothers to those mothering children without autism creates an expectation that there is a right way of mothering, or that some ways of mothering are more valued than others (Dash et al., 2023). In the current study, mothers, as occupational beings who were engaged in a challenging job and who were judged by someone else’s (their child’s) development according to normative standards, required support, appreciation, and reassurance to thrive. Dash et al. (2023) recommend communicating to mothers of autistic children that there is variation in how autism is thought about and understood. Accordingly, there are many possible ways to mother and society’s concern should be focused on mothers’ meaningful occupational engagement rather than on bringing their mothering in line with norms.

8.3.2 Possibilities in mothering autistic children

Across the autism journey mothers develop new understandings of themselves and others (Lilley et al., 2023). Engagement in the occupation of mothering helped mothers in the current study and others (Chiaraluce, 2014) to reconstruct their mothering identities to become empowered at micro to meso levels. They became experts on autism, autism health and education related

services and policies. Mothers honed their values. A central feature supporting this transformation was knowledge. Knowledge becomes power while knowledge deficits contribute to stress (Su et al., 2021). In the current study, mothers' willingness to try anything and everything, seek guidance, learn through trial and error in an effort to find a way of being and doing that fit with their child, created a new equilibrium between personal values for motherhood/family life and OI as a non-normative mother. Mothers' active practices, described through the thematic analysis, were orientated around doing and occupational performance centred. Although some mothers (for example, Olivia, Heather, and Imogen) became paralysed by problems related to the system, all considered action to be a form of coping. Some spent money on additional assessments, others on therapies; many joined autism organisations and consulted other mothers; they built relationships with teachers and school principals, canvased politicians, took autism parenting courses, accessed information on websites, and made changes to family routines. Like mothers in Lilley et al.'s (2023) study, mothers were pragmatic, resilient, and resourceful. Mothers' ability to affect change in their lives, and in the lives of their children and others, brings their practices in line with the potential for empowerment through mothering that is espoused in matricentric feminism (O'Reilly, 2019b; 2016b).

Through steady engagement in occupations across a lifetime, individuals build occupational identities that produce predictable occupational performances (McGrath, 2018). Some mothers in this study (for example, Imogen, Eloise, and Helen) used this self-knowledge of their own occupational competence and identity (related to occupational performances that may or may not have been linked to mothering) to actively and proactively change conditions for their child. Such proactive *doing* on behalf of their child in the current study provided opportunity for agency, self-development and OI expression. Although there is commonality in mothering, there is also possibility for variability in how mothering is prioritised, practiced, and experienced (Odgers et al., 2024). Mothers asserted their agency, as a mother of an autistic child, by choosing to engage in mothering activities which revealed their mothering values and priorities. Although motherhood can restrict a women's agency, mothering, as an active practice, had potential to reflect mothers' agency. Parallel with proactive engagement on behalf of their child, many of these mothers withdrew from other activities like employment, socialising with friends, hobbies, as well as restricting other family activities such as eating out going on holidays and trips. The alignment of their values for family life with that which was practically possible required sacrifice. This is problematic as, if represented only as a loss of mastery, control, and agency, motherhood is denied its capacity for affect (Dash et al., 2023; Stephens, 2004) and mothers may be unable to

grow in the role. Rather than limit opportunities, Tabatabai (2020) refers to failure as providing possibilities – moving beyond what is not working for these children and mothers to imagining a new way of parenting outside the norm.

Mothers of autistic children are seen as self-educating and actively advocating for their children (Anderson et al., 2020; Gill & Liamputtong, 2011; McKeever & Miller, 2004; Porter et al., 2024; Ryan & Runswick-Cole, 2008; Woodgate et al., 2008). Embracing the role of advocate is recognised as integral to shaping the identity of these mothers (Porter et al., 2024). Advocacy is about fighting for children's rights (Corcoran et al., 2015; Porter et al., 2024); it requires effort to make maternal voices heard (Woodgate et al., 2008) and those who shout the loudest are believed to receive most supports (Anderson et al., 2020). Mothers in the literature and in the current study (for example, Myra, Olivia, Helen, and Nessa) described pushing themselves outside their comfort zone to advocate (Fowler & O'Connor, 2021), behaving in ways they did not like and becoming people they never wanted to be (Dembosky et al., 2023). Advocacy was not an ad hoc endeavour. Mothers consciously committed to challenging the system and speaking out for resources and conditions their child needed irrespective of the personal impact on the mother.

Mothers such as Eloise came to advocacy with the advantage of skills and the financial means to acquire services and negotiate favourably on Lucy's behalf. Kate and Myra demonstrated how, with increased exposure to educational and healthcare services, they became more confident in understanding and explaining their children's needs. Experiential knowledge is invaluable in developing self-trust and confidence as a mother of an autistic child (Chiaraluce, 2019). Mothers, in particular Kate, Olivia, and Heather in the current study, echoed this finding, referring to trusting their gut instinct and having belief in themselves. Advocacy was an essential occupation or practice open to mothers in the current study to relieve situations of occupational injustice. While everyday occupations such as advocacy have the power to promote justice and change (Townsend, 1993), financial means, personal capacity, and experience with the system was found to enhance mothers' ability in this regard.

Injustices are played out in people's everyday lives at the level of the individual (Kinsella & Durocher, 2016). Unconscious and unquestioned actions and habits, alongside inadequate supports, contribute to the maintenance of privileged occupational participation of the dominant group (Bailliard, 2016). Changes to the sociocultural and structural environment, that have created the conditions for occupational injustice for mothers in the current study, could

potentially lead to increased satisfaction with their day to day lives. Occupation is embedded in context (Hammel, 2021) and it is this very context that can create injustices and also be used to moderate them. Quiet ('small p') politics provides new opportunities for social change through everyday decision-making that creates gradual shifts in dominant hegemonic norms and understandings (Hankins, 2017, p. 503). The current study showed that, through mothers' concerted efforts to be heard and have their child understood, it was possible to alter the social conditions in which their child functioned and, as such, the experiences of being a mother of an autistic child were enhanced. Some mothers (for example, Myra and Imogen) had reached a point in time where they were able to cautiously attend to occupations that were of meaning to their selfhood. However, while personal understandings of normalcy and success were altered through experiences of alternative mothering, the revision or expansion of societal attitudes effecting the perception and acceptance of difference took place on a person-by-person basis, leading to slow progress and requiring judicious effort by these mothers.

The intersubjectivity of lives from micro to macro levels (schools, healthcare, neighbours, shop keepers, friends, family, strangers) in some cases were seen to negatively impact the condition of motherhood and in all cases problematised it. Others in society have power to open up or close down occupational possibilities for these mothers. Shifts in perceptions, at all levels, may be crucial for these mothers to reach for an alternative potential so that, being such a mother would be valorised, and becoming, through occupations of meaning within this position, would be possible. For this to be realised these mothers must be supported to have voice and agency in the negotiation of their OI and to have recognition in making their everyday (small 'p') political acts (Winter, 2024). Barriers, that may be historical, cultural, social, economic, or political, that exist within the circumstances of their lives (McGrath, 2017), must be brought to public consciousness and negated. Relations can be harnessed as forces for change. In fact, conditions are difficult to change to any practical end without, as a starting point, a shift towards acceptance in the collective narrative on diverse ways of being; this is in line with the neurodiversity movement.

Arendell (2000) queries the extent to which a patriarchal construction of motherhood places mothers outside of the realm of the social, the changing, the active. She questions the extent to which the mother can influence society. The engagement of mothers in the current study in intensive mothering without achieving good mother status may position them to enact change from within. Through the quiet politics of everyday (Hankins, 2017), these mothers were reworking existing hegemonic norms in services such as schools to create new understandings and

openings. Those with powerful OI's as mothers of autistic children (for example, Heather and Eloise) were able to push back against behaviours, institutions, and policies that maintain oppression. Dewey's creative democracy recognised people's worth and potential to use whatever power they hold to try, to experiment, and to creatively, resourcefully, and collaboratively create conditions of mutual benefit (Hankins, 2017).

Mothers' participation was restricted yet their necessary advocacy on behalf of their child, and sometimes activism on behalf of others, ironically gave them influence at meso- levels that normative mothering does not always enact. In return, their engagement ought to be met with responsivity. Barnes (2008, p.1546) claims that, "To enable human flourishing requires openness, a willingness to listen, and a democracy of hope. It is a democracy because it welcomes everyone to participate in the conversation, encouraging them to experiment by pointing it in new directions". Runswick-Cole and Ryan (2019; p.1125) coin the term *unmothering* which forwards the idea that mothering should be a collective effort negating the need for full personal responsibility and intensive advocacy on behalf of the mother. Such a concept challenges neoliberal assumptions and disrupts power dynamics (Dash et al., 2023). Efforts to recognise the value and humanity of children with additional needs and their right to appropriate education, health and social care resources (Runswick-Cole & Ryan, 2019) would then be collaboratively addressed with greater potential of being upheld.

8.4 Conclusion

The care burden experienced by these mothers was orientated around the wellbeing and support of others, was undervalued by society, may not have been mothers' chosen way to be and do in this world, and speaks directly to experiences of occupational imbalance. Mothers' over-burden impacted their time and energy to engage in alternative occupations either those for pleasure or those related to employment. Experiences of imbalance were compounded by expectations of mothers to take primary responsibility for care, and the fact that they did, led to reduced occupational opportunities and an unjust obligation to care.

Their children's preferences and behaviour, coupled with their own non-normative mothering, can threaten the everyday participation of dominant groups leading to mothers' exclusion. Despite experiences of occupational injustice through marginalisation, mothers found belonging through active engagement with empathetic social support that demonstrates an understanding and acceptance of difference.

Mothers were little served by current structural supports in which delayed diagnosis, and a dearth of services, exacerbated maternal stress, added to their social and emotional burden, and created conditions for occupational injustice. Given the centrality of connections, money, and knowledge to the navigation of services, it was not surprising that social supports greatly impacted mothering experiences. For these mothers to flourish in their role, they needed the right type of social and structural support.

On becoming mothers, women adopted maternal occupations and roles in keeping with their society's ideals as to what is natural and normal for mothers. There was an acceptance of the mothering role despite the limits it can place on women's opportunities for engagement, their agency in being and doing, and their possibilities for belonging and becoming. The personal sacrifice expected of most mothers in our culture was intensified for those mothering autistic children in which mothering is often portrayed as a loss. Their mothering was represented by adapted occupational engagement requiring the development of special skills that, similar to the universal worth placed on caring, was under appreciated.

Prevalent mothering ideologies and singular normative mothering conceptualisations are problematised for mothers of autistic children. Caring, often conflated with mothering and equated with women's work, was expected of these mothers as a function of social norms. Disempowering definitions of mothering held by both mothers and society, including the enmeshing of mother and child, served to limit the mothers' growth through motherhood, impacting their OI and restricting their mothering potential. The occupational possibilities made available reflected societal ideals that could not be reached by these mothers. Society can better support these mothers to enhance their everyday experiences of mothering by reconceptualising care, balance, and motherhood and valorising alternative forms of intensive-inventive good mothering.

At the same time, mothering, as a proactive, relational practice offering agency and expressions of care, could be empowering, reaffirming and the basis of growth. Mothers' occupational performance was adapted to meet the needs of their child yet through the active practice of mothering, mothers could strengthen their OI and claim their own subjectivities. Re-envisaging a more inclusive perspective of mothering and mothers is required at a societal and individual level for these mothers to have recognition and regard.

Society might think to look to women, mothers, and mothers of children with additional needs such as autism, to develop values and skills of empathy and concern for the enhancement of society at large. Working collaboratively and collectively in recognition of our shared humanity may provide opportunity for all to flourish. The intersubjectivity of our world makes it imperative that we embrace diverse ways of being to enable mothers to become in mothering who they need to become.

The following chapter summarises the key conclusions and implications coming out of the current study.

Chapter Nine

Conclusions

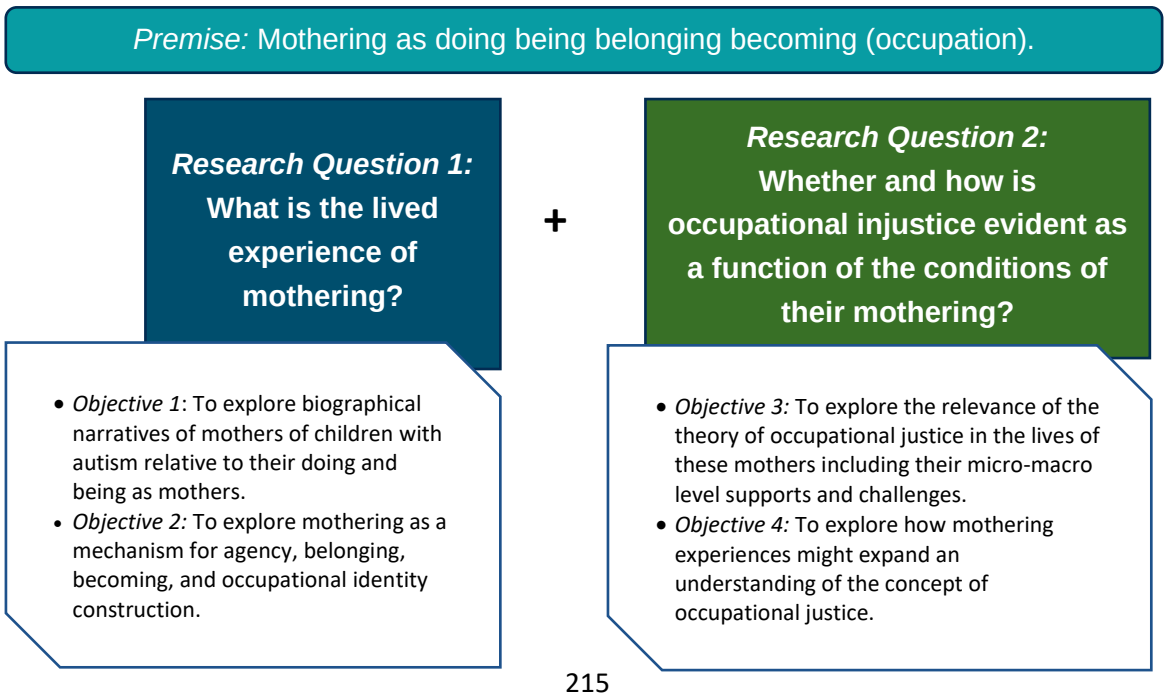
9.1 The mapping of synopsised conclusions to research objectives

The previous chapter generated conclusions that reflected the lived experiences of mothering autistic children, examined through a feminist inspired occupational justice lens. This chapter draws on these conclusions, as well as the conclusions presented in the findings' chapters (Chapters Five, Six, Seven). Although, the conclusions are interrelated, and a given conclusion may speak to more than one research objective, by way of demonstrating explicitly the study's contribution to knowledge in occupational science relative to that which it set out to achieve, the conclusions are mapped to specific research objectives. Additionally, the chapter presents the implications of the study and recommendations for research that will further knowledge in this area.

The study set out to answer the specific research questions and objectives reiterated in Figure 9.1. Sections 9.1.1/4 outline the study's conclusions in relation to each research objective.

Figure 9.1

Research premise, questions and objectives



9.1.1 To explore the biographical narratives of mothers of autistic children relative to their doing and being as mothers

Mothers in the current study were not a homogenous group. Differences in their children's age and personal challenges, and variations in mothers' individual circumstances and supports, increased the heterogeneity of the sample and resulted in some mothers having more or less choice and control in the doing and being of their occupational engagement. However, there was also much commonality in their narratives that often emerged from their engagement with social structures and norms.

Mothers' storied accounts of their lives from when they first thought of becoming mothers provided a depth of background information that gave context to their journeys through diagnosis, service use, and access to mainstream education. All mothers experienced an occupational transition on receiving the diagnosis that required personal adjustment and perspective change. The value of a diagnosis, as perceived by these mothers, was to increase understanding and accelerate access to services, which made the dearth of public services that followed all the more frustrating.

The fact that mothering was considered instrumental (by society, health and education professionals, family and mothers themselves) reinforced the idea that mothers (not fathers, teachers, or healthcare professionals) were ultimately responsible for the child. Dominant hegemonic perceptions that mothers care and cope were assimilated by these mothers. Because mothers understood this, they also recognised and accepted their essential responsibility to ensure their child's development. The doing-being-belonging-becoming of even those who believed this situation to be unfair was altered in response to this purpose.

In keeping with prevailing sociocultural norms for motherhood in Ireland, gender roles were evident. Most mothers understood their responsibilities towards meeting their child's needs in relation to education and therapeutic supports to be different to that of their child's fathers. They wanted to be, and believed they were expected to be, essential to their child's welfare and central to interactions with these systems resulting in a gendered care burden.

The lived experience of mothering was imbalanced and burdened to varying degrees for most mothers. Mothers adopted the role of primary carer and fulfilled multiple mothering roles. Much depended on mothers' skills in constructing accommodating environments and advocating for

their child which resulted in a care burden that was multifaceted – social, emotional, financial and temporal. When mothering represented unsupported occupational engagement and/or required much antagonistic advocacy, its burden was compounded.

Striving to do what was right, and be the mother their child needed, was effortful; it interrupted what mothers assumed they would do and become as mothers and was made more difficult by unsupportive interactions, inadequate services, and assumptions that mothers should cope and care. Effort was also required of others and services such as educators or childcare workers. When others were open to mothers' guidance and committed to adapt their interactions with these children, relations were generally smoother.

Mothers were under huge pressure to know what their child needed to grow and flourish in various environments, and to have money, time, and advocacy skills to support this. Competence in mothering autistic children demanded of these mothers an understanding of the operations and functions of the healthcare and education systems in order to focus their advocacy and create supportive environments. Adverse mothering experiences impacted negatively on mothering confidence and competence. In the absence of the additional knowledge and skill required of mothers, mothers were likely to feel inadequate at some point.

The passage of time facilitated perspectival change for mothers, giving them time to find and practice ways of supporting their child that helped their family to best function. Social support was also key to their adjustment to mothering their autistic child and the acceptance of non-normative mothering.

Blame and guilt were part of the mothering narrative. Mothers were disappointed in themselves for not shouting loud enough, for not acting soon enough; disappointed in professionals for not believing, not acting, not getting it right; and disappointed in structures and services for their inadequacy.

For children diagnosed as teenagers, societal assumptions around independence and further education, together with the teens' fast approaching adulthood, compounded mothers' anxiety for their teen's future.

Although past resolution of their child's challenges, particularly in education, gave mothers' comfort and hope, most mothers expressed worry or concern for the child's future opportunities. Mothers' fears reflected their assimilation of neoliberal expectations of adult independence and normative occupational engagement and was underpinned by a concern that society would not accommodate, and services would not support, their children into adulthood.

Mothers referred to, but did not vehemently complain about, their smaller lives (less active and sociable) now versus before the diagnosis. However, this may have compounded their fear that there was no end in sight for their care.

9.1.2 To explore mothering as a mechanism for agency, belonging, becoming, and occupational identity construction

Mothering their autistic child had the power to make mothers feel both content and disappointed with their mothering performance. Although mothers did not choose to enter the world of autism, they became skilled in mothering and meeting their child's needs. The reconstruction of their occupational identity as a mother of a child with autism took place across time in line with their increased capacity to advocate for their child and align their child's needs with the environment.

Through the active practice of mothering, it was possible for mothers to construct their occupational identity and claim their own subjectivities. Doing brought healing and purpose and provided an alternative, non-normative role which was differently meaningful.

Mothers were keenly aware of societal expectations of motherhood, of the doings of other mothers and children, and of the difficulty they had in reaching the standards of the ideological *good mother*. The transition to the form of mothering required of them was facilitated by relinquishing *good mother* aspirations and reconstructing their occupational identity, making perspectival and practical changes to daily life, and finding meaning in some aspect of being a mother of an autistic child.

Mothering autistic children placed limits on mothers' opportunities for engagement by orientating their agency in being and doing, and their potential for belonging and becoming, around concern for their child. Yet, out of loss, came possibility. Some mothers rallied through adverse mothering experiences, honed their advocacy skills and created communities of belonging. As a relational practice, mothering advocacy was empowering, and occupation-as-becoming was evidenced. As

a practice offering agency, mothering advocacy operated in an often-uncomfortable space within the public sphere. All mothers found their voice and used it to fight for their child's rights.

Drawing on some form of capital (social support network, information, money) post-diagnosis was beneficial. If mothers were without capital at the pre-diagnostic stage, they actively used occupation (and active practices) to create it across their autism journey.

Mothers who committed to participation in a preferred occupation of self-care, built this into their weekly routine. They prioritised this engagement in recognition of its value in supporting them to meet the challenges of mothering. This engagement was perceived as vital for their wellbeing and was supported by their family.

Despite experiences of marginalisation and exclusion, mothers experienced belonging through active occupational engagement when they were provided with empathetic social support that demonstrated an understanding and acceptance of difference.

9.1.3 To explore the relevance of the theory of occupational justice in the lives of these mothers including their micro-macro level supports and challenges

Occupational justice is little researched in this population despite some recognition in the literature that such issues may prevail for mothers of children with disabilities including autism. This study concludes that these mothers can and do experience occupational injustice. They are limited, by external factors, from doing what they want and need to do as mothers and relative to that which other mothers do.

Through adapting their mothering in response to their child's needs, both within and outside the home, mothers demonstrated care and compassion. Alongside the evident regard for their children and their enjoyment of mothering, mothers made personal sacrifices which, in practical terms, translated into altered careers, reduced social life, increased time-demanding alternative mothering including adapting and advocating. Mothering in this way differed in nature and extent to mothering neurotypical (non-autistic) children and created the potential for experiences of occupational injustice.

Certain child behaviours, in interaction with the environment, resulted in restricted occupational engagement and participation for mothers and consequent experiences of occupational injustice. Reduced access to childminders, babysitters, and few playdate invitations impacted mothers' opportunities to work, socialise, and engage in normative mothering activities. In this way, mothers experience of occupational injustice was aligned with their child's participation challenges.

A diagnosis of autism required mothers to recognise and be able to make explicit their child's needs in varied environments. This in turn demanded that mothers understood the functions, operations, and limitations of the health and education systems. Gaining the knowledge and skills required to understand their child's service needs and navigate these systems required time and energy, imposing on mothers' daily occupational engagement on a practical and emotional level and leading to experiences of occupational imbalance. However, such knowledge and skills help them claim some control and power over their mothering conditions.

Mothers experienced points of crisis in their narratives and this was largely due to inadequate services to provide them with direction and their child with support. Despite many struggling to mother, the extent of the advocacy required of mothers in both the healthcare and education arenas placed mothers under considerable pressure and was beyond that expected of normative mothering. This presents as a double penalty and is an identifiable support and service gap.

Many of these mothers lost trust in public services to act in a timely, and for some, competent manner. Many felt unsupported and frustrated by support services, or lack thereof, which added to their objective and subjective care burden. Overall, the time and energy required to gain access to diagnostic services within the public system was prohibitive resulting in the use of private services.

Private services provided a more efficient means of gaining a diagnosis and compensated for a dearth of therapeutic public services. Almost all mothers made use of these usually alongside public services. In relation to education, compensating for service inadequacy through private funds was more difficult. This required address at a meso- (school board, child welfare agencies) if not macro (government department) system level. Therefore, when these supports were inadequate, regardless of personal resources, children – and mothers by extension – experienced occupational injustice.

While on the one hand, in the interface between the child and the external environment, there was a reliance on mothers to recognise difficulties and solve problems, on the other hand, mothers believed some professionals had little trust in their opinion, perceived them as unnecessarily assertive, and consequently they were required to put considerable effort into being heard.

The existence of educational supports varied according to location. In areas where schools had not applied to establish a designated class, children who could benefit from a designated class, were without a local option for schooling. For those children with high academic potential, but who were unable to function in the current school system (even in a designated class), no appropriate educational options existed. Both these situations made for a demanding and possibly frustrating level of advocacy on the part of mothers, that was not fair on either child or mother and had a negative impact on mother's daily lives.

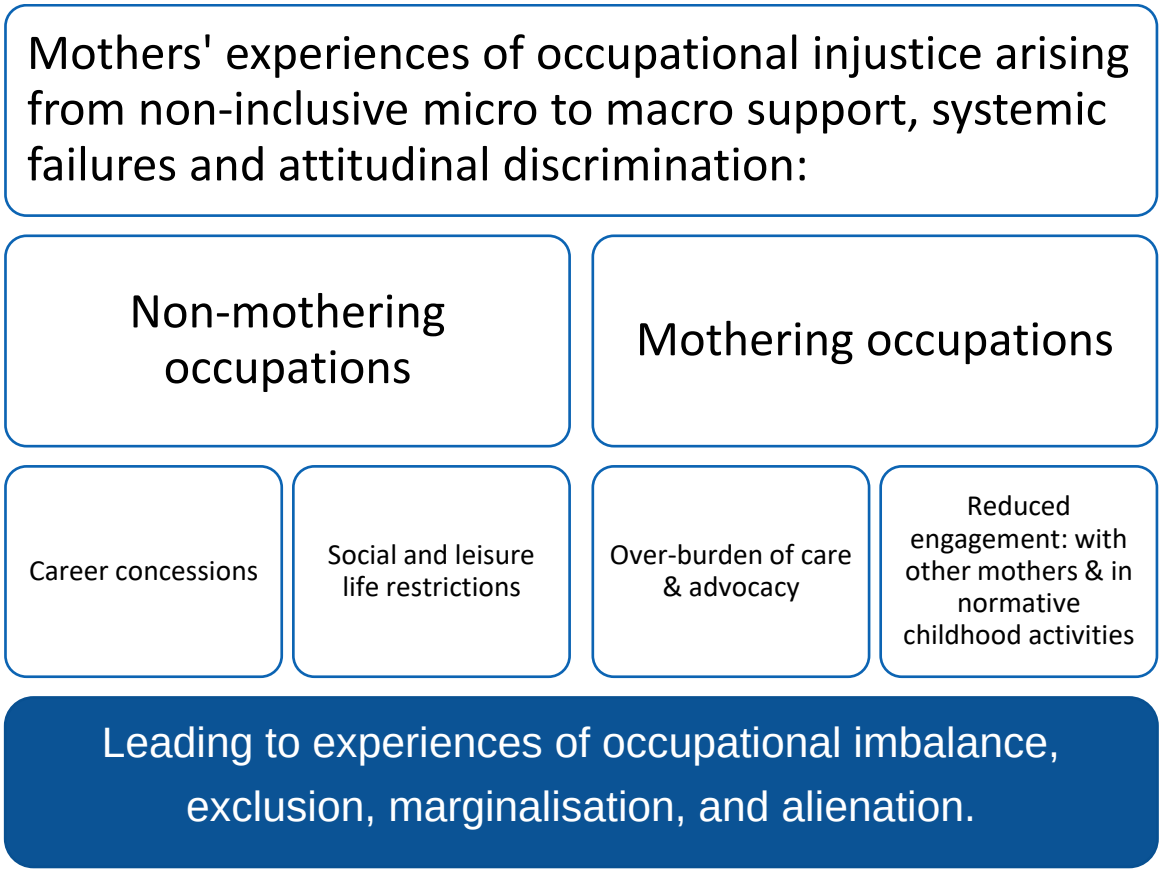
Inadequate childcare supports reduced mothers' opportunity for occupational participation particularly around employment (creating occupational injustice) and inadequate supports for childhood leisure activities, excluded mothers from normative mothering and the opportunity to belong to this community leading to marginalisation.

Exclusion either by self or others from normative mother-child activities, and poor social support and societal understanding of autism, led to feelings of isolation and experiences of marginalisation and occupational injustice. Mothers were marginalised because others did not think to, or want to, invite their child on playdates, to parties or include them on teams. Absorbing these sentiments, fearing embarrassment from their child's behaviour, lacking a mothering common ground, and feeling exhausted, led to self-exclusion from normative mothering.

Drawing on the study's findings, Figure 9.2 summarises these mothers' experiences of occupational injustice and illustrates its reach by highlighting the two-fold impact on both the mothering and non-mothering occupations of this population.

Figure 9.2

Occupational injustice experienced in mothering autistic children



9.1.4 To explore how these mothering experiences might expand an understanding of the concept of occupational justice

Feminism's longstanding history of attending to concerns of women and issues of inequality rendered it a complementary theory equipped to focus the theory of occupational justice on the nuanced experiences of these mothers. The dearth of literature connecting feminist interpreted mothering to experiences of occupational injustice justified the use of these theories to underpin the current study. In terms of expanding an understanding of occupational injustice, this study concludes that the application of a feminist theory facilitated deeper analysis of data relative to the concerns of this study:

1. Feminist theory highlights the possibility of the enmeshing of mother and child which detracted from mother's individual subjectivity/personhood. Feminism also recognises the conflation between mothering and caring and the lack of appreciation of both. Reduced individual subjectivity and a responsibility towards caring increased the quantity and intensity

of caring demands on mothers, led to mothering choices becoming obligations, limited mothers' doing-being-belonging-becoming, disrupted their occupational identity, and restricted their options for alternative occupational engagement. While acting as carer and agent for their child, they potentially reduced the possibility for individual subjectivity.

2. Feminism highlights the absorption by mothers of the societally expected and valourised mothering identity that positions mothers (through their own volition and social obligation) to perpetuate the social order by compensating for inadequate structures that lead to experiences of occupational injustice.
3. Appreciation of motherhood-the-experience in contrast to motherhood-the-institution, as forwarded by Rich (1976) in her seminal feminist work on motherhood, helps to make sense of noted contradictions of motherhood. When regard for their child (related to motherhood-the-experience) interacted with societal expectations of mothers' responsibilities (reflected in motherhood-the-institution), mothers became wholly accountable for their child but also had to fight for the provision of supports.
4. Mothering, generally perceived to be a private responsibility, was publicly judged, and mothers were held accountable for their children's behaviour and participation. Feminism recognises that the individualisation of mothering relieves others of social responsibility. Yet mothering, as a social construct, ought not be considered an occupation of personal responsibility; non-normative mothering in particular requires society's support.
5. In creating an entitlement to, and lawful requirement for, education to enhance child development, the Irish State obligated children and mothers to interact with normative social, physical, and institutional environments. A feminist lens questions why these mothers, despite little authority, were charged with the task of ensuring a fit between the child and environment particularly when the child's development demanded the involvement of inadequately provided, macro level structures in health and education.

These findings support the conclusion that when viewed through a feminist lens occupational justice should be considered with respect to carers. Experiences of occupational injustice were compounded by intersecting factors such as gender and motherhood. Non-normative mothering required non-normative provision and alternative supports. It became problematic when structural supports were inadequate. Exacerbating the challenge of mothering autistic children was the assumption that mothers could and should take full responsibility for their child's welfare and cope with adversity. In this sense, community expectations and societal attitudes contributed to experiences of occupational injustice. Occupational marginalisation due to prejudicial attitudes had relevance for these mothers but so too did societal attitudes in the form of projected and

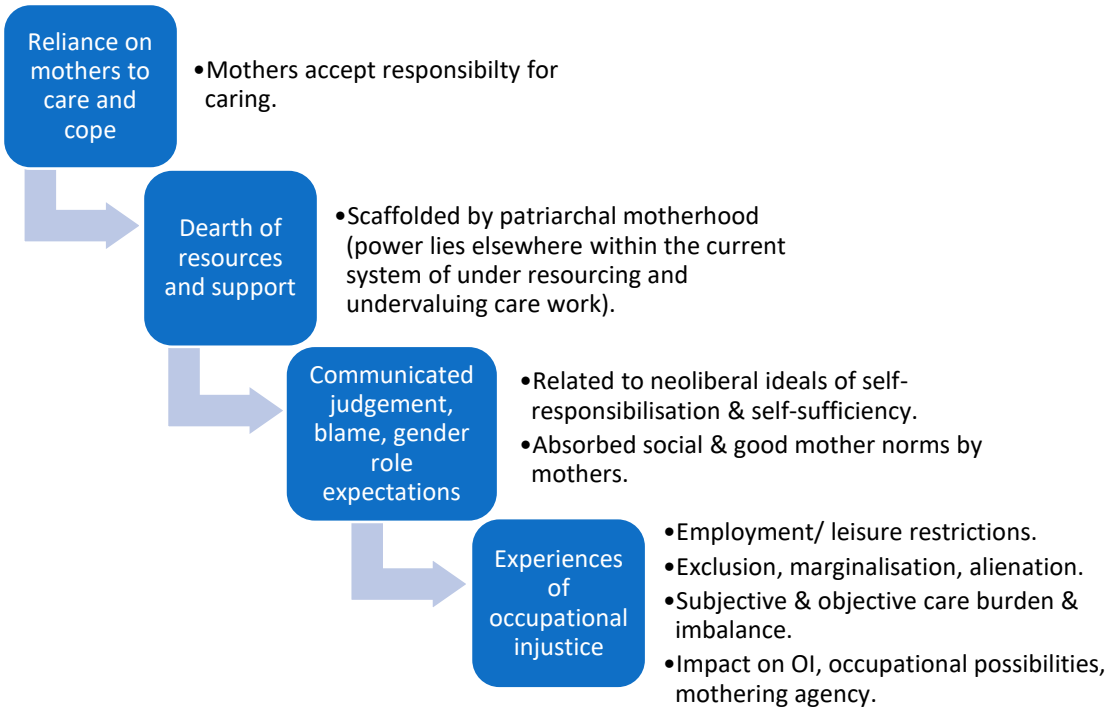
assimilated expectations of the responsibilities of motherhood (the institution), increasing the objective and subjective care burden and contributing to occupational injustice.

9.2 Final thoughts, implications, and recommendations

By way of a take-home message that highlights a principal finding of this study, Figure 9.3 summarises conditions contributing to occupational injustice and emphasises the relevance of the theory to the experiences of mothering autistic children in mainstream school. In short, society and families rely on these mothers to care and cope, in the absence of adequate supports and resources, against absorbed, but often unquestioned, sociocultural norms, expectations, and idealised standards, that they will, and should, perform within their gendered mothering role.

Figure 9.3

A take-home message presenting conditions contributing to occupational injustice



As expounded in the previous chapters, through the presentation of findings and their discussion in light of the literature, mothers' gender role acceptance, devaluation of caring occupations, patriarchal motherhood, neoliberal ideals are among the sociocultural factors that provide context to these conditions (noted in the above figure).

9.2.1 Implications

Based on the findings of this thesis in relation to the research questions and objectives, this study concludes that changes at various levels and in various ways are required for mothers to experience occupational justice and best thrive in mothering their autistic children:

Shift in societal attitude and expectation: Mothers are both social and occupational beings with a right to flourish and fulfil their potential through engagement in meaningful and purposeful occupations that promote health, wellbeing, and societal participation. To enhance these mothers' resilience, participation, and lived experiences of mothering, a more inclusive perspective on mothering is required which may go towards supporting these mothers to grow and become the mothers they need to be. Society must rethink the value it places on care and appreciate alternative forms of mothering. In turn, society may be enriched by accepting difference and developing values of tolerance and compassion. Structures built on a society that embraces non-normative maternal, gender, and child expectations may offer these mothers more possibility for occupational engagement and more choice around caring responsibilities.

Service performance and organisation: Gaining a diagnosis triggers momentous change emotionally and practically for mothers. Services must be mindful of how they interact with these mothers who are often worried and vulnerable. There is a need for positive interactions, hand holding and, ideally, wrap-around care post-diagnosis. Mothers are more likely to thrive when they receive competent and comprehensive support that is available, collaborative, respectful, and relevant to their needs. Mothers need to be empowered to hold the reins but not shoulder the responsibility. The extent of mothers' fears for the future inspires the need for reassurance which might best be given when multilevel and nuanced pathways of care, incorporating mainstream educational establishments, are developed to support the independent living of autistic adults.

For mothers to thrive, the foundations of the non-normative mothering evidenced in the current study were related to: 1. survival (surviving the period around the diagnosis and ongoing negotiation of service access, fighting for their child's rights), 2. control (in the form of building autism-related understanding, knowledge, and connections), and 3. occupational identity (developing a sense of belonging, feeling supported, moving beyond aspirations for normative living). In the current context of their mothering, facilitating mothers to develop skills, knowledge, and attitudes by adopting this perspective may provide direction and actionable issues for service intervention and supports.

Available and inclusive opportunities for occupational engagement: From micro to macro level, such opportunities for occupational engagement and participation are often unavailable or designed without consideration for non-normative groups of mothers and children. Formal macro supports should demonstrate inclusivity, and model it for imitation by informal relationships at a micro level, thus making mothers and autistic children less vulnerable to exclusion and exposed to fewer occupational injustices.

Advocacy responsibilities reversed: Given the likely challenges to mothering within the home environment, the requirement of mothers to also advocate for their child in healthcare and education settings adds undue pressure. It is recommended that community services have a responsibility towards advocacy and, in collaboration with families, interface with services on behalf of the child and parents.

A focus on occupational self-analysis: The relationship between occupational competence, occupational identity and mothering wellbeing underscores the importances of supporting mothers to feel competent in mothering. The current reality of mothering an autistic child is the relinquishing of some occupations of less concern to caring. To enable and legitimise mothers' participation in diverse and preferred occupations in addition to caring, and without placing them under increased pressure to selfcare, guided professional support and occupational self-analysis is recommended.

Collaborative and effortful input: The interdependence of society is reflected in its reliance on mothers to care and cope and in mothers' simultaneous expectation of support from services. Increased effort on behalf of all who interact with autistic children to adapt everyday practices to

accommodate to their needs is necessary. Committing to this purpose and working collaboratively may afford children, mothers, schools, and community to each thrive.

9.2.2 Suggested related research

Based on the findings of this study, areas that warrant further investigation include:

- Qualitative multiple case study comparisons of the subject position of mothers who are, and are not, involved in formal activism and autism organisations exploring, in particular, where they locate themselves within culturally circulating discourses on motherhood, mothering identity, and mothering as sacrifice and loss.
- The study's conclusions prompt further examination of occupational justice using a participatory action research approach to examine supports, existing and desired, for children diagnosed as teenagers, from the perspective of the teen, the mothers, and the service providers in health and education. The immediacy and nuance of required supports might be collaboratively mapped in terms of their remit, nature, and function, taking into account resources and current spend.
- The current study gave no airtime to the lived experiences of fathers. In this and other studies (for example, Miller, 2011) most mothers narrate the development of their mothering identity as independent of their spouse whereas Miller reports that fathers build their narratives as connected to the mother. Fathers' lived experiences are recognised as related but different to those of mothers. Also worthy of investigation is the relevance of occupational justice concepts to understanding the everyday experiences from the perspective of fathers.
- The conditions around assessment and diagnosis were overwhelmingly experienced as distressing. Further research might entail triangulation of data collection from all involved parties to explore the experience and meaning of navigating entry into the system, the interpretation of a diagnostic label by those providing and receiving the diagnosis, as well as the meaning of an autism diagnosis to society in general. This could provide a rounded account of experiences that may give direction to a refinement of the processes involved in gaining a diagnosis and establish their utility within the system and to individuals.
- The use of a feminist inspired occupational justice framework in exploring the conditions of mothering for alternative groups of women, such as single mothers or mothers with refugee experience, in the Irish context could provide additional support for the utility of feminism as a complementary theory to understanding experiences of occupational injustice.

9.3 Conclusion

This chapter has highlighted the study's findings, relating them directly to the research objectives. In doing so I have provided a balanced account of the lived experiences of mothering autistic children both problematising and identifying possibilities for mothers' doing-being-belonging-becoming, mothering identity, and agency.

By employing narrative methodology, namely the biographical narrative interpretive method, the study has attended to the unique voices and stories of these mothers. BNIM's rigorous framework for data collection and analysis, that privileges subjective experiences while anchoring them within their sociocultural and historical contexts, gathered a rich database of mothers' narratives. The analysis of this data has contributed to scholarship on mothering experiences within the Irish context, reducing the knowledge gap on this topic. The study has added to the occupational science understanding of mothering autistic children and extended the relevance of occupational justice through drawing on feminist theory.

The study has confirmed and expanded what was known of the lived experiences of mothering autistic children internationally in terms of burden and balance, insufficient services and supports. It adds to this by emphasising the societal expectations on mothers to take responsibility for understanding their child's needs and advocating for these to be met. Recognising the conditions of mothers' lives as occupational injustices renders these lives a concern for occupational science. This study contributes to the knowledge base by providing evidence that exclusion, marginalisation, overwork and lack of choice, do not enhance mothers' doing-being-becoming-belong and it confirms that the experiences of occupational injustice in the form of imbalance, marginalisaton, and alienation are apparent and rooted in structural deficits and attitudinal biases.

The extant literature on the use of a feminist lens on occupational injustice in mothering is minimal, particularly as applied to mothers of autistic children. By adding to this scholarship, the study has enabled a thorough investigation of these mothers' experiences, identifying subtleties within mothering, that adversely impact practices and which stem both directly and indirectly from external structural factors and absorbed norms. In contributing a feminist perspective, the study reinforces the belief that both mothering and care work are gendered, often conflated by society, and compounded by mothers' adoption of the role of primary carer and their reproduction of this social order. Importantly the current study demonstrates how, as gendered

labour rich in obligated choices and underpinned by good mother norms, mothering is restricted, further adding to experiences of occupational injustice.

In understanding mothering as an occupation, the current study contributes to mother-centred feminist literature. Feminist discourses on mothering as a site for empowerment and agency are provided with a practical form of expression through exploration of mothers' construction and reconstruction of occupational identities within their sociocultural contexts. Possibilities and potential for growth in belonging and becoming were evidenced in this study through practical resistance to normative mothering, adding to the literature in both feminism and occupational science. The various ways in which mothers survived and thrived autism mothering through occupational participation and engagement, explicated particularly through the BNIM cases, increases the depth of knowledge that exists on this topic.

The study has highlighted issues of importance to these mothers. The findings suggest that more could and should be done to enhance mothers' doing-being-belonging-becoming through mothering, to support their occupational identity construction, and to provide them with valourised possibilities for engagement. Given the emphasis in occupational justice on factors external to the individual, and the theory's established relevance to this population, improvement in these mothers' experiences of mothering their autistic child will require societal level shifts in the conceptualisation of care and mothers' work, and transformation in its regard for non-normative mothering.

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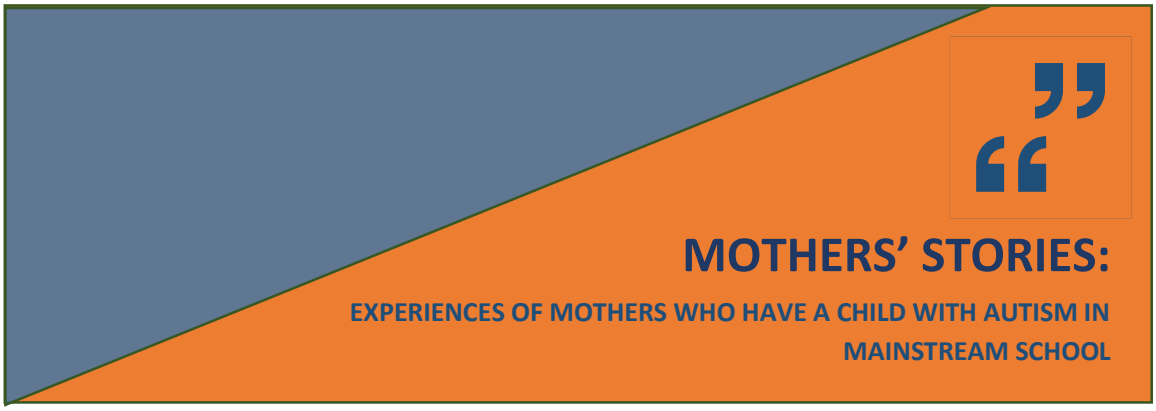
Appendices

Appendix 1: Recruitment poster advertising the study.



Introduction

Hi. My name is Sarah Quinn. I am a PhD student and lecturer of occupational therapy at Trinity College Dublin.

I am researching the experiences of mothers of children with autism.

I want to hear your stories.

Who can get involved?

- Mothers (over 18),
- who have a child with autism
- attending mainstream school,
- who are happy to tell their stories.

What's involved?

You will be interviewed by me twice. You will be invited to tell the story of your life since becoming a mother.

The interviews will take place at a time and place of convenience to you.

Interested?

If you are interested in the study and would like more information and/or have queries, please contact me.

CONTACT

Sarah Quinn
Email: sarah.quinn@tcd.ie
Tel: 085 2561494

Appendix 2: Development of the SQUIN (single framing question)

Early idea:

"As you know I'm researching the lives of women who have children with autism in mainstream schools. Can you please tell me the story of how your life has changed since becoming a mother?

- Assumptive.

SQUIN 1:

"As you know, I'm researching the lives of women who have an autistic child in mainstream school. So can you please tell me ***the story of your life from when you became a mother****?"*

"Please tell me about all those events and experiences that were important for you, personally. I'll listen, I won't interrupt. I'll just take some notes in case I have any questions for after you've finished telling me about it all. Please take your time. … Please begin wherever you like…"

- Following communications with Tom Wengraf the SQUIN was modified.

Tom: "One possible variant ....."from when you started to become a mother".
That would enable the feelings and thoughts about becoming/not-becoming/ a mother to be part of the story....

I think it's always good to start the storying by a SQUIN that evokes a subjectivity-to-start-with storying.
ot "when you joined the firm" but "when the idea of joining the firm first came across your mind". Just an idea."

SQUIN 2:

"As you know, I'm researching the lives of women who have an autistic child in mainstream school. So can you please tell me ***the story of your life from when you first thought about becoming a mother****?"*

"Please tell me about all those events and experiences that were important for you, personally. I'll listen, I won't interrupt. I'll just take some notes in case I have any

questions for after you've finished telling me about it all. Please take your time. … Please begin wherever you like…"

- Trialling and piloting the SQUIN led to further refinement.

SQUIN 3:

"*As you know I am researching mothers' lives so could you please tell me your life story and particularly from when you started ever thinking you could become or be a mother. So if you could tell me all the events and experiences that were important to you personally. I am not going to interrupt; I am just going take notes for questions for when you finish telling me about it all but you can speak for as long as you like and start wherever."*

Appendix 3: TQUIN instructions used to elicit inPINs

Questioning that elicits narrative (TQUIN – topic questions seeking narratives)

Aim: to push pausefully and gracefully towards narrative through eliciting inPINs. The inPINS is a Particular Incident Narrative that requires the re-living from withIN a single earlier lived experience. Push for as much detail as possible extending this to their thinking, feeling, sensing, doing.

1. **Ideal question structure:**

"You said…do you remember any particular occasion/incident/evert/moment/day when this happened?"
"You said…can you remember how it all happened?"

2. **Second best question structure and used most frequently:**

"You said…do you remember any particular example/time/situation/period when this happened?"

3. **Question structure used only where necessary:**

"You said…do you remember any particular occasion/incident/evert/moment/day that you felt/thought that way?"

Appendix 4: Development of SS3 Questions

STEP 1 – Early thoughts.

I read through all interviews and reviewed literature on motherhood. Identified recurring themes around:

- Caring – private practice, not individual self-centred, should be supported.
- Mothering – is a verb implies doing. Also encompasses identity and role therefore being. Suite of activities that are transitory and activity based.
- Essence: So it isn't an essence – this essentialist component is what second wave feminists struggled with, questioning whether maternity was an essence of female identity. Natural desire does not constitute essence. Need to understand biology and not avoid it.
- Representation of motherhood – as a loss for the woman. Is it child-centred? This needs more binaries, more fluid time understanding and less phantasmagory.
- Perception of motherhood changed over 21st century in terms of the types of mothers possible. Institution of motherhood – issues of power rather than attitudes.

Some questions this posed following this review:

What do women get out of being mothers?

What are the influences on and interactions of motherhood?

Is motherhood a natural desire or an essence?

Is motherhood experienced as an institution?

Literature on mothering as an occupation.

- Occupational justice and occupational science relating to motherhood. Mothers: Because having dependents and loved ones places additional obligation (good and bad). It's an extra dimension of potential injustice and is a challenge to feminism.

STEP 2 – Drafting of questions.

I generated questions around the **Doing of Motherhood.**

- Occupational history and profile.
- Chronology.
- Meaning & participation.
- Sociohistorical contexts.

STEP 3 – Consultation 1 – the Narrative Researcher.

Consultant felt greater focus was needed on the following:

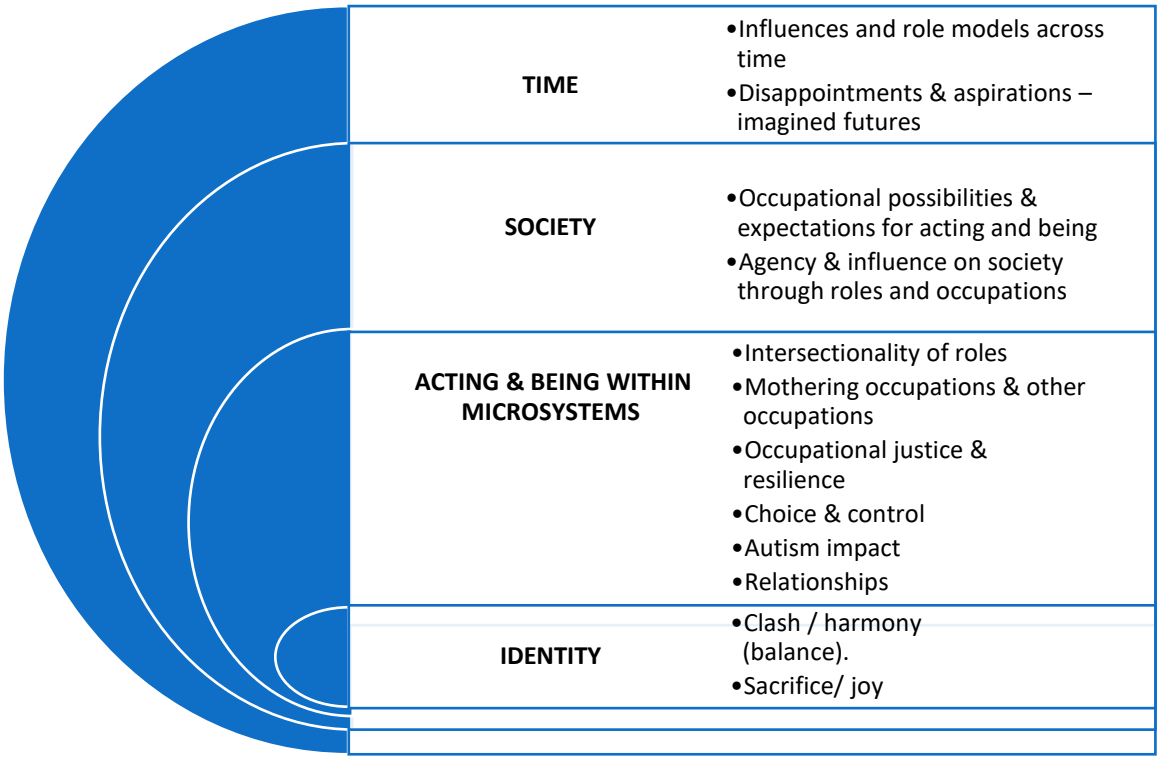
- Projected occupational engagement & alternative selfhoods.
- Consider how to capture perspectives on subjectivities within motherhood and across time discussed.

- Imagined lives at different points in time.
- How can the interview reflect the person's identity and particular narrative?

STEP 4 – Redrafting #1 questions.

Taking identity as mother as central to the person in this case, I developed themes for questions based on:

- Identity.
- Acting and being as mother.
- Society (occupational possibilities, agency…).
- Time (role models, imagined futures…).



Building on these I generated a set of questions around:

- Chronology.
- Perspectives on occupational engagement & roles.
- Perspectives on selfhood & mothering.
- Perspective on living in society.
- Life imagined and lived.

STEP 5 – Consultation 2 – the Occupational Scientist

Consultant suggested I consider how to include mothering as an occupation with regards to:

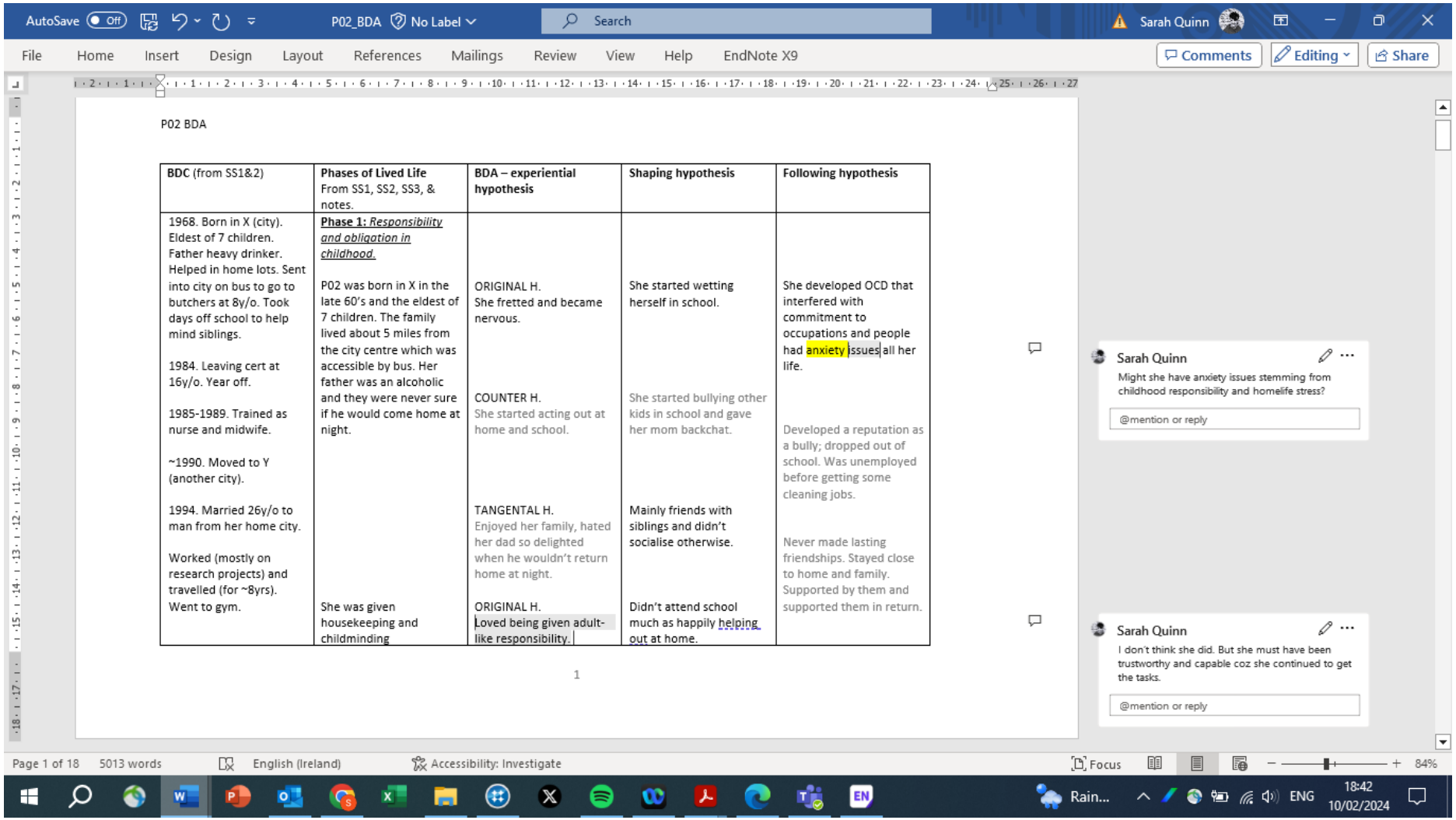
- Understanding the mother through occupation.
- Perspectives on selfhood & mothering.
- Occupational supports & needs.
- Forbidden occupations & ways of being.
- Occupations for coping.
- Impact of mothering on other occupations.

STEP 5 – Redrafting #2 questions

- Drawing on all of the above recommendations, I developed an interview guide that organised questions in a way that might flow in an interview.
- I ensured questions also represented the doing-being-becoming-belonging of occupation; incorporated questions that required mothers to make comparisons between occupations so that I might understand the relativity and individuality of their engagement.
- Following the first interview, I added questions about 'what is hard about motherhood' and 'have you become the mother you wanted to become'.

The interview guide centred around the experience of mothering and was divided into the following sections:

1. Past influences on subjectivity and occupational identity;
2. Transitioning to a new occupational identity;
3. Motherhood as occupational identity;
4. Situating mothering relative to other occupations;
5. Supporting mothering.



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P02 BDA

BDC (from SS1&2)	**Phases of Lived Life** From SS1, SS2, SS3, & notes.	**BDA – experiential hypothesis**	**Shaping hypothesis**	**Following hypothesis**
1968. Born in X (city). Eldest of 7 children. Father heavy drinker. Helped in home lots. Sent into city on bus to go to butchers at 8y/o. Took days off school to help mind siblings. 1984. Leaving cert at 16y/o. Year off. 1985-1989. Trained as nurse and midwife. ~1990. Moved to Y (another city). 1994. Married 26y/o to man from her home city. Worked (mostly on research projects) and travelled (for ~8yrs). Went to gym.	**Phase 1:** *Responsibility and obligation in childhood.* P02 was born in X in the late 60's and the eldest of 7 children. The family lived about 5 miles from the city centre which was accessible by bus. Her father was an alcoholic and they were never sure if he would come home at night. She was given housekeeping and childminding	ORIGINAL H. She fretted and became nervous. COUNTER H. She started acting out at home and school. TANGENTAL H. Enjoyed her family, hated her dad so delighted when he wouldn't return home at night. ORIGINAL H. Loved being given adult-like responsibility.	She started wetting herself in school. She started bullying other kids in school and gave her mom backchat. Mainly friends with siblings and didn't socialise otherwise. Didn't attend school much as happily helping out at home.	She developed OCD that interfered with commitment to occupations and people had anxiety issues all her life. Developed a reputation as a bully; dropped out of school. Was unemployed before getting some cleaning jobs. Never made lasting friendships. Stayed close to home and family. Supported by them and supported them in return.

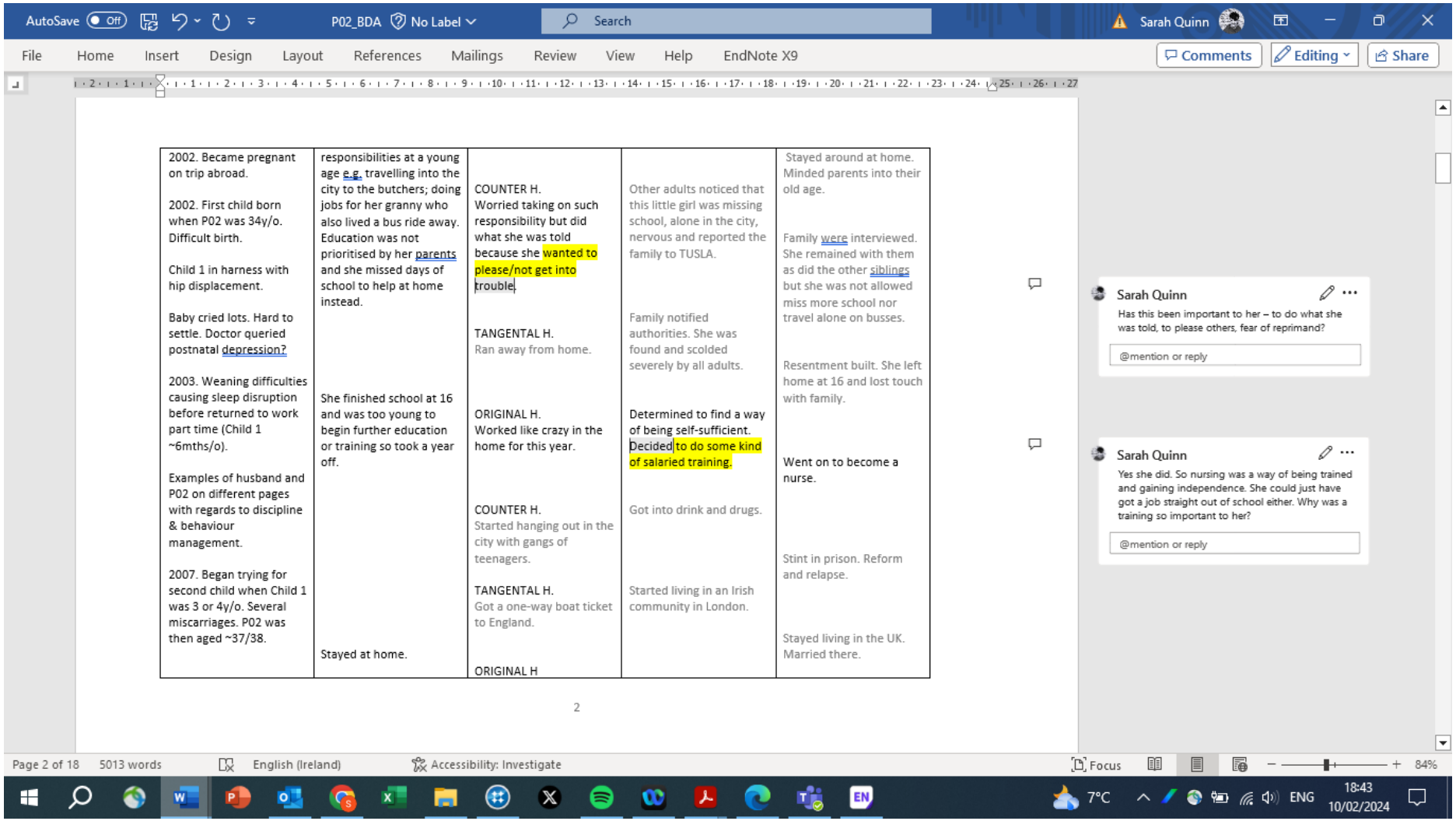
1

Sarah Quinn
Might she have anxiety issues stemming from childhood responsibility and homelife stress?
@mention or reply

Sarah Quinn
I don't think she did. But she must have been trustworthy and capable coz she continued to get the tasks.
@mention or reply

Page 1 of 18 5013 words English (Ireland) Accessibility: Investigate Focus 84%

Rain... ENG 18:42 10/02/2024

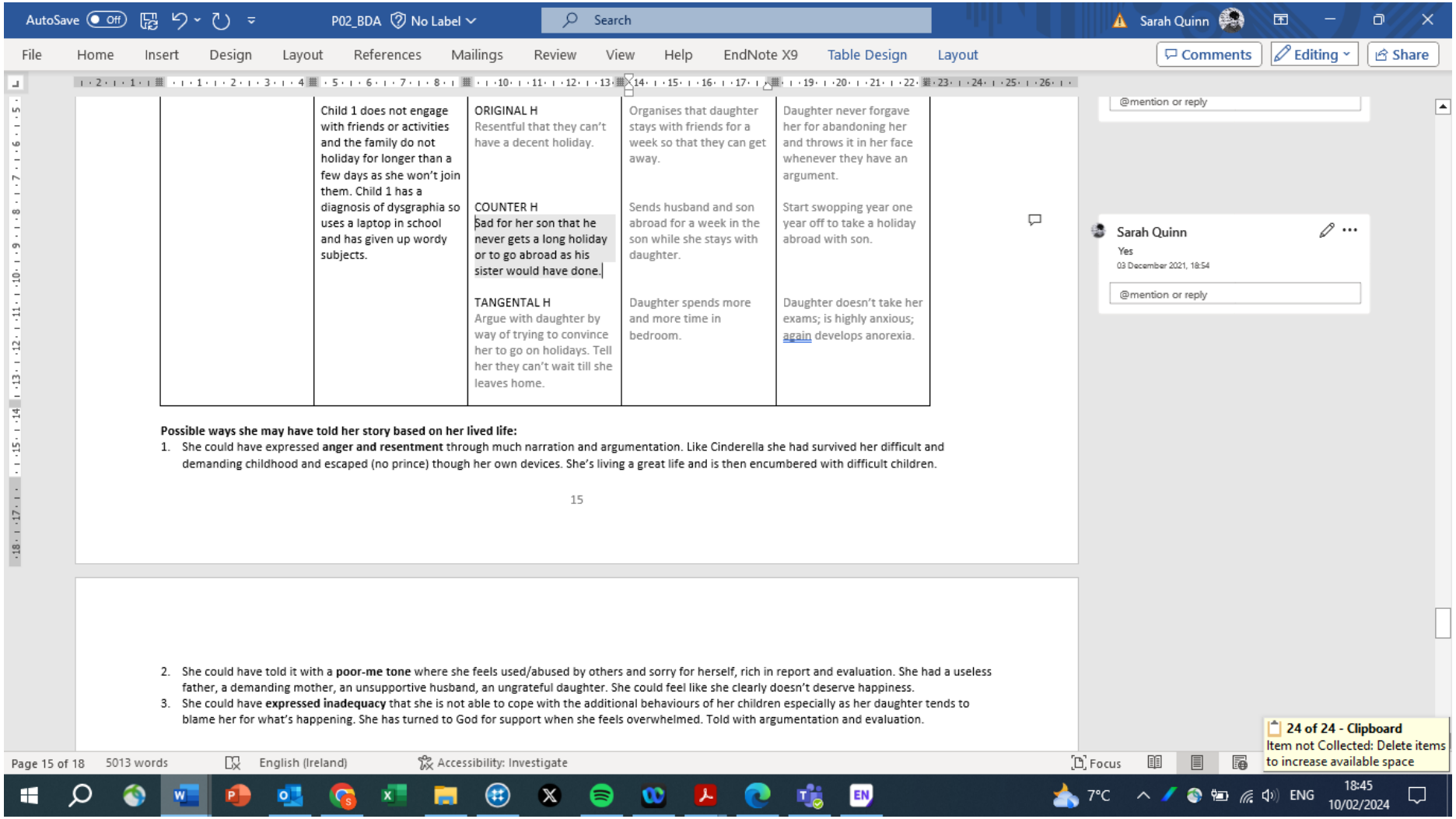


2002. Became pregnant on trip abroad. 2002. First child born when P02 was 34y/o. Difficult birth. Child 1 in harness with hip displacement. Baby cried lots. Hard to settle. Doctor queried postnatal depression? 2003. Weaning difficulties causing sleep disruption before returned to work part time (Child 1 ~6mths/o). Examples of husband and P02 on different pages with regards to discipline & behaviour management. 2007. Began trying for second child when Child 1 was 3 or 4y/o. Several miscarriages. P02 was then aged ~37/38.	responsibilities at a young age e.g. travelling into the city to the butchers; doing jobs for her granny who also lived a bus ride away. Education was not prioritised by her parents and she missed days of school to help at home instead. She finished school at 16 and was too young to begin further education or training so took a year off. Stayed at home.	COUNTER H. Worried taking on such responsibility but did what she was told because she wanted to please/not get into trouble. TANGENTAL H. Ran away from home. ORIGINAL H. Worked like crazy in the home for this year. COUNTER H. Started hanging out in the city with gangs of teenagers. TANGENTAL H. Got a one-way boat ticket to England. ORIGINAL H	Other adults noticed that this little girl was missing school, alone in the city, nervous and reported the family to TUSLA. Family notified authorities. She was found and scolded severely by all adults. Determined to find a way of being self-sufficient. Decided to do some kind of salaried training. Got into drink and drugs. Started living in an Irish community in London.	Stayed around at home. Minded parents into their old age. Family were interviewed. She remained with them as did the other siblings but she was not allowed miss more school nor travel alone on busses. Resentment built. She left home at 16 and lost touch with family. Went on to become a nurse. Stint in prison. Reform and relapse. Stayed living in the UK. Married there.

2

Sarah Quinn
Has this been important to her – to do what she was told, to please others, fear of reprimand?
@mention or reply

Sarah Quinn
Yes she did. So nursing was a way of being trained and gaining independence. She could just have got a job straight out of school either. Why was a training so important to her?
@mention or reply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Sarah Quinn
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Comments Editing Share
Child 1 does not engage with friends or activities and the family do not holiday for longer than a few days as she won't join them. Child 1 has a diagnosis of dysgraphia so uses a laptop in school and has given up wordy subjects.
ORIGINAL H
Resentful that they can't have a decent holiday.
COUNTER H
Sad for her son that he never gets a long holiday or to go abroad as his sister would have done.
TANGENTAL H
Argue with daughter by way of trying to convince her to go on holidays. Tell her they can't wait till she leaves home.
Organises that daughter stays with friends for a week so that they can get away.
Sends husband and son abroad for a week in the son while she stays with daughter.
Daughter spends more and more time in bedroom.
Daughter never forgave her for abandoning her and throws it in her face whenever they have an argument.
Start swopping year one year off to take a holiday abroad with son.
Daughter doesn't take her exams; is highly anxious; again develops anorexia.
@mention or reply
Sarah Quinn
Yes
03 December 2021, 18:54
@mention or reply
Possible ways she may have told her story based on her lived life:
1. She could have expressed anger and resentment through much narration and argumentation. Like Cinderella she had survived her difficult and demanding childhood and escaped (no prince) though her own devices. She's living a great life and is then encumbered with difficult children.
15
2. She could have told it with a poor-me tone where she feels used/abused by others and sorry for herself, rich in report and evaluation. She had a useless father, a demanding mother, an unsupportive husband, an ungrateful daughter. She could feel like she clearly doesn't deserve happiness.
3. She could have expressed inadequacy that she is not able to cope with the additional behaviours of her children especially as her daughter tends to blame her for what's happening. She has turned to God for support when she feels overwhelmed. Told with argumentation and evaluation.
24 of 24 - Clipboard
Item not Collected: Delete items to increase available space
Page 15 of 18 5013 words English (Ireland) Accessibility: Investigate Focus
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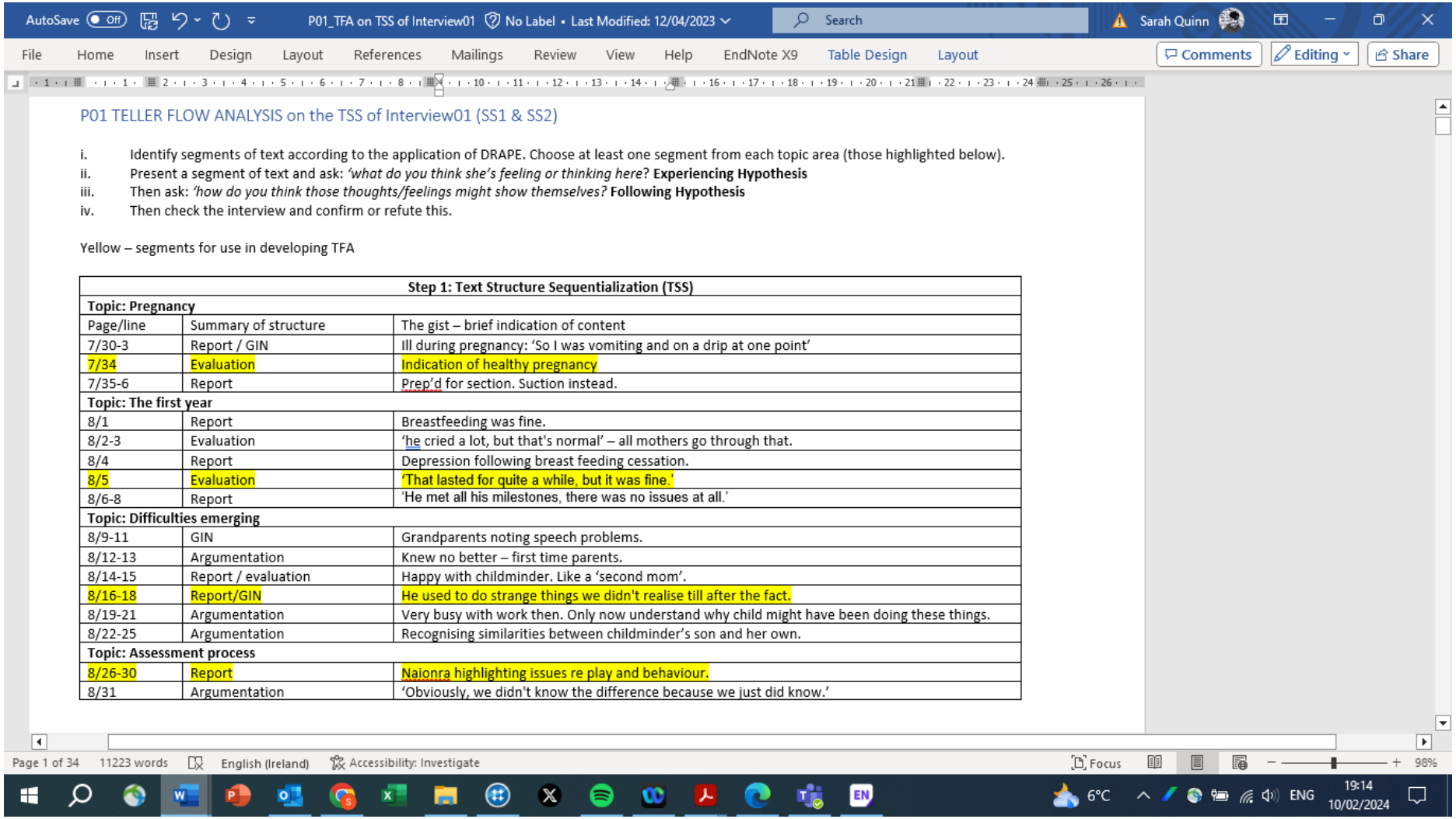
Appendix 6: Sample of Teller Flow Analysis (TFA) using the Text Structure Sequentialization (TSS) on P01's told-story

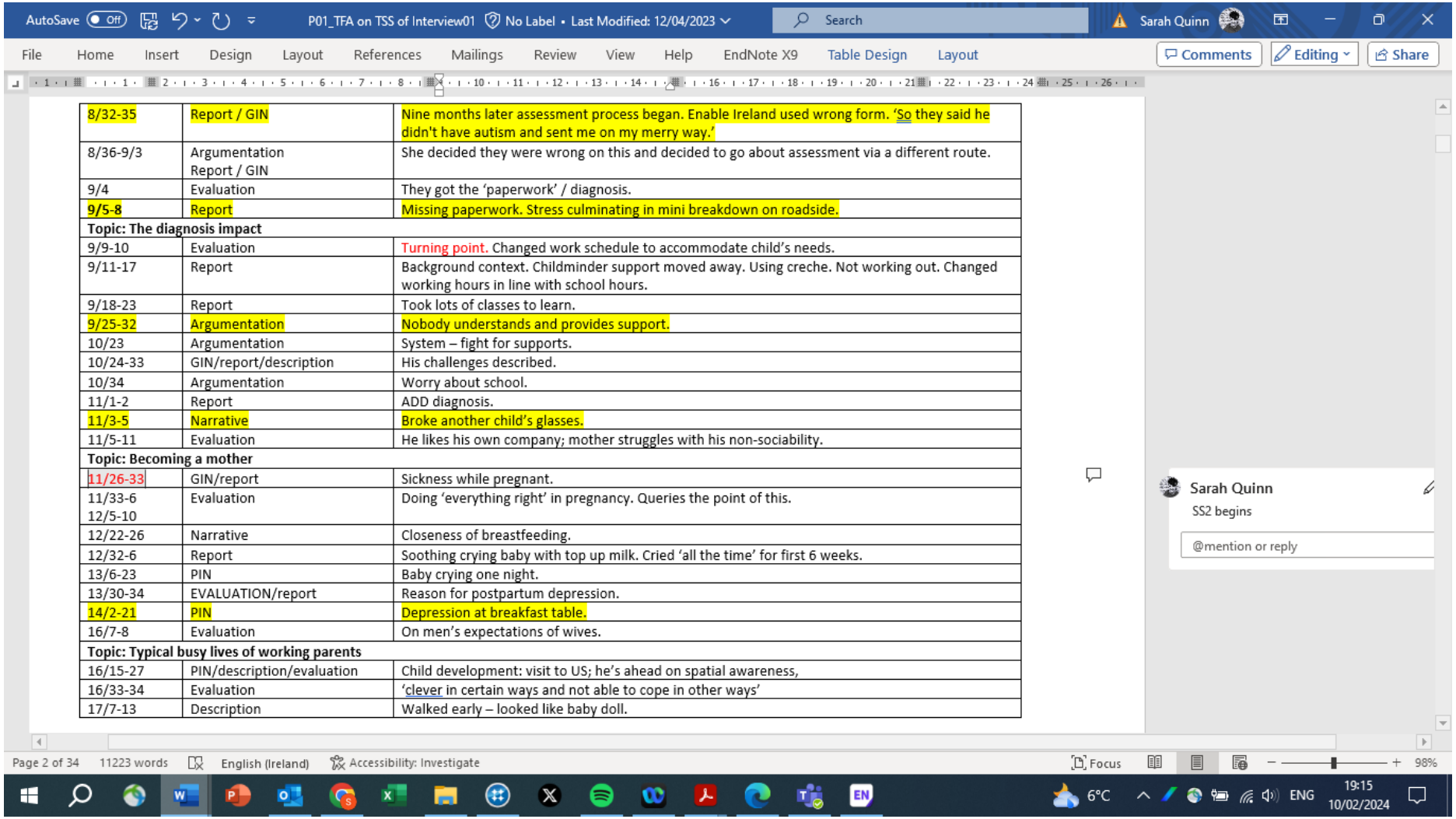


P01 TELLER FLOW ANALYSIS on the TSS of Interview01 (SS1 & SS2)

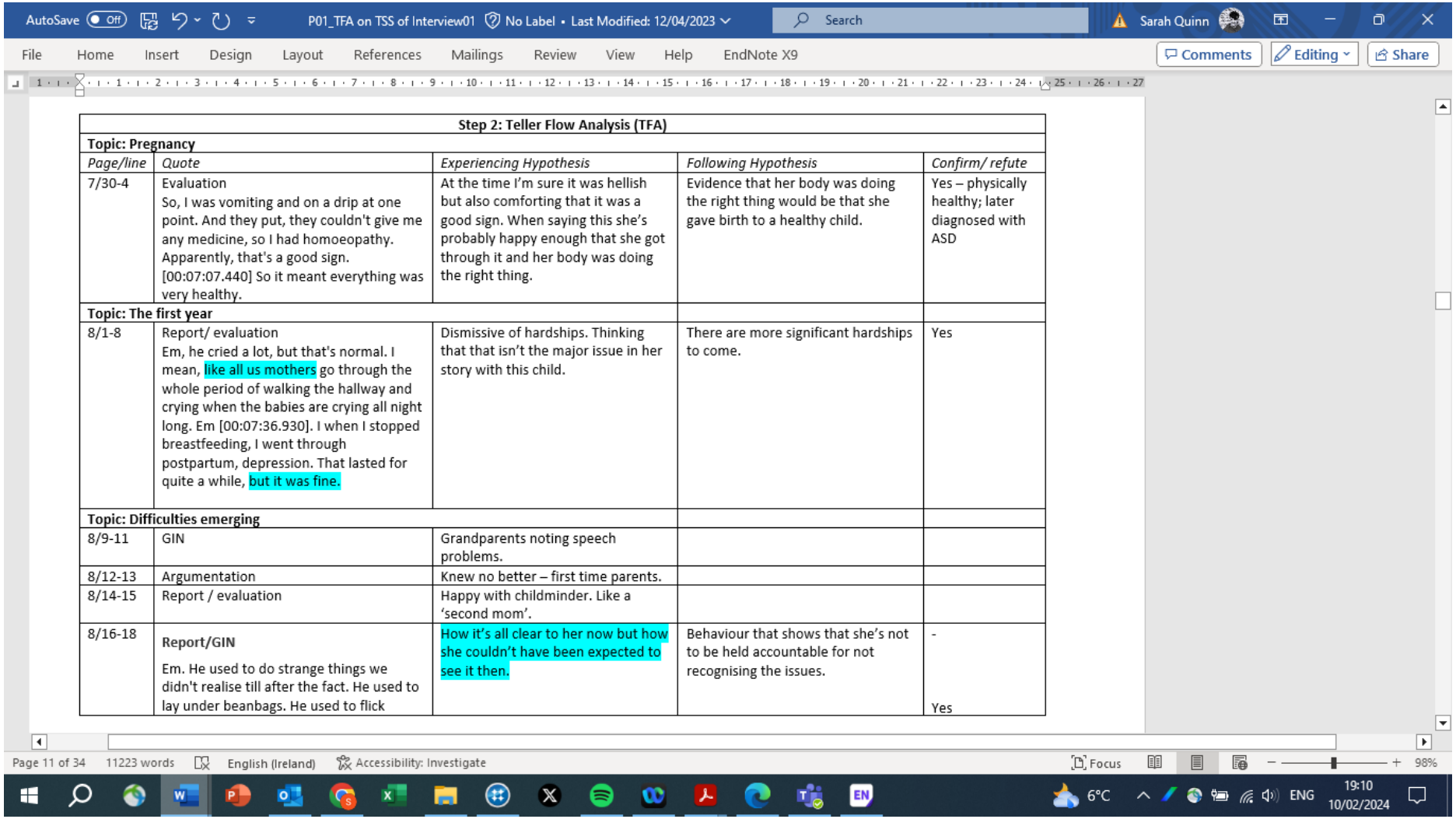
i. Identify segments of text according to the application of DRAPE. Choose at least one segment from each topic area (those highlighted below).
ii. Present a segment of text and ask: *'what do you think she's feeling or thinking here?* **Experiencing Hypothesis**
iii. Then ask: *'how do you think those thoughts/feelings might show themselves?* **Following Hypothesis**
iv. Then check the interview and confirm or refute this.

Yellow – segments for use in developing TFA

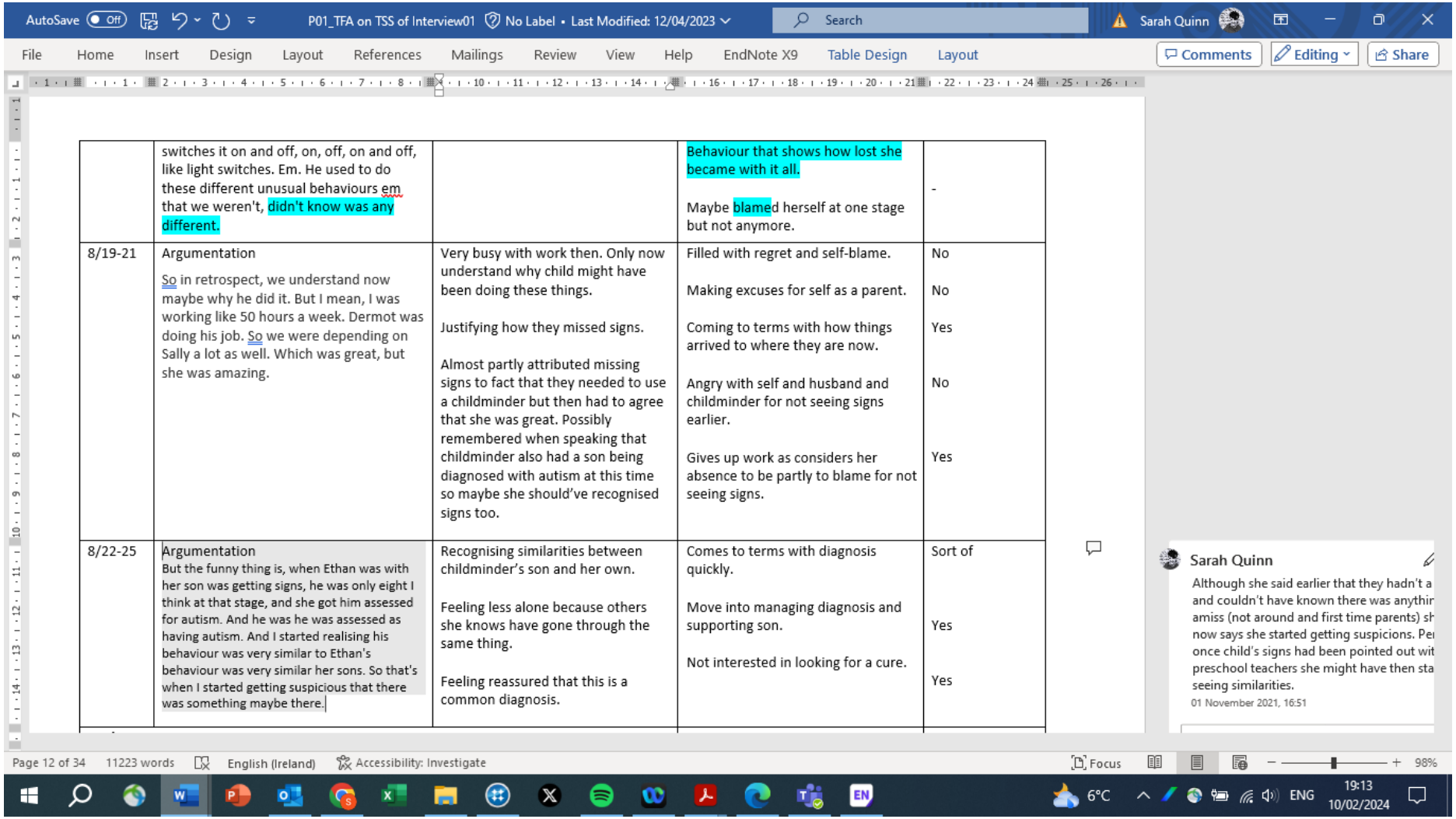
Step 1: Text Structure Sequentialization (TSS)		
Topic: Pregnancy		
Page/line	Summary of structure	The gist – brief indication of content
7/30-3	Report / GIN	Ill during pregnancy: 'So I was vomiting and on a drip at one point'
7/34	Evaluation	Indication of healthy pregnancy
7/35-6	Report	Prep'd for section. Suction instead.
Topic: The first year		
8/1	Report	Breastfeeding was fine.
8/2-3	Evaluation	'he cried a lot, but that's normal' – all mothers go through that.
8/4	Report	Depression following breast feeding cessation.
8/5	Evaluation	'That lasted for quite a while, but it was fine.'
8/6-8	Report	'He met all his milestones, there was no issues at all.'
Topic: Difficulties emerging		
8/9-11	GIN	Grandparents noting speech problems.
8/12-13	Argumentation	Knew no better – first time parents.
8/14-15	Report / evaluation	Happy with childminder. Like a 'second mom'.
8/16-18	Report/GIN	He used to do strange things we didn't realise till after the fact.
8/19-21	Argumentation	Very busy with work then. Only now understand why child might have been doing these things.
8/22-25	Argumentation	Recognising similarities between childminder's son and her own.
Topic: Assessment process		
8/26-30	Report	Naionra highlighting issues re play and behaviour.
8/31	Argumentation	'Obviously, we didn't know the difference because we just did know.'



8/32-35	Report / GIN	Nine months later assessment process began. Enable Ireland used wrong form. 'So they said he didn't have autism and sent me on my merry way.'
8/36-9/3	Argumentation Report / GIN	She decided they were wrong on this and decided to go about assessment via a different route.
9/4	Evaluation	They got the 'paperwork' / diagnosis.
9/5-8	Report	Missing paperwork. Stress culminating in mini breakdown on roadside.
Topic: The diagnosis impact		
9/9-10	Evaluation	Turning point. Changed work schedule to accommodate child's needs.
9/11-17	Report	Background context. Childminder support moved away. Using creche. Not working out. Changed working hours in line with school hours.
9/18-23	Report	Took lots of classes to learn.
9/25-32	Argumentation	Nobody understands and provides support.
10/23	Argumentation	System – fight for supports.
10/24-33	GIN/report/description	His challenges described.
10/34	Argumentation	Worry about school.
11/1-2	Report	ADD diagnosis.
11/3-5	Narrative	Broke another child's glasses.
11/5-11	Evaluation	He likes his own company; mother struggles with his non-sociability.
Topic: Becoming a mother		
11/26-33	GIN/report	Sickness while pregnant.
11/33-6 12/5-10	Evaluation	Doing 'everything right' in pregnancy. Queries the point of this.
12/22-26	Narrative	Closeness of breastfeeding.
12/32-6	Report	Soothing crying baby with top up milk. Cried 'all the time' for first 6 weeks.
13/6-23	PIN	Baby crying one night.
13/30-34	EVALUATION/report	Reason for postpartum depression.
14/2-21	PIN	Depression at breakfast table.
16/7-8	Evaluation	On men's expectations of wives.
Topic: Typical busy lives of working parents		
16/15-27	PIN/description/evaluation	Child development: visit to US; he's ahead on spatial awareness,
16/33-34	Evaluation	'clever in certain ways and not able to cope in other ways'
17/7-13	Description	Walked early – looked like baby doll.



Step 2: Teller Flow Analysis (TFA)				
Topic: Pregnancy				
Page/line	*Quote*	*Experiencing Hypothesis*	*Following Hypothesis*	*Confirm/ refute*
7/30-4	Evaluation So, I was vomiting and on a drip at one point. And they put, they couldn't give me any medicine, so I had homoeopathy. Apparently, that's a good sign. [00:07:07.440] So it meant everything was very healthy.	At the time I'm sure it was hellish but also comforting that it was a good sign. When saying this she's probably happy enough that she got through it and her body was doing the right thing.	Evidence that her body was doing the right thing would be that she gave birth to a healthy child.	Yes – physically healthy; later diagnosed with ASD
Topic: The first year				
8/1-8	Report/ evaluation Em, he cried a lot, but that's normal. I mean, like all us mothers go through the whole period of walking the hallway and crying when the babies are crying all night long. Em [00:07:36.930]. I when I stopped breastfeeding, I went through postpartum, depression. That lasted for quite a while, but it was fine.	Dismissive of hardships. Thinking that that isn't the major issue in her story with this child.	There are more significant hardships to come.	Yes
Topic: Difficulties emerging				
8/9-11	GIN	Grandparents noting speech problems.		
8/12-13	Argumentation	Knew no better – first time parents.		
8/14-15	Report / evaluation	Happy with childminder. Like a 'second mom'.		
8/16-18	**Report/GIN** Em. He used to do strange things we didn't realise till after the fact. He used to lay under beanbags. He used to flick	How it's all clear to her now but how she couldn't have been expected to see it then.	Behaviour that shows that she's not to be held accountable for not recognising the issues.	- Yes



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	switches it on and off, on, off, on and off, like light switches. Em. He used to do these different unusual behaviours em that we weren't, didn't know was any different.		Behaviour that shows how lost she became with it all. Maybe blamed herself at one stage but not anymore.	-
8/19-21	Argumentation So in retrospect, we understand now maybe why he did it. But I mean, I was working like 50 hours a week. Dermot was doing his job. So we were depending on Sally a lot as well. Which was great, but she was amazing.	Very busy with work then. Only now understand why child might have been doing these things. Justifying how they missed signs. Almost partly attributed missing signs to fact that they needed to use a childminder but then had to agree that she was great. Possibly remembered when speaking that childminder also had a son being diagnosed with autism at this time so maybe she should've recognised signs too.	Filled with regret and self-blame. Making excuses for self as a parent. Coming to terms with how things arrived to where they are now. Angry with self and husband and childminder for not seeing signs earlier. Gives up work as considers her absence to be partly to blame for not seeing signs.	No No Yes No Yes
8/22-25	Argumentation But the funny thing is, when Ethan was with her son was getting signs, he was only eight I think at that stage, and she got him assessed for autism. And he was he was assessed as having autism. And I started realising his behaviour was very similar to Ethan's behaviour was very similar her sons. So that's when I started getting suspicious that there was something maybe there.	Recognising similarities between childminder's son and her own. Feeling less alone because others she knows have gone through the same thing. Feeling reassured that this is a common diagnosis.	Comes to terms with diagnosis quickly. Move into managing diagnosis and supporting son. Not interested in looking for a cure.	Sort of Yes Yes

Sarah Quinn
Although she said earlier that they hadn't a and couldn't have known there was anythir amiss (not around and first time parents) sh now says she started getting suspicions. Pe once child's signs had been pointed out wit preschool teachers she might have then sta seeing similarities.
01 November 2021, 16:51

Page 12 of 34 | 11223 words | English (Ireland) | Accessibility: Investigate | Focus | 98%

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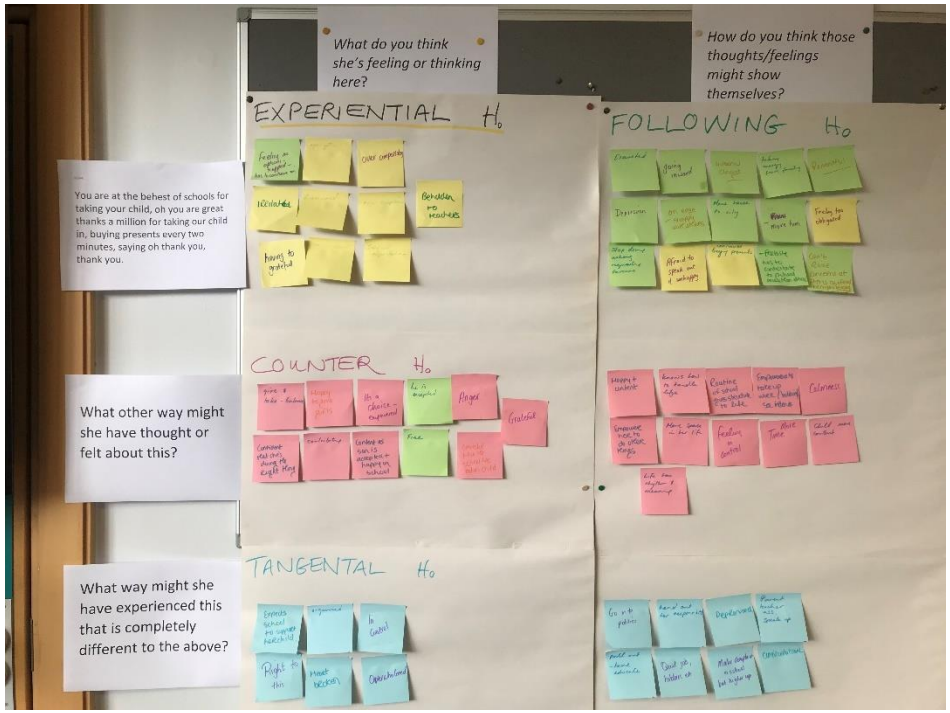
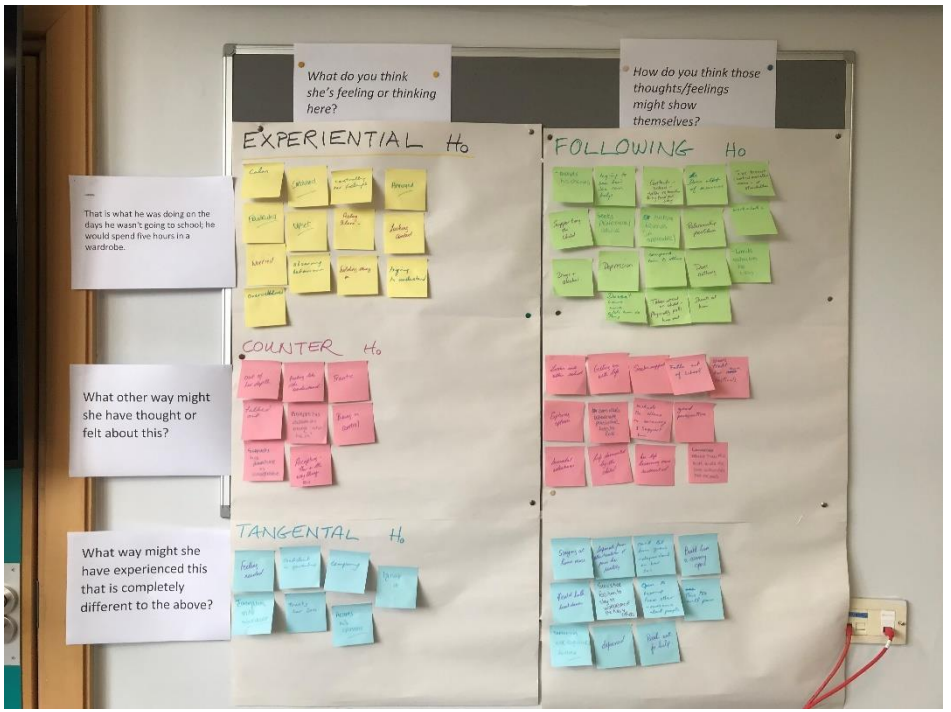
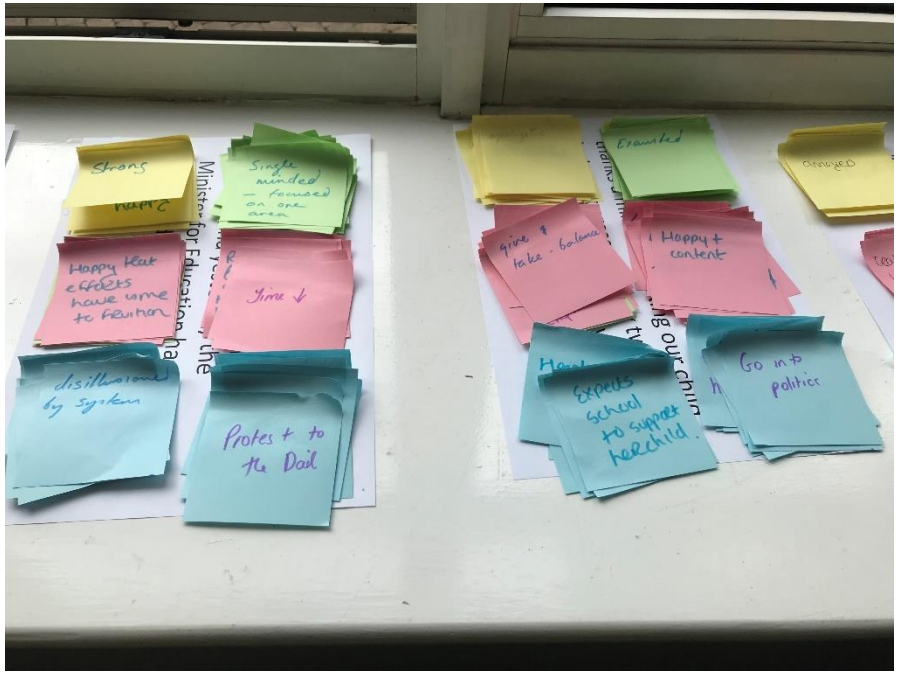
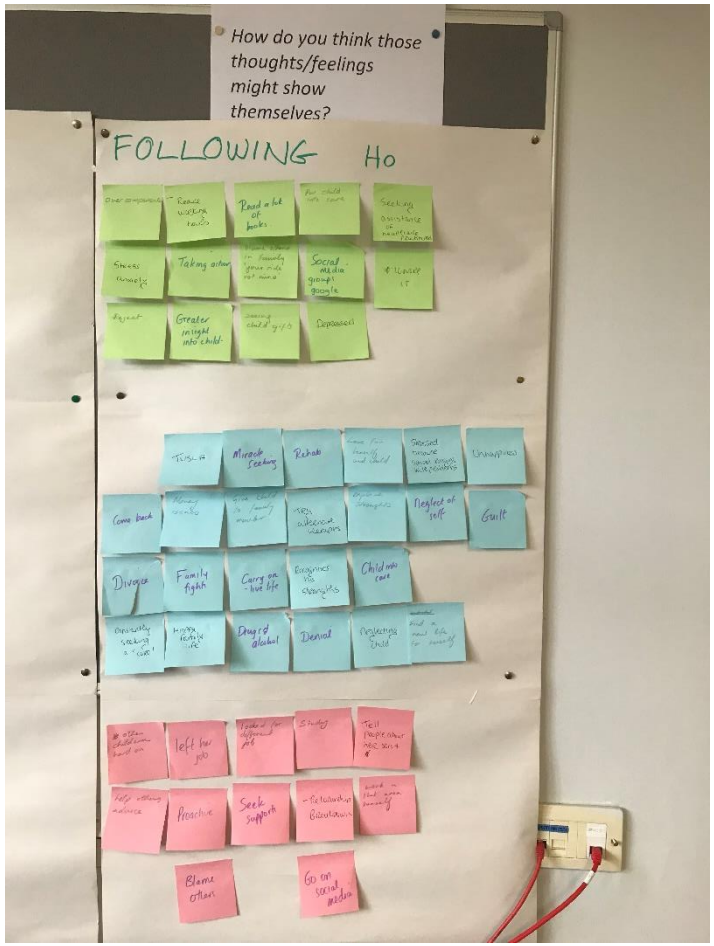
Teller Flow Analysis (TFA) based on Test Structure Sequentialization (TSS) excerpts from interviews with gold star cases.

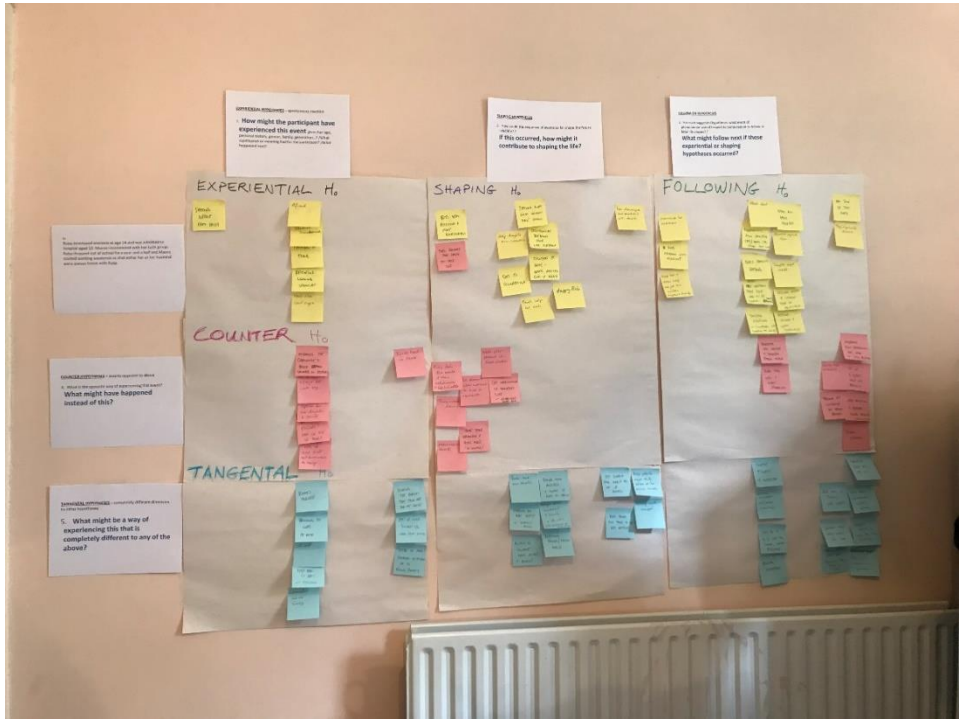


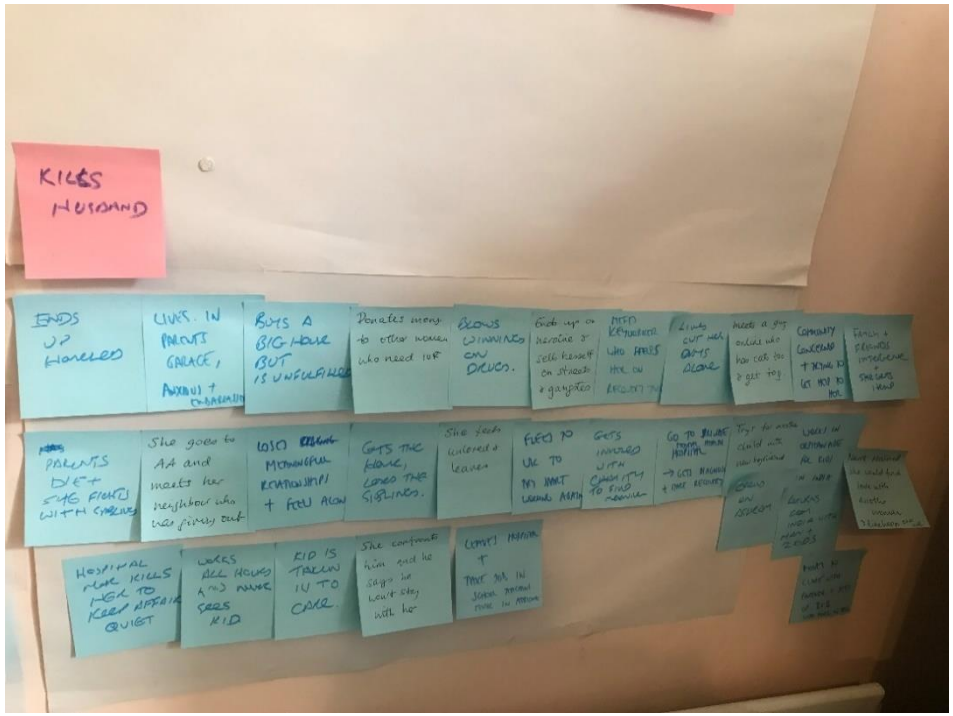


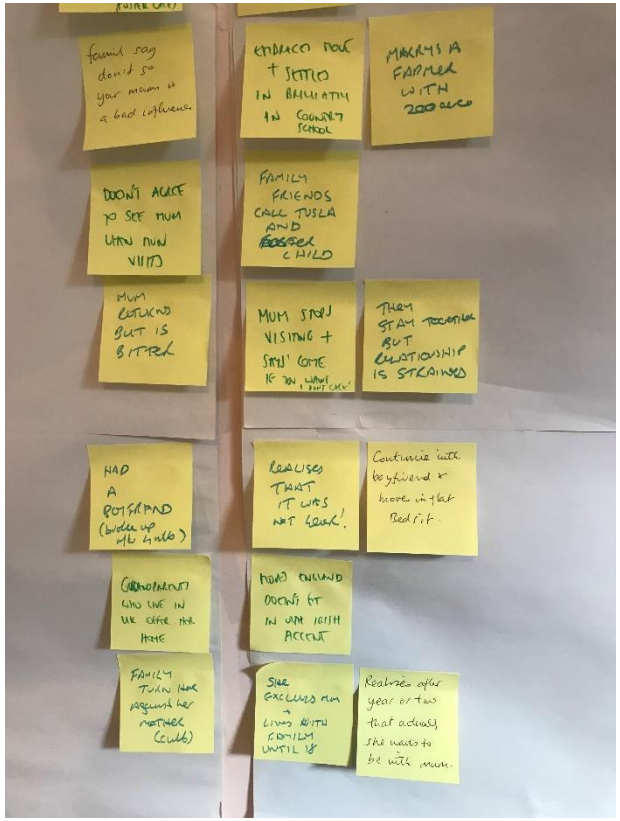

Strong
Single minded — focused on one area
Happy that effects have time to fade
Time ↓
disillusioned by system
Protest to the Dail
Exhausted
give & take - balance
Happy + content
Expects school to support her child
Go into politics


How do you think those thoughts/feelings might show themselves?
FOLLOWING
Ho
Read a lot of books
Social media groups/ google
Greater insight into child
Depressed
Miracle Seeking
Rehab
Unhappiness
Neglect of self
Guilt
Divorce
Family fight
Carry on with life
Drug'd alcohol
Denial
Left her job
Proactive
Seek Support
Blame Others

Biographical Data Analysis (BDA) based on the Biographical Data Chronology (BDC) using excerpts from interviews with gold star cases.

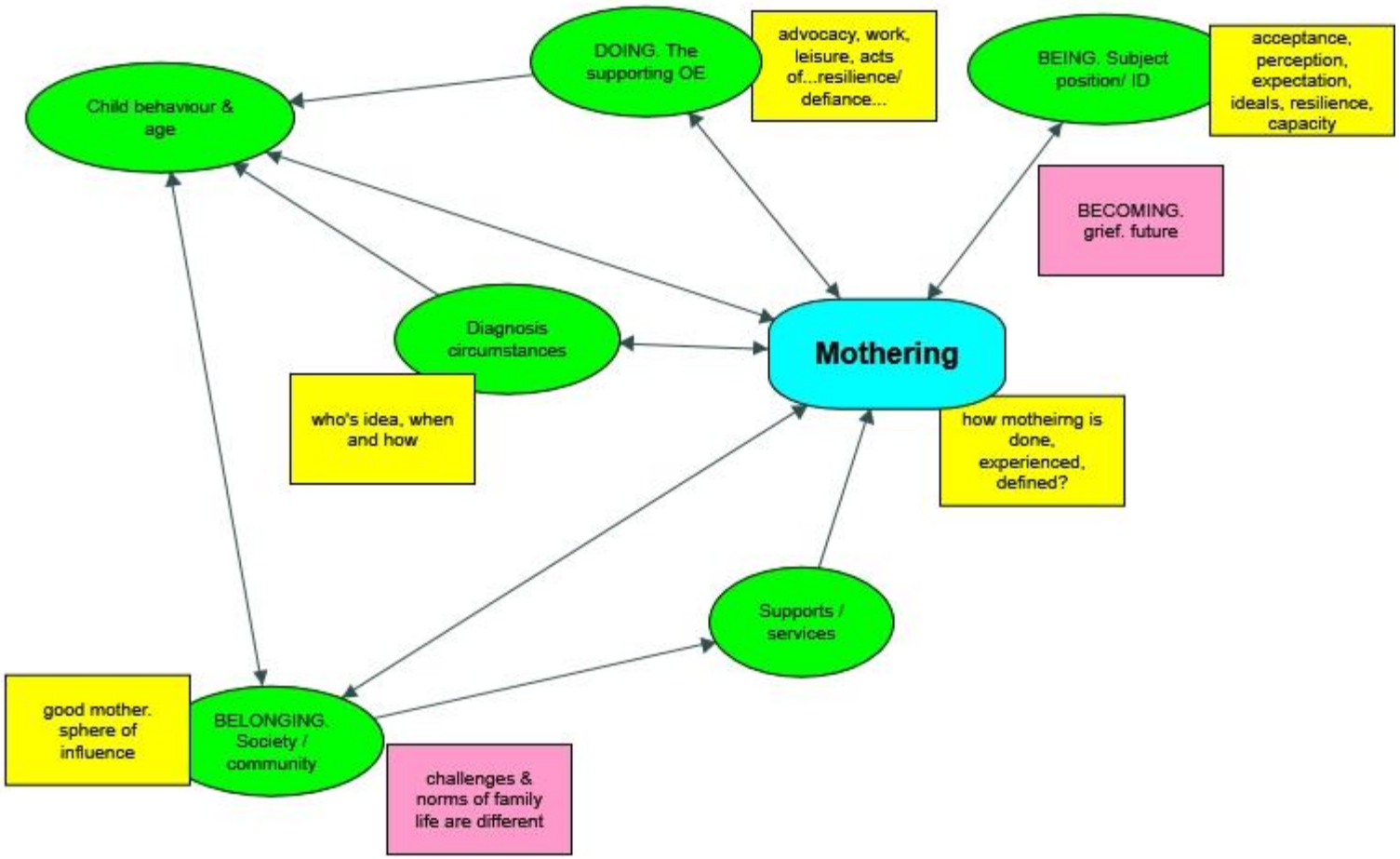



KILLS HUSBAND
ENDS UP HOMELESS
LIVES IN PARENTS GARAGE,
BUYS A BIG HOUSE BUT IS UNFULFILLED
Donates money to other women who need it
GROWS CANNABIS AND DRUGS.
PARENTS DIE + STAG FIGHT WITH SIBLINGS
She goes to AA and meets her neighbor who was firmly out
LOSES MOTHERFUL RELATIONSHIP + FEW ALON
GETS THE HOUSE, LOSES THE SIBLINGS.
She feels unloved + leaves
FLEES TO UK TO MY MUM
GETS ARRESTED WITH CANNABIS TO FIND MEDICINE
HOSPITAL MUM KILLS HER TO KEEP AFFAIR QUIET
WORKS ALL HOURS AND NEVER SEES KID
KID IS TAKEN IN TO CARE
She confronts him and he says he won't stay with her

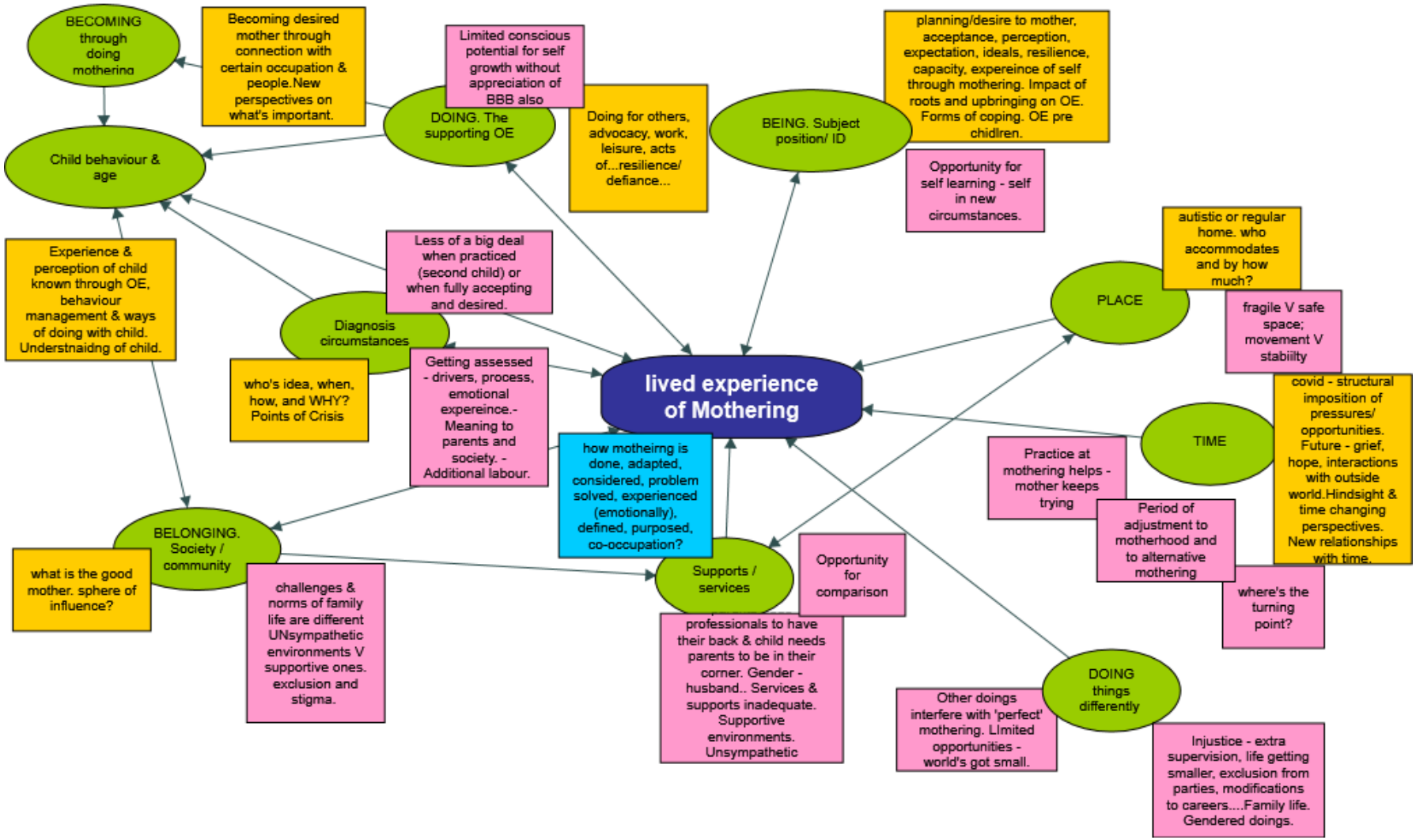

found say don't so your mum is a bad influence
EMBRACES FOOD + SETTLES IN BALLYMOTH IN COUNTRY SCHOOL
MARRYS A FARMER WITH 200 ACRES
DOESN'T AGREE TO SEE MUM WHEN MUM VISITS
FAMILY FRIENDS CALL TUSLA AND FOSTER CHILD
MUM SEEMS OUTWARD BUT IS BITTER
MUM STAYS VISITING + STILL COME IF SHE WON'T
THEY STAY TOGETHER BUT RELATIONSHIP IS STRAINED
HAD A ROTTWEILER (GROWS UP WITH KIDS)
REALISES THAT IT WAS NOT WORK.
Continues with boyfriend + moves in for Redrift
(GRANDPARENTS) WHO LIVE IN UK OFFER HER HOME
MUM FINDS DOESN'T FIT IN WITH IRISH ACCENT
FAMILY TURN HER AGAINST HER MOTHER (GUILT)
SHE EXCLUDES MUM → LIVES WITH FAMILY UNTIL 18
Realises after year or two that actually she wants to be with mum.

Appendix 8: Conceptual mapping using NVivo

Deconstructing the raw data (Reflexive Thematic Analysis Phase 2). Ideas on mothering following coding of first five participants' interviews (S1, 2, 3).



Ideas on mothering following coding of all 17 participants' interviews (S1, 2, 3).

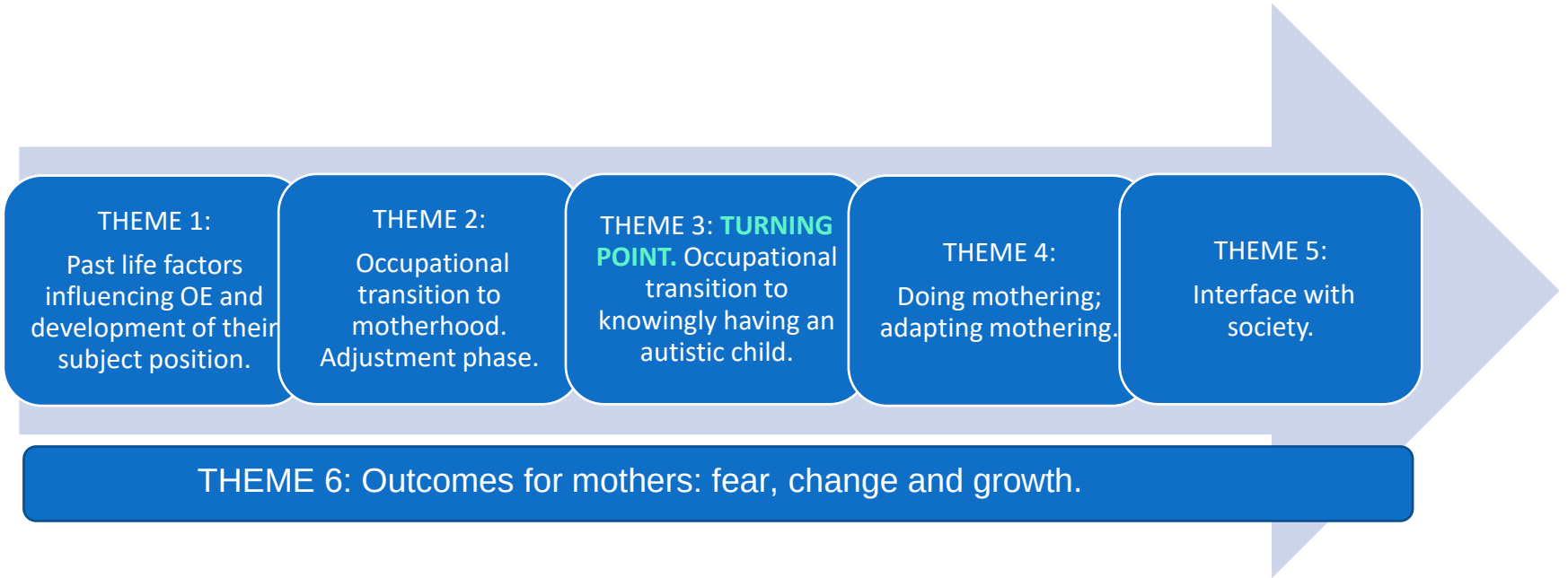


Appendix 9: Initial ideas about what the data could mean – Reflexive Thematic Analysis Phase 3 Generating themes

Using thematic analysis on narrative and non-narrative data (SS1, 2, 3) a pattern that became evident in the findings was that of a timeline that tracked the mothers' experiences from when they first ever thought of becoming a mother.

This way of assembling mothers' narratives fit intuitively with their life-stories. However, despite its illustration below, mothers' lives were not linear. All the while mothering and mothering adaptation was taking place, mothers were interacting with society, learning, and becoming changed.

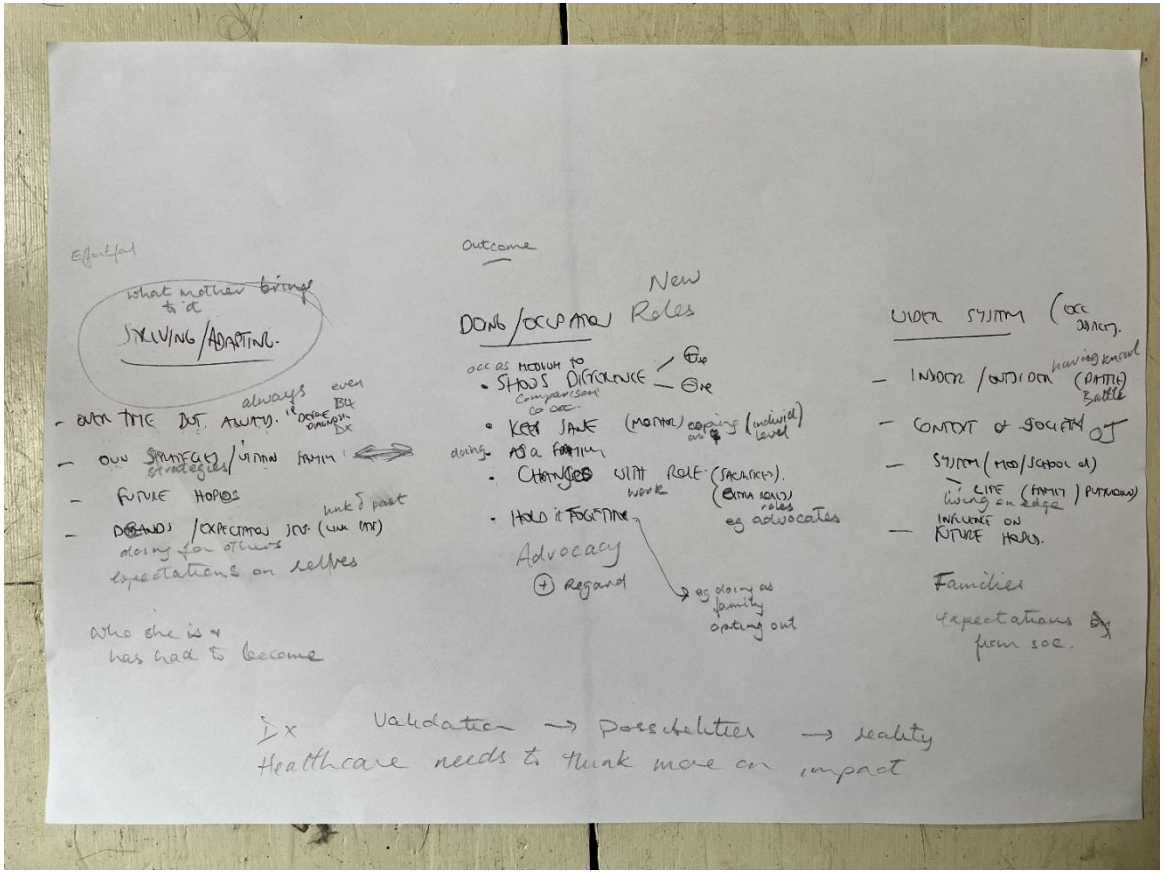
Generic timeline reflecting thematic analysis of mothering experiences.



Taking THEME 4 from the above timeline, the following is an example of engagement with step 2 and 3 in reflexive thematic coding where initial codes were grouped under initial subthemes before being reviewed and reconceptualised in line with the study's purpose and theory (steps 4 and 5) to produce the study's ultimate thematic interpretation.

Theme	Subthemes	Codes
THEME 4: Doing mothering; adapting mothering	1. Understanding their autistic children	…
	2. Mothering their autistic child	…
	3. Personal and emotional cost of mothering	…
	4. Impact on family life	• Different focus and norms for doing • Restrictions on families' occupational engagement • Power of doing – brings family together, divide it, imposes on it • Need for support, appreciation, and reassurance
	5. The utility of meaningful doing	…

Record of part-discussion with qualitative researcher and authority on occupational justice.



Appendix 11: Patton's Reflexive Questions

Patton's Reflexive Questions adapted to guide reflexivity in this study.

Reflexive Screens:	Gender, culture, social position and marital status, education, occupation, family background, political and professional beliefs.	Useful in: Introducing me to the reader.
Questions for me as narrative inquirer:	What do I know and how do I know what I know?	Reflection for data collection & analysis.
	What shapes and has shaped my perspective?	
	How have my perceptions and my background affected the data I have collected and my analysis of those data?	Research report.
	How do I perceive those I have studied?	
	With what voice do I share my perspective?	
	What do I do with what I have found?	
Questions for mothers in this narrative inquiry:	How do participants know what they know?	Reflection for data analysis.
	What shapes and has shaped their worldview?	
	How do they perceive me? Why? How do I know that?	
Questions for readers of this study:	How do audiences make sense of what I give them?	Reflection for research report.
	What perspectives do they bring to the findings I offer?	
	How do they perceive me? How do I perceive them?	
	How do these perceptions affect what I report, and how I report it?	

Appendix 12: Participant Information Leaflet

Mothers' stories: Experiences of mothers who have a child with autism in mainstream school.

PARTICIPANT INFORMATION SHEET

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

Introduction

I am a PhD student and lecturer in Occupational Therapy in Trinity College Dublin. This project is researching the occupational lives of mothers who have children with autism in mainstream school. **Occupation in this research project does not refer to work but refers to all the things you do, need/want to do**. I would like to understand what you do that is meaningful to you and whether or not you feel you experience occupational injustice i.e. that you are not able to do things you need/want to do because of, for example, time, resources, supports, obligations and gender.

Why I am doing the project:

I am doing this project because I want to examine the relationship between what you do/cannot do and the fact that you are a woman and mother of a child with autism. I believe our roles and obligations in life can facilitate, or deprive us, from doing things that are essential to us being ourselves. I feel it is important to understand how life is for other people so that we can learn how to support them.

Why you have been asked to take part:

You have been invited because you are a mother of a child in mainstream school who has autism. I feel that you can contribute much to my understanding and knowledge of the (occupational) lives of these mothers generally.

What you will have to do if you agree to take part:

If you agree to take part, I will ask you to sign a consent form and we will have an interview where I will ask you for your story. The interview method I am using is open-ended. I will not have pre-set questions but, after you tell me your story, I will ask you to tell me some more about the issues you have raised. The interview might last about 1½-2 hours and will be at a place of convenience to you, including the option of having it virtually (for example, via Skype). If you agree, I will record the interview.

I may wish to meet you again for a shorter second interview to clarify issues and ask you specific questions. You can participate in the first interview and decline to participate in the second. I will ask you to sign a new consent form if you are being interviewed a second time.

Your participation in the project will remain confidential and your information anonymous:

Your name, your story and responses to the questions will not be disclosed to other parties. I will use a number of code to identify you rather than your real name. Only I will know this number and will not share it with or given to anyone else. I will use a pseudonym in any write up or publication of the project and will ensure that no clues to your identity appear. Any extracts from what you say that are quoted in the write up will be entirely anonymous. If you say anything that might reveal who you are, I will remove this from the write up and instead refer to it in general terms. Your story will be used for the purpose of this project only and will not be used in any other project without your explicit consent.

What happens to your information:

Following your interview I will transcribe, or employ an approved service to transcribe, the recorded interview. No audio recordings will be made available to anyone other than the research/research team and transcriber, nor will any such recordings be replayed in any public forum or presentation of the research. The soft copy of this transcript will then be held in an encrypted file on a password protected computer and the hard copy will be stored in a locked cabinet to which I alone have access. The information you share will always be kept private, be held for no longer than seven years, and then both hard and soft copies will be destroyed. Your information will be used in no other study without your explicit consent. The study will comply with the General Data Protection Regulation (GDPR) 2016 at all times.

The advantages of taking part:

There may be no direct benefit to you, but you may enjoy sharing your experiences and opinions. Your participation will help me know more about the occupations and any joys or injustices experienced by mothers with children with autism so I can write, teach and speak about it in an informed way.

Any disadvantages of taking part and what:

There is a risk that you may share some personal or confidential information that you do not wish to speak about or that you may feel uncomfortable talking about. However, I do not wish for this to happen. At any time you may decline to answer any question or stop the interview.

You do not have to take part in the study:

Your participation in this project is entirely voluntary. You are not obliged to take part. You may withdraw at any time during the interview or project and have your interview recordings destroyed. You may request to omit individual responses or for changes to be made to your answers.

Provisions for debriefing:

I will give you an opportunity at the end of the interview to add to, withdraw or clarify responses. Additionally, if you wish, I will give you a copy of the interview transcript. At this point you will have the opportunity to request that any information you have shared is removed and I will do so. If you become upset during interview we will take a break and resume the interview when you are ready and willing. If you become upset after the interview, there are a list of support groups below that you are advised to contact. You may also contact the researcher to debrief.

Services that offer support for if the participant becomes upset at any point in the project:

- DUBDOC Out of Hours GP Service: Telephone: XX XXX XXXX
- GP Out of Hours Service Nationally: http://www.hse.ie/eng/services/list/3/outofhours/GPOOH.html
- Samaritans: http://www.samaritans.org/how-we-can-help-you/contact-us or call: XXX XXX (ROI)
- ASPIRE Directory of Supports: http://www.aspireireland.ie/cmsWP/directory-of-service/

In the extremely unlikely event that illicit activity is reported I will be obliged to report it to appropriate authorities.

What happens next?

If you think you might be interested in taking part in this research please contact me via email (sarah.quinn@tcd.ie) or phone (XXX XXX XXXX). I can then answer your queries. You should take a week to consider participating. Only when you are ready, would we arrange an interview.

Researcher's details: Sarah Quinn; email: sarah.quinn@tcd.ie; tel: XXX XXX XXXX

Supervisor's details: Dr. Gillian Wylie; email: wylieg@tcd.ie; tel: XX XXX XXXX

Data Protection (GDPR)

Data Controller: Trinity College Dublin

Data Processor's Contact Details: Sarah Quinn; email: sarah.quinn@tcd.ie; phone: XXX XXX XXXX

Data Protection Officer's Details: dataprotection@tcd.ie; phone: XX XXX XXXX

- Your data will be used as part of the research on the 'Mothers' stories: Experiences of mothers who have a child with autism in mainstream school'.
- Your data (information) is being processed for the purpose of legitimate interest (Article 6;1(f), General Data Protection Regulation, 2016) and for the purpose of scientific research purposes (Article 9;2(j), General Data Protection Regulation, 2016).
- Researchers Sarah Quinn and Dr. Gillian Wylie (supervisor) will have access to your data which gathered during this study.
- Your data will be assigned a code. The keycode will be placed in a locked cabinet in Sarah Quinn's office in Trinity Centre of Health Science in a separate location from all hardcopies of your information.
- The data will be stored for 7 years in line with Trinity College Dublin policy and then destroyed.
- Electronic files of data will be stored on encrypted files on password protected computer.
- It would be impossible to conduct this research without processing of your data, therefore data processing is necessary. Data processing is any operation which is performed on personal data, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction (Act 4(2), General Data Protection Regulation, 2016).
- Measures will be taken to reduce risk when processing the data, however should a data breach occur, this may cause you harm. This harm will be significantly reduced as your data will not have any identifiable information on it. Instead of your name, a code number will be used on your interview transcripts. Other names you reference will also be delated and the information you shared referred to in general terms. If necessary, you have the right to lodge a complaint with the Data Protection Commissioner and with TCD's Data Protection Officer (contact details can be found at the top of this document.
- Until data is analysed by the researcher, you have the right to the following;
  - to request access to your data and a copy of it in an accessible/portable format.
  - to have any inaccurate information about you corrected or deleted.
  - to have personal data deleted.
- Your data will used for this research only and will not be used for any other research without your explicit consent.

Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Sarah Quinn who can be telephoned at XXX XXX XXXX. If the researcher team learns of important new information that might affect your desire to remain in the study, Sarah will tell you.

Appendix 13: Background information on the researcher (who is an instrument of data collection and analysis in this study) to provide additional context to the findings

Demographics	I am white, middle class, heterosexual, Irish female in her late 40's. I am married, living in mortgaged period house in a commuter town. I am educated to master's level (M.Phil). I work in a university – a semi-state institution. My husband has a secure job in the private sector. I have two young children – a son and a daughter.
Family background	I grew up in the centre of a small town living in a crumbling Norman castle with an acre of garden including an orchard where I played. We were given much freedom to run about the house, garden, and town with friends. I was raised Roman Catholic. In keeping with expectations of 70's/80's Ireland I attended mass weekly as well as confession and devotions whenever required. I was educated by nuns in and priests in post-primary. Mother, born 1936, was a homemaker and applied herself fully to her nurturing role. She was patient, fair, kind, giving and non-judgemental. She was clever, artistic, capable but subtle; she cooked meals that were more exotic than her contemporaries, i.e. she moved beyond meat and two veg. This may be contributed to the exposure that her own parents had when they emigrated to Connecticut in the 1920's sometime after the civil war in Ireland. They had been members (as were many) of the old IRA. My grandfather longed for the countryside having grown up as one of 12 on a large farm. They returned to Ireland; my grandmother always missed the interesting food and people she knew in the US. My father, born in 1933, held a degree in Mechanical & Electrical Engineering from UCD and worked in the national telephone service. My father's family were upper-middle class; they had a maid. Both he and his siblings had a flair for the dramatic, were opinionated, clever, confident and undeterred by the opinions of others. My Dad filled a room with his personality. He was fun but also impatient. My childhood memories are of my mother invariably smiling and working in the kitchen and my father, when not at work, was tinkering around repairing things. My sister and I helped with housework on Saturdays and cleaned up after dinners. My younger brothers were required to help in no way at all, despite my protests. Our house was not sexist in the conventional sense –

girls were given the same attention and inheritance as the boys. The same expectations for academic success was held for both genders. My mother explained that my brothers had no chores because they were younger and not because they were male.

Mammy was always home for us and available to us. Suddenly at 12-year-old my single uncle became ill, and my mother began to spend half of each week away from home working in his shop. My sister took over my mother's household duties. This situation continued for about two years. I continued to play around the place with friends but became much more independent, more confident, and maybe a little less kind.

At 15 years old we moved house 70 miles away to be closer to my father's work. He died, aged 55, when I was 16. Unfortunately, my mother didn't drive, and we lived three miles outside the new town and seven miles from our new school, un-serviced by bus. Practically, life became very difficult. Three months after my father's death my older sister had a baby. There could have been shame attached to this in Ireland in 1989 but we didn't feel, nor would we have tolerated, any.

My mother was our home. My husband's memory of staying there was of constant calls of "mom, mom, mom" from her adult children who needed her help to do or find something.

Education and professional career

It was always expected, though never said, that my siblings and I would attend tertiary education. Following my qualification as an occupational therapist in 1995 I worked in a variety of settings with a variety of client groups in Ireland and Australia. This included working privately with young children with autism in their homes. I won a scholarship to study for a research master's degree and then took a job as a lecturer in TCD where I continue to work. While here I also worked with an OT support service for students with mental health conditions including autism.

I have developed a community-engaged learning module which has involved fostering relationships with diverse community partners, several of these are autism-organisations. Across several years I supervised student-facilitated groups in a local women's prison. I am involved in other projects with varying foci on groups considered vulnerable such as refugees and those with experience of homelessness.

For several years I volunteered to co-facilitate drama workshops in a women's prison, the outputs of which were showcased in a community arts

	festival. I also volunteered in Africa on environmental projects and in an orphanage.
My joys	Spending time with people informally. My children. My husband, friends and family. Painting. Making and doing. Designing and restoring. Travelling. Understanding new cultures and systems. Sudoku. Interesting food. Yoga. Mountain hikes. Blue skies. Smiles and friendly strangers. I am excited by design as well as creative and independent thinking.
Sorrows & beefs	That I do not have more children. That I don't have parents. That people find humility to be a weakness not a strength. That people are status and power hungry and are mis-directed (according to my beliefs) in their focus and ambitions.
Political beliefs	I hold socialist tendencies. I'm not hugely Political though committed to advocating for people's rights and the environment – small p political.
Personal beliefs	<u>On mothering</u>: I contend that there is no absolute *right* way to mother. As with most roles and occupational engagement, there may be some *less right* ways to mother (if they arise in this study, it is not my purpose to judge). I believe in the right of children to have happy and healthy lives with opportunities to flourish and I hold that mothers are entitled to the same. In my childhood I developed a keen sense of fairness. In my teens I began to feel keenly issues of injustice and inequality and developed a stronger acceptance of difference. As an adult I am happy to accept everyone for who they are or want to be. I hope I am non-judgemental and open-minded though I do lean more towards appreciating the unusual and artistic than the mainstream and conservative. I'm not sure where I stand on God. Dislike: inequality, favouritism, injustice, bullying behaviour, waste and destruction.
Knowledge-basis	Occupational science. I believe we become through doing-being-belonging. I understand the world through interacting with it sensorially and verbally, then always reflecting on my experiences. I think we can have lots of experiences and learn little from them unless we make our learning explicit through teasing out this learning in reflection. I agree that I am too much in my head unless I am producing art or feeling pain. I think our understanding of the world is constructed through our direct and indirect experiences with it. Knowledge can be described through numbers but better through language or artifact that does not aim to generalise but values the particular.

Appendix 14: Communication with reference group member regarding review of findings chapters in an effort to enhance trustworthiness

Dear X

Thank you very much for agreeing to help me enhance the trustworthiness of my analysis and give your opinion on my interpretation of the information I collected for my study.

I acknowledge that each mother's experience was individual to them. Although I do not want to generalise my findings, there are likely elements of their stories that will speak to the experiences of many mothers in similar situations.

Notwithstanding the likelihood that there are other valid interpretations of the interview information, I would ask you to give your opinion on:

1. The plausibility of my interpretation. Is my interpretation credible – why/ why not?
2. The relevance of my interpretations to situations and contexts of which you are aware or have lived experience. Does my interpretation provide insight into what's happening for others and why? Can you relate to them – or do you think others could?

I have attached my Methodology Chapter (to give you context) and my three Findings Chapters (which are my interpretations of what was shared with me in interview). I hope I have given you enough excerpts from the original transcripts for these interpretations to make sense to you.

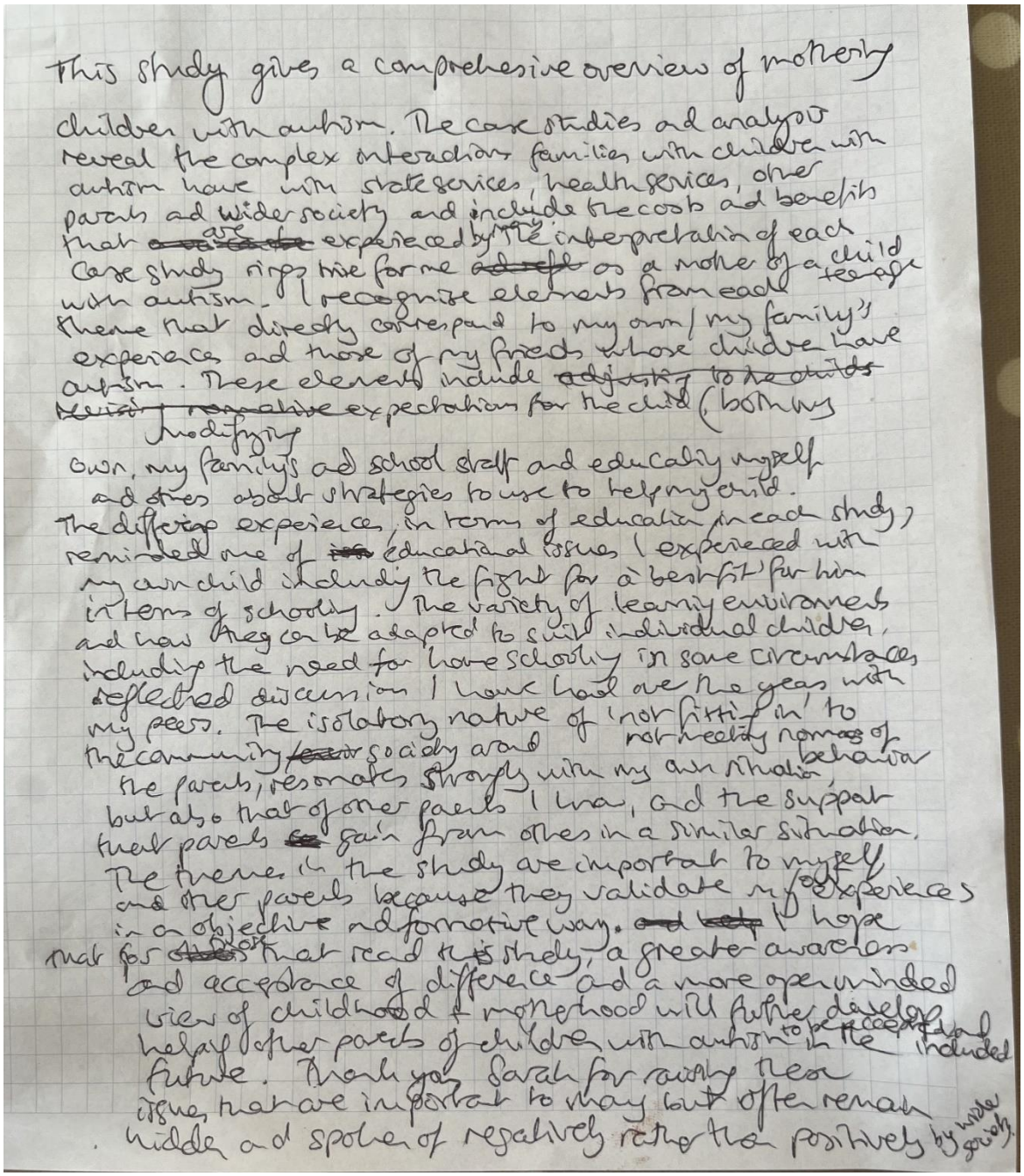
It is important to me that my interpretations are meaningful to mothers of autistic children and speak to their experiences. In addition to hearing your response to the above questions, I'd welcome any additional insights you might have on the interview information you have reviewed that might extend my interpretation of their experiences.

Thanks again for your help with this.

Yours sincerely,

Sarah

Response from reference group member:



This study gives a comprehensive overview of motherly children with autism. The case studies and analysis reveal the complex interactions families with children with autism have with state services, health services, other parents and wider society and include the costs and benefits that are experienced by the interpretation of each case study rings true for me as a mother of a child with autism. I recognise elements from each theme that directly correspond to my own / my family's experiences and those of my friends whose children have autism. These elements include adjusting to the child's [illegible] negative expectations for the child (both my own, my family's and school staff) and educating myself and others about strategies to use to help my child. The different experiences, in terms of education in each study, reminded me of [illegible] educational issues I experienced with my own child including the fight for a 'best fit' for him in terms of schooling. The variety of learning environments and how they can be adapted to suit individual children, including the need for home schooling in some circumstances, reflected discussion I have had over the years with my peers. The isolatory nature of 'not fitting in' to the community socially and not meeting normal behaviour norms of the parents, resonates strongly with my own situation, but also that of other parents I know, and the support that parents can gain from others in a similar situation. The themes in the study are important to myself and other parents because they validate my experiences in an objective and formative way. I hope that for those that read this study, a greater awareness and acceptance of difference and a more open minded view of childhood & motherhood will further develop, helping other parents of children with autism to be accepted and included in the future. Thank you Sarah for raising these issues that are important to many but often remain hidden and spoken of negatively rather than positively by wider society.

Mothers' stories: Experiences of mothers who have children with autism in mainstream schools

PARTICIPANT INFORMED CONSENT FORM

LEAD RESEARCHERS: Sarah Quinn and Dr. Gillian Wylie

BACKGROUND OF RESEARCH: This project is researching the occupational lives of mothers who have children with autism in mainstream school. Occupation refers to all the things you do, need/want to do. Motherhood brings with it both gains and losses in women's identity. As mothers tend to be the main caregivers of their children with disabilities, and mothering a child with autism can be challenging, I would like to understand what you do that is meaningful to you and whether or not you feel you experience occupational injustice i.e. that you are not able to do things you need/want to do because of, for example, time, resources, supports, obligations and gender.

PROCEDURES OF THIS STUDY: Being a part of this study will mean participating in a 1½ to 2 hour interview with the researcher (Sarah Quinn), and being invited to participate in a shorter second interview a few months later.

There are no perceived risks to participation, however, if you become upset during or after the interview you may stop the interview for a break; resume interviewing at a later date; or leave the study. The researcher will provide debriefing and direct you towards supports.

PUBLICATION: The information you and other mothers provide will be anonymised, analysed and written up for publication in academic journals and conferences. No personal material that could identify you will ever be shared outside the research team.

DECLARATION:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, this consent form and a document providing information about this research. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I understand the description of the research that is being provided to me.
- I agree that my data is used for research purposes and I have no objection to my data being published in a way that does not reveal my identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.

- I understand that I may stop electronic recordings at any time, and that I may at any time, even subsequent to my participation have such recordings destroyed (except in situations such as above).
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researcher/research team.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that if I withdraw from this study my data will be automatically removed from the study and destroyed unless I request/agree otherwise.
- I understand that my participation is fully anonymous and that no personal details about me will be recorded.
- I understand that this study will comply with General Data Protection Regulation (GDPR) 2016 requirements.
- I have received a copy of this agreement.

PARTICIPANT'S NAME: _____

PARTICIPANT'S SIGNATURE: _____

STATEMENT OF RESEARCHER'S RESPONSIBILITY:

I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S CONTACT DETAILS:

Sarah Quinn

Email: sarah.quinn@tcd.ie

Mobile: XXX XXX XXXX

SUPERVISOR'S CONTACT DETAILS:

Dr. Gillian Wylie

XXXXXXXXXXXXX

XXX XXX XXXX

RESEARCHER'S SIGNATURE: _____ Date: _____

As a starting point to understand how the gold star cases came to speak about their lives the way they did, given the objective happenings of their stories, a summary of the Biographical Data Analysis and the Teller Flow Analysis are laid out for comparison in the tables below.

As explained in Chapter Four, how the story is told is described using elements of the acronym DRAPE, meaning: **Description** (about events but not necessarily about a particular event); **Report** (relayed information about a lot of events across time); **Argumentation** (took a position or deliberated); **Particular Incident Narrative** (narrates an incident or story); **Evaluation** (draws a conclusion/moral).

IMOGEN: *Comparison of phases of the lived-life with the structure of the told-story*

BDA material	**TFA material**
Phases of the Lived-Life From SS1, SS2, SS3, & notes. **<u>Phase 1: Being independent abroad</u>** Born (late 1970's) and reared outside Ireland in a rural area. Family dysfunction with violent father and untrustworthy mother. Looked out for her sister and brought her to parties at weekends. University. Broken engagement to marry. Made unemployed. Married Irish husband within 3 months of reuniting (having met years earlier). Moved to Ireland following husband who returned that summer as lacked visa to remain. *Phase 1 is signified as owning her own life. Being responsible and also being spontaneous. Notable expectations of care and conformity, self-imposed or otherwise.* **<u>Phase 2: Becoming an adult and starting family-life in Ireland</u>** TURNING POINT. Bought house in Ireland – settled. Worked in hospitality. Two children are born. **<u>Phase 3: The collapse, altering of doing-being-belonging-becoming</u>**	***Structure of the Told-Story*** From SS1 & SS2 only **SS1** **i. Having an autistic son** Pregnancy & first year of Ethan's life: Report / evaluation of this being difficult requiring some sacrifice. Followed the rules to make sure child would be healthy. Busy with child and then work. Bonded through breastfeeding. Ethan's difficulties emerging. Describes experience of assessment process and impact of diagnosis impact using argumentation. **SS2** **ii. Becoming and being a mother:** Some joy and guilt. Uses argumentation and evaluation. Typical life of busy working parents: Uses description. Pressure and guilt of being a mother: Mostly argumentation. **iii. Change and trauma** (14 pages – longest section in her story) Mostly Narrative / description. Signs of autism noted. Childminder (main support), who maintained routine, leaves. This "wrecks" her

TURNING POINT. Childminder moved away. Mother died. Went home to organise father's affairs. Ethan diagnosed with autism. Reduced work hours and finally left job fully. Got carers' allowance. Training courses in how to parent autistic child. Child minds other children after school till both Ethan and his brother are diagnosed with ADHD. Stops minding other children. *Phase 3: characterised by a dedicated doing to make things better.* **<u>Phase 4: Re-establishing & reconnecting with self</u>** TURNING POINT. Ethan on ADHD medication which works well. Begins retraining to alternative career. Ethan starts secondary school. Works part-time. *Phase 4: characterised by hope and doing for change.*	life. Assessment & diagnosis. Mother's death. Missing deadline for SNA. Breakdown on roadside. Here is when she referred to past life family difficulties. Efforts to cope with Ethan's needs with little support: Mostly argumentation. Mothering autistic child: Mostly description. **iv. Hope & new start** Description, narrative, some argumentation. New diagnosis (ADHD) means medication. Improved management possibilities. Retrained using her degree to career that fit family life/needs.
The Biographical Data Analysis (BDA) can be summarised as: Cycle of family traumas which are owned by others but managed by Imogen. This leads to cycles of caring and responsibility so that families' lives function. The first phase is characterised by *doing for herself whilst also caring for her sister*. After a period of independence both in her home country and Ireland she has her first child and moves into a second phase of caring and responsibility-taking. In this phase she takes *full responsibility* for the operation of the day-to-day lives of her second family. This she supports by leaving her job, taking autism training courses, and retraining in a career that allows for school hours of employment.	P01's Teller Flow Analysis (TFA) first gave voice to a vigilant mother-to-be who reported coping and caring. On the diagnosis of Ethan and emergence of deficiencies in supports (including misdiagnosis, childminder's house-move, inflexible SNA application deadline), she became a mother under considerable stress. Her life story began with mostly report and some argumentation/evaluation and shifted to include somewhat pressured (traumatised) narrative, argumentation and evaluation as she told stories of management of Ethan's challenges and negotiation of systems/supports. Dedicating herself to being the best she could be for her child and family, Imogen used evaluative voice to explain and describe decisions around the changes to her routines and occupations. She became mother-fixer and mother-in-control. As Ethan's additional needs became more manageable, she used realistic narrative and understanding argumentation to describe her current situation, finally emerging as an informed mother with brighter prospects.

MAEVE: *Comparison of phases of the lived-life with the structure of the told-story*

BDA material	TFA material
Phases of the Lived-Life From SS1, SS2, SS3, & notes. **Phase 1:** *Responsibility and obligation in childhood.* Born late 1960's. Lived bus ride from city centre; eldest of seven children. Father an alcoholic. Housekeeping and childminding responsibilities at a young age, consequently missed days of school. Leaving cert at 16; professional training at 17. Qualified at 20; took additional diploma. **Phase 2:** *Independence and freedom through moving out of home.* Moved to another city. Worked professionally. Went to gym. Holidayed/travelled. Met now husband. Pregnant (unplanned) on trip to abroad in early 2000's. **Phase 3:** *Discontent and problems in child rearing.* Daughter, Ruby, born when Maeve was 34 y/o. Forceps birth. In hip harness. Baby cried ++ and difficult to settle. Socialised with other mothers on mat leave. Weaning problems. Returned to work (PT) at 6mths. Different parenting styles between Maeve and husband. Maeve engaged with faith group. Several miscarriages. Son, Joseph, born when Maeve was 41. Disengaged with faith group. Public health nurse, and later school, queried son's development re play and behaviour. Husband's employment routines changed – home more. Maeve back in gym when son 4mths. Ruby developed mental health problems at age 14. Parents, on professional advice, withdrew her from extracurricular activity. Admitted to hospital aged 15.5 yrs. Violent and abusive towards parents. Maeve visited daily. Maeve reconnected with faith group.	***Structure of the Told-Story*** From SS1 & SS2 only **SS1** ***i. Hard to love daughter Versus humanity reaffirmed with birth of son.*** Mostly reported how daughter, Ruby, was unplanned, proved to be difficult to manage. Poor mother-daughter bond. Father connected with Ruby. Often undermined Maeve's discipline. Some description and evaluation of how things were at the time. Ruby marked the end of Maeve's travelling and good times. She continued to be difficult, developing mental health problems, before diagnosis. "Fell in love immediately" with Joseph. Protective of him. Joseph diagnosed with autism and ADHD but strong bond and able to support him. Reduced social life; prioritising children and home. **SS2** ***ii. Making up for lost time as a free and independent adult.*** Report and evaluation. Little opportunity for development in childhood. Given lots of household responsibility. Enjoying fun as adult in chosen activities. ***iii. Façade of coping with child rearing.*** Ruby's arrival (unplanned) killed the fun. Difficult and therefore not so easy to love. Much reflection on self and evaluation of past events: Now recognises struggle with Ruby led to panic attacks and shattered confidence. Given her personal and professional experiences, held a self-expectation of coping. Used narrative to explain husband's bond with Ruby; little support of Maeve; undermining of Maeve's discipline as Ruby grew. ***iv. Pulling together in crisis management*** Ruby had power in house; she developed mental health difficulties. Followed professional advice (despite this/consequently) Ruby hospitalised. Traumatic and torturous time for all. Humiliating

Joseph having difficulty regulating emotions. Teacher reported paranoia and temper. **Phase 4:** *Understanding and adjusting.* On discharge, at 16, Ruby dropped out of school. Maeve started working weekends. Ruby had full-time adult supervision at home. Diagnosed with autism and ADHD. Returned to school at 17.5y/o for her leaving cert cycle. Diagnosed with dysgraphia. Joseph diagnosed with autism and ADHD within months of sister's diagnosis. Maeve engages several times weekly with faith group. Manages children's medication. Works part-time.	hospital visits. Husband and Maeve on same page. Used description. ***v. Easier times. Rebuilding relationships.*** Faith group reflections (self-scrutiny) & extreme crisis led to Maeve relinquishing control. Relationship burnt to ground and rebuilt. Ruby's autism diagnosis. Fresh understanding of world from Ruby's perspective. Planting seeds rather than dictating. Used evaluation. ***vi. Birth of love affair with son.*** Relieved when miscarried. Fear of repeat experience with Ruby. Immediately loved and bonded with Joseph. Easy child. Husband supportive. Resumed valued activities (had control on life). Worried re Joseph socially. Addressed difficulties when Ruby's crisis passed. Joseph diagnosed with autism and ADHD. Used narrative and argumentation. ***vii. Modification to priorities, activities and interaction style.*** Much evaluation. Life shrunk. Shed dross. Available to children. Let go of overt control. Subtly influencing children's choices. Faith in God. Hope for resumed normal social behaviours for children and family activities. Used evaluation.
The Biographical Data Analysis (BDA) reads objectively as ***a story of not having enough time for herself to have fun***. Cheated of a childhood she made a considered and controlled escape (through professional training). Her experience of freedom, independence and having things her own way in life was cut short by an unplanned pregnancy. A life that began with domesticity reverted to this with the birth of her first child whom she found difficult. Maeve accepted the obligation of family and the responsibility of children and modified her activities accordingly. As a result of having children with additional needs, she experienced some traumatic events. In its current form, mothering for Maeve included, among other activities, consulting professionals; interacting with schools; praying and attending her faith group; and seldom socialising.	Maeve, in the Teller-Flow Analysis (TFA), was found to have told ***the story of a flawed creature trying to do her best for those she loved***, narrated with description and much evaluation. Initially, Maeve did not recognise her baby daughter as a gain greater than the loss of the freedom and independence that it represented. An earlier voice might have described Ruby as the villain of her story – difficult from birth *("she was hard to settle, it was hard to meet her needs"*). Ruby's culpability for the poor mother-child relationship was validated with the birth of Maeve's second child, Joseph, with whom she immediately *"fell in love"* and formed a strong bond. His birth also reaffirmed Maeve's own ability to love a child and be loved in return. However, the experience of a climatic event (Ruby's illness) and additional persistent stressor (Joseph's school behaviour problems) coinciding with the opportunity for self-

	reflection (at her faith group self-scrutiny), resulted in Maeve recognising her own contribution to the mother-daughter situation. This marked a clear turning point in how Maeve perceived herself in relation to Ruby and a commitment to new ways of engaging with her ("*and I am there to help her to do whatever she needs"*), leading to changes in expectation for her own occupational engagement. Maeve's present-day voice took full responsibility for their earlier troubled relationship. She expressed her story without tears, anger or resentment, but with a tone of acceptance and an acknowledgement that she was a work in progress. *"I have made lots of mistakes, I am still making mistakes, but I think I am getting a little bit better…I still have an awful lot to learn."*

ELOISE: *Comparison of phases of the lived-life with the structure of the told-story*

BDA Material	TFA material
Phases of the Lived-Life From SS1, SS2, SS3, & notes. **Phase 1:** Preparation and training. Using professional qualification to fund continued education. Entering the workforce. Born in suburbs of a city, mid 1970's. Parents from the country. Only daughter of five children. Attended university for one year before leaving to pursue professional training. Returned to complete degree in university, supporting herself financially. Additional professional training. Dual qualification in health and education. Worked in education. **Phase 2:** Parents died. Moved back into healthcare to pursue big career. Mother died. Career switch to healthcare. Father died some years later. Promotion in work. Experienced some ill-health. **Phase 3:** Efforts to conceive. Creating a family. Persisting with education. Married and began IVF. Conflict with boss. Took voluntary redundancy and started a master's degree. Pregnant during first year of masters. Emergency C Section. Lucy born 6 weeks early. Continued with Masters.	***Structure of the Told-Story*** From SS1 & SS2 only SS1 ***i. Circumstances leading up to Lucy's birth and its impact on Eloise's career*** Uses report / description: Married late. IVF. Child is autistic. Had a very senior role in work. Completed a master's degree. Considered adoption. Took unpaid leave while having IVF. Four brothers; lacking female support. Studied fulltime while working. Did postgraduate course. Parents died. Medical problems. Took voluntary redundancy. Uses narrative: Daughter born prematurely through emergency c-section. Uses description: Doing masters during pregnancy and first year with baby. Uses evaluation: Husband's career unaffected. ***ii. Lucy's diagnosis and how this continued to shaped Eloise's productivity*** Uses report: Lucy diagnosed with autism at 2.5yrs. Eloise working part-time. Paid privately for Lucy's therapies. Lucy 3y/o started preschool, private tutor at home. Uses argumentation / description: Eloise took carer's leave and started second masters.

Following masters took a part-time position in education while also giving private tuition in evenings. **Phase 4:** Working towards diagnoses. Paediatrician gave tentative diagnosis of autism. Put on AON waiting list. Four months later Lucy diagnosed at 2.5y/o by private psychiatrist. Hired an in-home ABA tutor. Six months later: Lucy started preschool. Assessment of Need – inconclusive. No Multi-disciplinary Team; outsourced assessments. (One of these assessments happened when her aunt was staying over). On waiting list for ADOS & ASIR. Diagnosed moderate to severe autism; Lucy 4y/o. Lucy started school. Engaged private psychologist to assess for ID – diagnosed with moderate ID. **Phase 5:** Dealing with things. Attended a family member's birthday abroad. Apologised to aunt. Took carer's leave. Second master's degree. Established advocacy campaign for provision of designated special classes in schools in her area. On year later: Met prominent TD in Dail.	Eloise started part-time job in education. Concurrently led an advocacy campaign for designated special class provision. Serious health issues. On sick leave for a year. **SS2** ***iii. The effort involved in becoming pregnant and its consequences for her blossoming career.*** Narrative with some argumentation and evaluation: IVF story. Resultant decreased work productivity/attendance. Excluded from senior management meetings as absent for obligatory meeting during IVF. Formal reprimand from boss. Voluntary redundancy to concentrate on IVF – felt like last chance to create a family. Some secrecy around IVF initially. Told brothers of Lucy's conception at his christening. Godmother to lots of children – practical and responsible approach to children. Uses evaluation. Story about the interview to gain a place in professional training. Uses narrative (in-Pin). Uses report: Raising her younger brother. ***iv. Life as a mother*** Description and evaluation: Getting on with things. Little female support. Being different to other mothers; isolated with Lucy. Autism diagnosis – expected this. Took carer's leave as they had worked so hard to have Lucy, she felt she should be her primary carer. Also difficult to work and organise Lucy's therapy. Second master's degree during weekends while on carer's leave. Retrained into less demanding role. Capable and tenacious. Much argumentation and evaluation. Narrative: Stories about her own parents. Dad's death.

Engaged private psychologist to assess for ADHD as Lucy's attention had deteriorated. Diagnosis confirmed. **<u>Phase 6:</u>** <u>Juggling own health and autism advocacy.</u> Met government bodies and TD's regarding establishment of designated classes. Eloise received a serious medical diagnosis and took sick leave from work. Lucy offered place in designated class in local school (Gaelscoil). Unable to accept due to language difficulties. No designated class in Lucy's senior primary school. Attended the Dail to speak with minister's advisors; minister recommended enacting 37A Admission to School Act. Six months later: Organised large meeting re autism supports with TD's. >300 present.	Evaluation: Mother – woman before her time. Argumentation and evaluation: Autism diagnosis through HSE was horrendous, despite already knowing Lucy had autism. ***v. Addressing injustices with advocacy campaign*** Uses description and narrative: Meeting in Dail. The campaign – meetings & successes. Feels her area is discriminated against – no special classes in mainstream schools. Inverse prejudice. Husband – very supportive. Uses evaluation: Dad praying for her to meet a good man. Pregnancy – difficulties connecting with new baby as had deliberately tried not to connect during pregnancy fearing pregnancy would fail. Uses argumentation: Buying presents of appreciation for teachers for just doing their job. Uses evaluation: Medical appointment clashed with important campaign meeting creating stress around missing meeting rather than potential diagnosis. In-Pins/narrative re: Second masters – made a complaint. Couldn't give aunt enough time around the period of Lucy's HSE diagnosis – fell out. Sought private consultation for ADHD and ID diagnoses – one private clinician was also horrendous. Narrative: around meeting someone she knew in clinician's waiting room when she was upset. Eloise receives a serious medical diagnosis that demanded sick leave for a year. Uses narrative and evaluation and description: re campaign's successes. Lucy's junior school established a designated class. Minister compelled schools in her area to establish designated classes. Description of birthday celebration fundraiser.

The Biographical Data Analysis (BDA) read objectively as ***a story of moving forward, redirecting activities in response to current needs.*** Eloise was action orientated; she worked towards goals, demonstrating huge commitment to studying, her career, conception, her family, and her advocacy campaign. When occupationally engaged (through *doing*), Eloise applied herself conscientiously and, in the main, was rewarded with achievement and success. She made choices that may be interpreted as responsibility taking. It was neither exceptional nor standard practice for a woman of Eloise's age and background to proceed from school to college. Eloise worked through university to support herself; she took on a senior management position in her thirties and then elected to take voluntary redundancy as her career interfered with her efforts to start a family. She chose to retrain to accommodate the needs of her family, to work part-time to allow her time to care for her son. She adopted the role of spokesperson for improvements to her master's programme and chose to establish an advocacy campaign which she continued to fight while on sick leave. Many challenges presented themselves particularly since trying to start a family, but Eloise responded to each by finding an alternative way forward. Her productivity and inclination to respond when things were not working, resulted in much busyness, engagement at a macro-system level, and parallel commitments. Hard work and application paid off till life presented challenges that were less controllable. Still, Eloise tackled these by working to make them better.	The Teller-Flow Analysis (TFA) was expressed as a ***tale of unfulfilled promise.*** Life challenges interfered and altered the direction of Eloise's career and compromised her opportunity to shine. Eloise was a doer and achiever. She presented herself as a fighter who was capable and committed, strategic and determined. What she prioritised and how she addressed her challenges, separated her from other parents/mothers and marked her as different. She also saw herself as an outsider who was not born into this affluent community. She was confident that her method of *doing* was clever and right, which was reinforced by the successes of her campaign. She worked very hard and was invariably successful in her endeavours. In telling her story in this way, she sought some recognition for her and the campaign's accomplishments, especially those that were quietly achieved. With her eye on the prize, she prioritised the battle even at the cost of her own health. She faced many challenges, but her tendency towards positivity, responsibility, and action, meant that Eloise was addressing problems head on. She was battle-worn but not yet weary or worn out. She seemed to enjoy engaging with meso- and macro politics. Eloise planned for action, fought back and worked towards her goals, never questioning her choices, expressing concern merely for the extent of the service-deficit and likely never-ending fight. Only in the period leading up to her voluntary redundancy did she not achieve success, not work uncompromisingly, and not behave in a way that she was proud. But this was **not** her "true self". Eloise spoke at length with much argumentation and evaluation on the story of her life since she had first ever thought to become a mother. She had a lot to say, many stories to share and opinions to express.

SADHBH: *Comparison of phases of the lived-life with the structure of the told-story*

BDA Material	TFA material
Phases of the Lived-Life From SS1, SS2, SS3, & notes.	***Structure of the Told-Story*** From SS1 & SS2
Phase 1: *Much attention, autonomy and co-decision making as an only child. Stability of mother, yet instability otherwise.* Born in a city in the early 1980's. Moved city. Attended primary school. Mother moved to a rural county. Sadhbh stayed in the city to start secondary school (age 12). Sadhbh moved to live with her mother mid-way through first year of secondary school. Mother's job changed to be divided between city and county. Sadhbh and her mother moved to the city (age 15 y/o). Mother spent one night per week in county and Sadhbh had a minder on this night. Graduated from university in early noughties. Mother diagnosed with cancer. Unplanned pregnancy. Started a second (professional degree). **Phase 2:** *Independence and responsibility for someone else (first time). Becomes a mother, unplanned. Trains and embarks on career while mothering.* First child born (Alex, considered female) – unplanned – in year 1 of second BA when Sadhbh was 22y/o. Graduated mid noughties. Job in city. Summers spent with Alex and her mother in countryside. **Phase 3:** *100% an adult now. Mother dies. Expands her family with two more children.*	**SS1** ***i) Becoming a mother and falling in love with her own children.*** In her SS1, using mostly report with some evaluation and argumentation, Sadhbh chose to tell me about: • not initially wanting children, • having an unplanned pregnancy, • its timing at the start of her second degree, • her mother's death (emulating her mothering), • listing births of additional four children after realising it was fabulous to have children, • parenting differently due to autism. **SS2** ***ii) Not liking children.*** Explaining her position on children before becoming a mother. Narrative – Evaluation – Argumentation. ***iii) Having her opinion count in childhood.*** Staying with her mother's friends in the city till she was ready to join her mother. Being an only child and having lots of attention from her mother. Description, some evaluation. ***iv) Working hard in second degree (professional course) while mothering.*** Juggling baby, college work, practice education. Changing her study habits to accommodate her new life demands. Mostly description. ***v) Being pregnant but reluctant to tell her mother.***

Mother's cancer spread. She died age 58y/o when Sadhbh was 27y/o and Alex was 5y/o. Extended family provided much practical support while mother ill. Alex attended all-girls' school and achieved well. Sadhbh did a masters. Planned pregnancy. Second child, Iarlaith, late noughties. Two years later, third child, Riodha, born. Family relocated to rural county (to mother's homeplace) for year while on maternity leave. **Phase 4:** *Signs of children's additional needs emerging.* 2011-2012: Alex attended small local school in rural county. Diagnosed (privately) with dyspraxia. Iarlaith had a speech delay and glue ear. Following year, the family returned to city and Alex returned to original school. Two year later, fourth child, daughter, Radhnaid, born. Iarlaith started school. Sadhbh started job sharing. **Phase 5:** *Autism enters. Life characterised by confusion and upheaval.* Alex had much school refusal in first & second year of secondary school. Tusla involved. Alex identified as non-binary in second year. Planned 5th pregnancy. Alex diagnosed with autism at 14y/o. Given a part-time SNA in school.	Story of how her mother found out about her pregnancy. Narrative. ***vi) Her mother and her child.*** Stories of their summers together. Emulating her mother's parenting. Narrative and evaluation. ***vii) Her mother's illness & death.*** Extended family supported mother. Sadhbh's relationship with extended family. Evaluation and description. ***viii) Birth of her second child.*** Differences between first and second child. Missing her mother. Narrative with some evaluation and argumentation. ***ix) Hard work having a fourth child.*** Stories of caring for house and older children with an infant. Life going smoothly. Pregnant with fifth child. Narrative and report. ***x) Diagnoses – still fabulous children.*** Alex is diagnosed with autism. Iralaith and Riodha move schools. Iralaith and Riodha are diagnosed with autism. Iralaith – language issues; Riodha – fighting in yard. Narrative and report. ***xi) Managing Alex's educational needs.*** School refusal. Sitting in wardrobe; missing school. Tusla's involvement. Changed school. Dropped out. Tried grind school. Dropped out. Description and narrative; argumentation and evaluation.

Phase 6: *Responding to children's educational needs.* Sadhbh studied for a diploma in Autism. Last child (son), Fiach, born. Iarlaith (~9y/o) was unhappy at school. He, and younger brother Riodha, moved school. Iarlaith and Riodha were diagnosed with autism. Alex, in 3rd year, refused to attend school. Tusla involved. He left school to study for his junior cert at home. Following year, Alex changed schools, sustained this for few months. Support from autism services for home tuition (7 hours per week). Following year, Alex got part-time place in an alternative school.	***xii) Parenting autistic children.*** Losing Riodha at Puck Fair. Writing phone numbers on their arms. Jumping in with penguins at a zoo. Uses narrative. ***xiii) Mother's mothering.*** Giving children equal status as given to adults – comparing her childhood with her mother to her friends' childhoods. Uses evaluation. ***xiv) Close bond with children.*** Story about Riodha's face blindness. Uses narrative. ***xv) Learning from mistakes.*** Didn't attend to Alex's issues at school quickly because had fourth toddler. Regretted this so responded quickly to Iarlaith's school issues. Moved his school. Uses argumentation. ***xvi) Rationale for choice of schools.*** Wanted children to be bilingual as she is. Uses argumentation. ***xvi) Scattered.*** Puts in lots of hours at work to stay on top of it and compensate for disorganisation. Uses evaluation.
The Biographical Data Analysis (BDA) reads objectively as ***a story of an autonomous only child (doing her own thing) discovering the joy and stress of a large family.*** Disruption through house moves, compensated by having mother's individual attention as an only child without a father. Allowed much freedom to make her own decisions from childhood. In early	The Teller-Flow Analysis (TFA) was expressed as a ***love story for her mother and children***. Being an only child and coming from a place of complacency towards children generally, Sadhbh falls in love with being a mother. She has little time to express herself as an independent adult before having a child. Her deceased but adored mother's approach to mothering was hugely influential in how she perceives her children. Her

adulthood experienced the sorrow of her mother's illness, compounded by the calamity of an unplanned pregnancy while studying. Pressure of studying with a baby was rewarded by graduating with a professional degree that offered job clarity and free summers to spend with her child and mother in the country. A further four planned pregnancies across the next 14.5 years indicated she deliberately expanded her family after her mother's death. Crisis in son's education preceded his diagnosis of autism, prompting assessments of other children. Some bumps in her road with house moves but generally led a life expected of a clever girl of an educated mother culminating in university. A calamity (pregnancy) clearly worked out well and mothering children became how she wanted to live her life. Challenges continue in the educational domain for her autistic children.	SS1 provided an account of an unplanned and undesired pregnancy that acted as a significant turning point in her life in relation to family. She went on to have five children in total – moving from being an only child in a family of two to being one of a seven-person family as an adult. Her SS2 revealed no evidence of begrudgery or self-pity despite having at least three children with additional needs and little outside support. She described having a fourth child as hard work yet had a fifth. Sadhbh's tone was often light; she laughed lots. Her narrative used argumentation, evaluation, and description. Her stories were entertaining, and peppered with humour, giving the impression that she was coping well. Her stories on behalf of her children that related to her advocacy, interactions with support agencies, and interface with education were descriptive, argumentative and even evaluative, but seldom referenced her own thoughts, feelings, and personal experience of being in the story. Sadhbh's admiration and love for her mother was clear as was the privilege she felt at being mothered as a first-class citizen whose opinions were valued, whose preferences accommodated and who was secure in the knowledge that she was the centre of her mother's world. In emulating this mothering, she made deliberate efforts to understand her children's worldviews and respond to their particular needs.

Appendix 17: Notes on comparisons/commonalities across mothers

IMOGEN

- Like HELEN she wants Ethan to have companionship.

MAEVE

- Like ELOISE she is a X by profession and very capable practically.
- Like NIAMH & HELEN she had an alcoholic father – Maeve queried her emotional development.
- Like IMOGEN she resents a little the excessive input required by her family and therefore the reduction in time for her own occupational engagement.
- Like IMOGEN she engages in mindful downtime occupation though with more commitment than IMOGEN.
- Like NESSA she wanted a second child so that first would not be an only child.
- Like HEATHER she has become less judgemental and more understanding of others. This changes how they interact with the world.
- Like OLIVIA she recognised something was different about her child and wasn't believed by teachers but unlike OLIVIA she didn't push it further.

PAULA

- Like CLAIRE she tensed up when on her own managing child.

MYRA, HEATHER, ELOISE

- All similar in their motivation to help others in similar situations.

HEATHER

- HEATHER's child likes to spend time in nature like PAULA's. Both possibly have ID. Both have somewhat tricky behaviour to manage.
- Like ELOISE, HEATHER has given her all to advocacy and has a reputation for assisting others navigate the systems. Both gave up their careers for this. Both apply themselves 100% to what they do and their cause in this instance is autism supports and inclusion. Autism has become their job and their children's 'rights' their passion.
- HEATHER no holidays for expense reasons – no holidays for NESSA because of difficulty to manage children and for MAEVE because daughter won't go.
- HEATHER found her tribe among the mothers of children with disabilities like ELOISE. Important to have a tribe echoes SADIE's need for same and finding it among the 'earth mothers'.
- Through advocating HEATHER has found her voice and embraced confrontation, much like MYRA who, prior to this, described herself as 'backward' (shy).
- HEATHER emphasises the importance of restocking the well – selfcare. Small gestures of kindness to nurture herself. SADIE also needed to restock and did this through breastfeeding support group or prior to that choir.
- Just like ELOISE, HEATHER is anti the 'victims' attitude of some who have children with special needs. They are both more about sorting things out; acting rather than moaning.
- Like SADIE, HEATHER said mothering was 'hard work'. Both would give their life for their children but it's still hard work.
- Like PAULA, who was not a 'go with the flow' type, HEATHER was very independent and didn't roll with the punches.

- Although the school improvements may not be of use to her son, HEATHER sees it as his legacy (sensory room) to help other children, much like ELOISE who campaigned for a unit in her daughter's junior school which she is now leaving.
- Like NESSA, HEATHER's world had got small.
- Like MYRA & IMOGEN, HEATHER hit rock bottom emotionally and was depressed. She refocused this energy while MYRA took advice and took the reins, and both became empowered.
- HEATHER, like NESSA worries ++ for the future.
- HEATHER's husband, like NESSA's and MAEVE's, worked long hours when they had their first baby, and they felt alone.

TESS

- Like MYRA and NESSA she is living in the bosom of her very involved and supportive family; she is close to home and has that physical and emotional support.
- Like many (incl. HEATHER, PAULA, OLIVIA…) she sees what's wrong, figures it out and looks for confirmation from professionals, e.g. her son's dyspraxia.
- Like others TESS holds assumptions around maternity and mothering. A natural process. So something like a diagnosis must come as a shock.
- Like PAULA, there are ++ barriers to engaging in their own and family leisure activities. What's similar about how they each told their narrative – started with pregnancy, problems with babies, getting assessed. PAULA was content with services. TESS had to fight but ultimately was fairly happy with them.
- Like SADIE her plans for future family life were interrupted and didn't work out.
- She recognised the importance of occupational engagement (selfcare) for herself – leisure for her mental health. HEATHER was a proponent of mother's mental health.

JANE

- Like MYRA & SADIE, she always loved kids and wanted to have children. Like SADIE, she found it hard to wait for her husband to be ready.
- Like HEATHER & Olivia, there was a long process of figuring, convincing and fighting to get a diagnosis; all were relieved to get diagnoses.
- Like MYRA, she saw how detrimental forcing her child to do homework was to their relationship and to the child's life. She somewhat took the reins and told school what her child needed but maybe not to the same extent, same extent wasn't needed for this child.
- First turning point was recognising that her child was not not doing stuff on purpose but that she had additional needs and second was having this properly explained to her in an ADHD parenting course.
- Like SADIE and NESSA she found the Domiciliary Care Allowance excruciating to complete.
- NOTE to SELF: Here I'm noticing that nodes overlap – JANE needs to do with her child what some other mothers needed for themselves e.g. reassurance, creating and being a supportive environment (applies to mother for child as well as others for mothers).
- JANE's husband thinks he needs to be the disciplinarian, yet OLIVIA says that she has this role in the family. She thinks her husband is a wonderful father – fun and loving. She's the routine maker and disciplinarian and he defers to her in this.
- HEATHER felt she needed to super-parent; JANE concedes that these children take more time and a new way of parenting than neurotypical kids.
- IMOGEN, JANE, HEATHER and MYRA – all full-time mothers and all devoted to mothering their neurodivergent children – all satisfied with themselves as mothers (no mother-guilt). So, what's important here: time to spend with child (divided between house and kid but free after school for kid) and devotion to mothering (so acceptance that additional effort & learning on their behalf is required to mother these children).

ELOISE

- Like MAEVE – both dealt very well with perfunctory and practical tasks; took a while to connect with first babies.
- MEAVE hadn't really want to have a baby to start with and ELOISE had tried so hard for the baby that she was afraid she'd lose it. Both initially disconnected (deliberately and otherwise) with baby yet both said that their children are their priority.
- Like HELEN – upholds justice, defends others.
- Like HELEN and MAEVE she had lots of childcare experience as a child and always wanted a family. ELOISE's and HELEN's caring may have been more voluntary than MAEVE's. NOTE to SELF: Where caring and housework was demanded (e.g. Maeve), or in cases where they were made to feel shame as a child (e.g. Olivia), were my participants less likely to want children?
- Like KATE she's not getting much back by way of communication from her child. But unlike KATE she tends to invest time in her by doing advocacy as her form of mothering while KATE is all about connecting with the child. Both have been schooling their children diligently in lockdown. Both children (Lucy and Rufus) received ABA.
- Like OLIVIA they both said motherhood gives purpose.

SADHBH

- Alex, like MAEVE's Ruby, the later-diagnosed children experienced school refusal. Maybe the social world becomes difficult only in secondary school also those diagnosed earlier have learned ways of being and doing by this stage. More nuanced needs.
- Who else said 'we fucking need help' – definitely IMOGEN.
- ***'Didn't Know'*** could be a theme for many – didn't realise what was ahead of them when they were getting child assessed – thought there were services that would help them. Didn't know how to manage child; what to do next…IMOGEN.

OLIVIA

- Fought for diagnosis like HEATHER. Had to convince professionals. Mother seen as barmy.
- Response of professionals is very important here and in other cases, even if they can't fix a problem (e.g. HEATHER).
- Domiciliary Care Allowance was excruciating to complete (like JANE and SADIE).
- Like HEATHER she needed to scream to be heard and tantrums were effective. So the child's development and progress is very dependent on the parent's bolshiness. What if the parent isn't like this and can't become this? Mirrors life but with graver consequences because these are in need of support to meet basic milestones.
- Like TAMSIN and MAEVE she has very poor self-worth but is absolutely dedicated to her children.
- Like MAEVE she needed to get away from home to feel freedom of self. MAEVE was bound by family obligations and chores; OLIVIA was bound by family shame and societal stigma. MAEVE's were easier to escape.
- Similar to PAULA she needs to make her use of time purposeful. Chilling watching TV would make her feel guilty.
- But it makes me feel better in my head when he challenges me and I want to murder him, I am able to say, Olivia, he can't help it. And it actually really helps me because he is very challenging. so this diagnosis is not for the outside world really, except to get resources in school, but it is useful within the home - quite different to Sadhbh (SADHBH)

NIAMH

- Somewhat like TAMSIN in finding it a privilege to mother and shape another being's life.

KATE

- Like SADIE felt her true self when pregnant.
- Like CLAIRE she's aware that she doesn't fully know what she's supposed to do next – both acknowledge that they have to be therapists etc and they don't necessarily know what to do.
- Different to CLAIRE in so far as KATE has grown in confidence and is gaining a sense of her own capacity while Claire is becoming angry and frustrated with the system, feeling disempowered and like she needs to shout.
- Very similar child to CLAIRE's from the point of view of classically loosing vocab etc. (regression) but these mothers are very different on the face of it – one is a scientist while the other is knee deep in alternative medicines and energies etc. How are each coping with life? Social capitol seems to be important for survival.

HELEN

- Dysfunctional upbringing like OLIVIA and both wanted their own functioning families (although OLIVIA didn't realise she wanted one at all till she had it).
- ***'Build up overtime'*** – ways of being develop insidiously over time. No crisis yet child's social reach and expected functioning decreases with age instead of increasing.

Appendix 18: Possible told-stories based on Imogen's BDA

Consider:
What is responsible for her getting to this end point/ where she's at now?
How might she present these facts – what kind of tone could she tells these facts/ this story in?

Hypothesis 1
P01 could tell her story as: **A story of survival.** A life of challenges yet she survives because of who she is and she comes out the far end successful. She was fun and independent and on track despite childhood difficulties – she'd survived well. Then she came to Ireland and started a family. Autism tried to ruin everything but also turned out to be just another huge challenge that she learns to cope with. She's come out the other end almost and is now thinking of herself again. Description

Counter H1
Woe is me. **Self-pity.** I keep getting stuff thrown at me. First my family and then autism. Life has been challenging in parts. She could have got to this point in life via an easier route, minus family dysfunction and autism. They have interfered with and slowed her personal career growth. Argumentation

Hypothesis 2
P01 could tell her story as: **Making a difference.** Despite being spontaneous and chasing fun when younger, she pretty much always did what was expected and toed the line and worked within the system. Her experience of autism services were so poor that it's made her more determined to do her best for children as a new civil servant. Argumentation

Counter H2
So disillusioned with supports she is now going to work to suit her and her family. Argumentation / Evaluation

Hypothesis 3
P01 could tell her story as: **Born carer**. There has always been people hanging out of her. Life as a carer and problem solver and fixer. But enough is enough. At some point I must sort stuff out for myself. It was inevitable that she would end up in her current job. Evaluation

Counter H3
Responsibilities have been thrust upon her and she's just accepted that without complaint. Gives, cares, fixes and often at own expense. Solider on. Weak figure. Description

Hypothesis 4
Emphasis on the need to escape – first her family home (on an island) to the city, then her country to Ireland and deciding not to return. Trying to **live her own life** the way she wants to and grasping potential routes out to do this. Brave, exciting, determined person. But then she gets hit with

autism diagnosis of son so ends up being stuck on another island (Ireland) with more family problems. Argumentation / evaluation

Counter H4
No matter what she does to escape family issues and problems not of her own making they always catch up with her. Domed and destined to be pulled down.

Notes from above on phases of lived-life

Potentially idyllic childhood except for father and for what that brought out in her mother. Presented as her making the best of things. Argumentation

Or

Story of her childhood traumas which are bound to catch up with her later in life. Argumentation

Getting on with life as to be expected. College. Marriage. Could be presented as earlier dysfunctional family life affected her follow through of marriage with first fiancé. Evaluation.

Or

She looked for convention – marriage and college – because of dysfunctional family life.

Could be presented as DESCRTIPTION of wild side (partied as a teen) but must also be suppressed because of expectations and responsibility (thrust on her by dysfunctional family/ taken up by her because she's capable and oldest child). Continuous compromise between what she wants to do and what she is required to do. Sometimes one wins over the other.

OR

Spontaneity is only in response to having to take responsibility and of having disruption to household. Really she'd like predictability but hasn't yet found a way to ensure this. Argumentation.

Could present this as: She's finally able to do things her own way and create a life she wants to live separate to her upbringing. Report

OR

She's going down that route of marriage, kids… recreating what her mother had. Instead of being isolated on an island she's isolated in Ireland. No way of escaping her past – inevitable. Evaluation

This could be a ‘poor me’ – bad family life again. Inevitable. Evaluation.

Or

At least I know how to cope with adversity. Evaluation.

Presented as: it’s all down to her again. It always is. EVALUATION. She falls into familiar pattern of coping through engagement, pushing herself out there, and compromising the piece of her occupational engagement (OE) that is about her. This is different to her ‘doing’ as a youngster – then she brought her sister with her places and parties so she could still engage in activities of choice. Now her responsibilities have increased because she’s a mother.

OR

She’s taking over, taking control of the situation, and in this way excluding others or at least at this OE is sending the message that she’s coping. Doing and activism is a way of coping but might also be masking what is happening under the surface for her

All the effort is beginning to pay off. Feeling self-reliance is the only way to go. She has always had to make things work – her personal effort and innate skill are shaping a life worth living. Evaluation

OR

She can’t believe she is living this life – she cared for her family/ son and is now working a job where she cares for others. She has traded her career drive for job that works for her family life. She’s a cop out.

So leaving her country was BRAVE as well as spontaneous. Also, an independent minded thing to do. Doing her own thing uninfluenced by pressure from others.

Appendix 19: Confirmation of ethical approval

From: David Mitchell <DAMITCHE@tcd.ie>
Sent: Wednesday 27 May 2020 15:18
To: Sarah Quinn <saquinn@tcd.ie>
Cc: Gillian Wylie <WYLIEG@tcd.ie>
Subject: Re: Research Ethics Application

Dear Sarah,

The Committee has reviewed your application and is happy to give ethical approval.

All the best with the research!

David

Dr. David Mitchell
Assistant Professor, Conflict Resolution and Reconciliation
Course Coordinator - MPhil Conflict Resolution and Reconciliation
Trinity College Dublin at Belfast
9 Lennoxvale
Belfast
Northern Ireland
BT9 5BY

Tel: +44 (0) 28 9037 3989
@davidmitchelldr
@Trinity_Belfast

Appendix 20: SS3 interview questions for P17

Questions will not all have been asked nor asked in this order. Although I made in the moment decisions based on the flow and content of the conversation, each of these heading topics will have been discussed during SS3.

Past influence on subjectivity and occupational identity:

1. **Chronology –** gaps. Do you think this captures your lived life objectively?
2. You have described yourself, what you were like, before having children but w**hat did you like to do? Favourite way to spend time? What gave you a buzz?**[14]
3. If you can bring yourself back to the time when you were marrying X, what did you think your **life would look like today**? **Family life different to imagined?** You mentioned it being important to find Mr Right and have your **perfect family – Did you have an ideal of what kind of mother you'd become**? Was the yearn for perfect family related to what you feel you missed as a child?

Transitioning to new occupational identity:

You experienced lots of challenges since becoming a mother…

4. Is there anything that you had to **give up doing**? How was that for you? What takes up most of your time now compared to before children?
5. Is there anything in particular that you did that you found **kept you going** after having children especially when Isaac started having difficulties and after getting his diagnoses? Even a small thing that you did – chatting… (resilience through doing…)

Motherhood as occupational identity:[15]

Thinking of yourself as being a mother…

6. Can you describe an **activity that embodies motherhood** for you? (who, what, where, when, why) How do you feel when you're in it? Why is it important to do?
7. What is important to you as a mother? Have you **priorities** for your children?[16]
8. Do you think your mother role models as you grew up influenced the way you mother now for good or bad? How? Help form an idealised version of motherhood?
9. Many mothers find they take most of the **responsibility for the family and make most accommodations for home to run smoothly**. How do you feel about this? How do you **balance your roles** with working fulltime?
10. Do you think it is a **different experience to being a father**?
11. Do you think your **relationships with other people** influence what you do – as a mother and for yourself? Where do other people fit into your mothering?
12. **What does being a mother mean to you? What do you get out of mothering?**
13. **Do you think being a mother has changed how you view yourself? ..when in the mothering activities…before V's after becoming a mother.**

[14] COMMENT made 3.1.21: "Kinda did this in SS2 – independent responsible nurturing forthright defender of underdog"

[15] COMMENT made 16.12.20: "Push for Intersectionality of roles, Occupational justice & resilience, Choice & control, Autism impact?"

[16] COMMENT made 13.1.21: "Might already have answered this – education, good food."

14. **What's hard about mothering? How has autism an impact on your life and mothering?** Bring 'resilience through doing' in here. Has it been possible to create the perfect family? Become your ideal mother?
15. **Three words** that describe you as a mother?

Situating mothering relative to other occupations:

16. Has being a mother now effected the way you do other things?
17. Think of yourself doing something that makes you **feel most like yourself/ at one with how you want to be** – what is it; describe doing it; describe feelings in it?
    Compare to mothering activities.
18. Think of yourself doing something that makes you **empowered**/ have **control** – what is it; describe doing it; describe feelings in it?
    Compare to you mothering activities.

Supporting motherhood:

19. Do you think society values your work as a mom?
20. Have **societal attitudes** ever stopped you doing anything or made you feel bad/good about yourself for what you're doing?
21. As a mother of a child with autism do you feel accepted (integrated) and supported by society?
22. How could society **make the journey easier** for mothers with children with autism? What support would you need to be the mother you wanted to be? ***Bring fairness and justice in here. School accommodations?***
23. **Have you been able to become the mother you wanted to become…?**
24. How do you think your **life will look in 10 years** from now? Isaac will by 27y/o. (What would need to happen for it to change – more positive?) What will you be doing?
25. Is there anything that you need and want to do between now and then? What's going to support or hinder that?