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'A mother first, last, and always': A theological study, through life stories, of mothering a child on the autism spectrum.

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Abstract

'A mother first, last, and always': A theological study, through life stories, of mothering a child on the autism spectrum.

This research seeks to offer a practical theological reflection on the experience of mothering a child on the autism spectrum.

I begin by exploring contemporary literature on disability and autism to critically assess the tensions between the everyday challenges of daily mothering, and the wider impact of social attitudes and policies which occlude this experience. Adopting a feminist phenomenological approach, I then undertake an analysis of mothers' life stories. These include my own autoethnographic writing, published memoirs and life story interviews. I draw on these to construct a theological reflection on the challenges experienced by mothers of children with a diagnosis of autism and use this as a basis to critique the existing theological literature in this field. Finally, I propose that the lived experience of the mothers necessitates a theological response which attends to the complexity and unsettled nature of lived experiences which resist incorporation into normative epistemic frameworks. It requires a theology of 'unresolvement'.

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Prologue: The beginning.

After a long and arduous pregnancy, I remember his first months seeming effortless. We existed in a blissful bubble. Placid but inquisitive, he fed well, slept well, laughed and cuddled. He was affectionate, but not needy. I was naively smug in my ability to mother this tiny human. We knew each other intuitively, him and I. Two halves of a whole. But as his first birthday neared… our symbiosis began to fragment; dissolving slowly, but insidiously.

By 8 months old, my once peaceful baby had become habitually disconsolate. His cries were impossible to predict and even more impossible to soothe. Something had shifted with him and I. Imperceptible, yet pivotal. A gnawing unease had begun to form in my belly. The intuitive ease with which I had always been able to anticipate his needs had evaporated, seemingly overnight, and I was paralysed by my inability to understand him. Something was wrong.

It felt like weeks since he had slept. Those days had turned into nights, nights in which day light was simply replaced by the glow of the alarm clock, the minutes and hours ticking by almost mockingly. Those nights his cries, seemingly without purpose or interruption, would seem to last an eternity. I nursed. I held. I sang. I paced. One particular night marked the end of a week so long I could no longer do anything but sit on the bed and rock, trying futilely to guide my screaming child to a breast he did not want. By the time morning came, the soft light flickering through the curtains, I too was weeping. 'Please stop', I murmured, over and over, a record scratched and jumping, constantly repeating; a desperate nursery rhyme which calmed neither he nor I.

My mother joyfully threw open the bedroom door, brandishing a huge balloon and a bouquet of flowers. 'It's Mother's Day!' she exclaimed. I had forgotten. Of course I had, the night had lasted weeks. The realisation that I had welcomed my first Mother's Day broken and weeping, and that I had not been the one to first waken the wonderful creature before me with the flowers and excitement which she greeted me, wrought fresh sobs from my chest. My mother's smile faltered as she took in the scene before her. Wordlessly, she took the baby from my arms. 'It's…he's…and I…I can't,' I wheezed between sobs, staring down at the now empty space in my arms. With my baby deftly tucked under one arm, my mother turned her attention to her baby, now grown. Gently, she eased me back into bed.

'Oh, my darling,' she said. 'But you can. There will be many more mother's days, and many more nights like this before them. This baby will take every last ounce of energy and love you have, and you will still find more to give him. That's what it means to be a mother. And that's why we get the flowers.' As always, my wonderful mother was right. There would be many more Mother's Days. There would be many more flowers. But there would also be many more tears.

Introduction
Nature of the Thesis

This thesis critically examines the distinct maternal experience of parenting a child on the autism spectrum. Illuminating the complex and often conflicting emotions of this experience through my own and other's shared life stories, it will seek to reflect on how practical theology may attend to the occluded theological challenges these narratives present. Swinton and Mowat suggest that 'the questions that emerge in the light of the human experience of God are often different from those which emerge from the solitude of the academic's office' (2006, 7). This particular research topic has emerged in the light of what has been a deeply challenging lived experience. My son was diagnosed with autism aged 6. The years prior to this were filled with confusion, frustration, fear and guilt. My beautiful, sweet natured child would disappear without warning, leaving behind a furious, terrifying stranger, whose actions and motives were inexplicable even to him. While we have always travelled hand in hand, just him and I, the road has been far from smooth.

It has now been 5 years since his diagnosis. While we have journeyed a long way from the dark and bewildering days of pre-diagnosis; that road has been paved with tumultuous, twisting and circuitous emotions. As a theologian, who became a mother of a child with autism, I attempted to locate my maternal experience within the theologies available to me. Surely, I considered, I would find myself somewhere on these pages? Surely, I would stumble across our pain, our joy, our fury or our triumph on a shelf somewhere, and be able to apply some meaning or understanding to our experience? This was not the case. Despite increasing interdisciplinary research confirming that autism, peculiarly and significantly, has been found to impact maternal well-being and mental health more profoundly than other developmental conditions (Estes et al 2009, 376; Giallo et al 2011, 466; Zhang et al 2015, 29), very little attention has been given as to *how* autism affects mothers; what challenges autism presents in everyday life, how these challenges meaningfully and substantially change the lived experience of motherhood, and how this really *feels* for the women who are living it.

In the course of this research, I was approached by a friend and educator who inquired whether I would be willing to facilitate what she, quite aptly, called 'A Meet and Greet[1]' for other mothers of children with additional support needs. In supporting these families, this

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[1] For the clarity of non-Scottish readers, 'greet' in this context refers to the practice of 'greetin'', a very Scottish way of describing sobbing one's heart out.

wonderful woman saw that the network of support available to them was insufficient in attending to what they really needed. These women did not need to be taught more about autism, or how to parent their autistic child. Parents of children on the spectrum learn very quickly to be experts not only in autism but in their own spectrum children, becoming their advocates and champions (Nicholas et al 2016, 926).

Rather, what she identified, and what I myself had been becoming aware of, was that they had no space to speak of their struggles. They were silenced, often ashamed, in their struggle; caught between love for their children and utter exhaustion. In reflecting upon this silenced struggle, theirs and mine, I considered that perhaps one of the most challenging aspects of the parental experience of autism is that it is often hidden; it is marginalised socially, academically, and theologically. In order to demonstrate the particularity of this occluded issue, I will go on to contextualise the complex, interrelating and conflicting socio-political conditions that shape the experience of autism, and which coalesce to create a distinct maternal challenge.

Situating the Context- Autism in Scotland

Autism is a life-long, developmental condition currently impacting 1.035% (103.5 per 10,000) percent of the Scottish population[2]. It is characterised by delayed development in early childhood, and abnormalities in three specific areas of cognitive function: social interaction, communication, and behaviour[3]. However, whilst autism can be seen to exist as a distinct diagnostic category [4] , its symptomology is so diverse and multivariant in both severity and complexity that it remains a much misunderstood condition.

In 2001, The Scottish Government issued 'The Scottish Strategy for Autism,'detailing 26 short, median, and long-term goals in achieving its aim:

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[2] https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/9/
Accessed 12/02/20 11.49am
[3] International Classification of diseases
https://icd.who.int/browse10/2016/en#/F84.5
[4] There are a multitude of terms used to describe both autism and those with an autism diagnosis. Whilst 'Autism' and 'Aspergers' were initially thought to be separate diagnosis, increasingly these terms are being used interchangeably to describe what is now commonly referred to as ASD (Autism Spectrum Disorder). It is important to note that are contestations around appropriate terminology for describing persons with autism (see Kenny et al (2016) *'Which terms should be used to describe Autism? Perspectives from the UK Autism community.').* However, this remains largely personal preference. Given that I am representing a multitude of voices in this thesis, I do not adopt any one term but rather use a full 'spectrum' of terms interchangeably to reflect the diversity of opinions and research relating to the definition of autism.

> …that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives (2011, 9).

With the estimated national cost for individuals with ASD (Autism Spectrum Disorders) estimated at £2.292 billion per annum, and financial costs to families estimated to be between £3,813 and £4,479 per annum, [5] the importance of providing timely and appropriate support to individuals and families affected by autism has very real material implications for public policy in Scotland. Given the breadth and pervasiveness of autism symptomology, successful strategies for autism support are expected to traverse health, education, and social welfare policy. Despite Scotland's commitment to the just treatment of people with autism, there is currently no cohesive autism strategy implemented nationally; rather, regional health boards are expected to put forward their own strategies for meeting the aims of the Scottish Strategy for Autism's 2011 report. As of 2015, Glasgow City Council's autism strategy was still presented as a 'draft' report[6]. With strategies varying dependent on region, access to diagnosis and support for families within Scotland can arguably be seen to be inconsistent and insufficient in meeting national aims.

Indeed, despite approaching almost a decade since the release of the 2011 Scottish Strategy report, many of the central short-term goals have still yet to be achieved. In 2014, a study published by Autism ACHIEVE Alliance[7] found that in children, the average wait from referral to diagnosis was 331 days. A more recent article from the National Autistic Society (2016)[8] continued to petition for the government to bring autism diagnosis time in line with the current NHS guidelines for 18 weeks from referral to treatment. Research has shown that delays in receiving a timely diagnosis can significantly impact outcomes for children and contribute to significant mental health affects for parents and care givers (Zelzazo et al 2001, 40; Sansoti et al 2002, 81).

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[5] https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/10/ Accessed 12/02/20 11.49am
[6]
http://www.glasgow.gov.uk/Councillorsandcommittees/viewSelectedDocument.asp?c=P62AFQDNT10GT1UT2U Accessed 12/02/20 14.11pm
[7] Waiting for Assessment Executive Summary (2014) ACHIEVE Alliance https://www.autismnetworkscotland.org.uk/files/2014/11/AAA-ASD-Waiting-for-Assessment-Executive-Summary.pdf Accessed 12/02/20
[8] https://www.autism.org.uk/get-involved/media-centre/news/2016-07-06-scottishguidelines.aspx Accessed 12/02/20 15.20pm

Within my specific local authority (whose autism strategy also remains in draft format), there are currently no guidelines for follow-up support from health care professionals following a single diagnosis for ASD[9]. Parents who receive a stand-alone diagnosis of autism are often left with more questions than answers after receiving a diagnosis, and few places to go to ask. Often, parents are directed to non-profit organisations and local carer groups for information and support following a diagnosis, however utilisation of these services depends on the proactive and independent engagement of the parent in seeking social support and advice. This is particularly concerning, as for many parents the days and months following diagnosis can be an extremely confusing and distressing time. Furthermore, the everyday demands of caregiving can often inhibit individuals from having the time and financial resources available to them to access support (Tomeney 2017, 907). For parents living in Scotland, the experience of autism can thus arguably be seen to be profoundly shaped by inconsistent and inadequate social policies which prolong and complicate the process of attaining support. In this respect, I have considered the lived experience of Scottish mothers particularly revealing in illuminating the complexity of challenges associated with raising a child on the autism spectrum as deeply social, political and relational.

A Distinct Maternal Experience

While current research pertaining to autism care giving predominantly utilises the relatively gender-neutral term of 'parenting,' the literature itself paradoxically reflects that the experience of parenting even typically developing children remains strongly gendered. Karen Christopher, in her analysis of dominant motherhood ideologies amongst working mothers notes that even women who consider themselves to be independent and economically stable in their own right, often continue to adopt traditional patterns of gendered division of labour within the home, performing almost double the amount of housework as their male partners (2010, 74). This 'sexual and familial division of labour' (Pollock 1999, 71) is extensively reflected in the literature examining parenting of children with additional support needs, particularly in relation to autism spectrum disorders. Research conducted by Marshall and Bonita indicates that the care giving demands of parenting a child on the spectrum are consistently more occupied by the mother in comparison to the father (2005, 105). Tomeney

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[9] This differs in the cases where Autism presents with other co-morbidities which typically require medication, such as ADHD and Tourettes (Tic Disorder).

et al also support this assertion, observing that 'mothers, who often serve as primary caregivers, appear to be particularly affected by these unique challenges' (2017, 907).

Although fathers are certainly impacted by this parental journey, they are not the subject of this thesis. An insight into the lives of fathers would doubtless offer a significant contribution to this discussion, however I propose that their experiences differ to those of mothers significantly enough that they would be beyond the scope of this thesis to attend to. As I will demonstrate in subsequent chapters, mothers have been particularly and peculiarly implicated in the history of autism (see chapter two, section 2.2b); consequently, this thesis looks to the lives of mothers as affected by the experience of autism in ways which are *distinctive* to mothers.

The emotional responses which can be seen to accompany the myriad of challenges faced in mothering a child with a lifelong developmental condition such as autism are often complicated and conflicting. The struggles of parents whose children are on the autism spectrum are thus often carefully and skilfully hidden. To express grief or disappointment in our mothering situation can feel like a denial of our child. We fear that perhaps we do not love him or her enough if we admit to such emotions. The stigma associated with confessing such complicated feelings is also prohibitive, and so the world of an autism mother can be a lonely, silent place. This experience is also theologically silent, as we have yet to develop a theology which adequately reflects the complexity of this particular maternal experience. Current theologies of disability are limited, and often still rely on essentialist notions of disability as something which is fully embodied or medicalised (Swinton 2012, 444). Conversely, theologies of motherhood often depict a normative experience of mothering, which does not attend to the added complexity of caring for additional support needs.

Motherhood is hard. What is harder still is that we are often left unable to speak of how hard it can be without fear of shame or judgement. As a consequence the real, lived experience of motherhood can become hidden, stigmatised and silenced. The feelings, experiences and stories we hold inside can become lost as we are unable to find a meaningful space in the narrative of motherhood which allows for them to be told. Joan Laird describes this as the 'unstory;' the stories that are too shameful or painful for us to share (Laird 1991, 437). It is this aspect of motherhood, the 'unstories' which we feel compelled to keep hidden, that is too often neglected in our reading of maternal experience. In situations such as these Heather Walton observes that 'there may be times when we take brave decisions to share experiences

that are -painful to us, because their telling may be of benefit to others' (2014, pxxix). And so, brave or otherwise, in revealing and reflecting on our 'unstories', this thesis intends to highlight aspects of maternal experience which have hitherto been hidden from theological discourse and explore how such narratives may prove generative in provoking new ways of thinking theologically about occluded lived experiences.

Revealing the Unstories- The Theological Turn to Lived Experience

The significance and revelatory power of lived experience is increasingly being considered a valuable and legitimate form of knowledge making within practical theology (Walton 2014, 100; Miller-McLemore 1994, 30). While there remains continued apprehension from within the discipline as to the reliability of lived experience as a credible theological source (Swinton and Mowat 2006, 67; Graham 1996, 174) feminist practical theologians in particular have illuminated the transformative potential of women's experience in providing vital sources of theological knowledge and in generating fresh insight and meaning into taken for granted social, theological and public practices (Bons-Storm 1996, 135 ; Walton 2014, 170).

Michael De Certeau proposes that while accounts of lived encounters are significant, these cannot be extracted from the complex and interweaving material and social realities of everyday living (1980, xi). In developing theologies which attend to the lived experience of women, theologians such as Bonnie Miller-McLemore (1994, 2016) and Ada Maria Isasi-Díaz (1996, 2002) have similarly advocated for an interrogation into the seemingly banal, yet complex practices of everyday living which shape women's reality and, subsequently, their meaning making.

Despite these disciplinary strides, as stated, I had found that my own lived experience was absent from the texts I so urgently explored. The harder I sought, the more 'missing' I seemed to be. And yet, I was aware that key aspects of my experience of mothering were not confined to myself alone. There were other women around me who shared the complicated and fluctuating spectrum of emotions that come hand in hand with parenting a child on the autism spectrum. This thesis will seek to reflect on my own lived experience, alongside the shared experiences of other local women who have children on the autism spectrum, in order to discern what is distinct about the practice of mothering a child with autism. By exploring our shared yet different lived experiences, I intend to demonstrate an occluded form of motherhood which may provoke new theological reflection.

Structure of the thesis

This thesis has been constructed through an interdisciplinary approach. Autism, central to the experience of mothering I seek to explore, is situated within competing contexts of medical, social and public policies. A theological reflection on the maternal experience of autism therefore must attend to these complexities in order to provide a holistic examination of the complicated and conflicting forces which shape this distinct lived experience. While this research looks to contribute to a theological tradition which thoughtfully engages with the revelatory potential of lived experience, it does so with an awareness that experience is situated in and therefore inextricable from its social and historical contexts (De Certeau 1980, xi; Veling 2005, 6; Walton 2014, 7). In locating the issue of 'mothering with autism' in relation to the social, historical and political contexts of disability generally, and autism specifically, I intend to firstly highlight how the complex and interrelating constructs of autism significantly, and often negatively, impact the experience of mothering. Secondly, I hope that in providing insight into the issues relating to autism, I will generate a greater theological understanding of autism itself, and of the often overlooked experience of mothering an autistic child.

Consequently, I adopt a pluralistic approach to my research topic, which I address in this thesis in three parts. The first part looks to critically engage with contemporary literature in disability, autism and parenting to provide an interdisciplinary context of the theo-political dimensions of the experience I am seeking to illuminate. The second part contextualises my own experiences in relation to the literature explored and introduces the lived experiences of other myself and other mothers who share their experiences and insights into the everyday struggles of motherhood in the context of autism. The third part will look to explore how theology has traditionally responded to these issues. It then asks whether, in the light of the insight generated from the sharing of our lived experiences, such theologies can be seen to adequately attend to the challenge of mothering a child on the autism spectrum. The specific concerns of each chapter are set out below.

Part One

In Chapter One, I begin by critically examining contemporary literature on disability, examining how the competing discourses of the medical and social model have constructed dichotomous and polarised understandings of disability. I will explore how disability is constructed as 'other' within society, reflecting on how schemas of 'normalcy' have had an

enduringly destructive impact on the lives of disabled individuals. Engaging with feminist disability literature, I will highlight the disciplinary turn towards attending to embodied lived experiences which are counter normative. Finally, I will problematise the invisibility of certain groups within the disability agenda, particularly that of children and those with cognitive development conditions, in representing a limited portrayal of disabled experience.

In Chapters Two and Three I trace the history of autism in its emergence as a recognisable, distinct condition. Given that lack of understanding and knowledge of autism is often cited as a considerable barrier to acceptance and inclusion, this chapter contextualises the impact of socio-political forces on medical discourse, looking specifically at how in the case of autism, these forces functioned to delay, misrepresent, and impede the development of research for several decades. Detailing what are now commonly accepted as the defining characteristics of autism, I will highlight that such symptomologies are often significantly stigmatised both for individuals with autism themselves and for their care givers. I will propose that this stigmatisation, in addition to the way mothers are peculiarly and damagingly implicated in the presentation of autism, coalesce to form a distinctly challenging maternal experience. I will argue that the complex social milieu in which autism emerged has shaped popular perceptions (or misperceptions) of autism, functioning to marginalise autistic individuals and their families and prevent the understanding necessary to provide appropriate social and theological support.

Part Two

In Chapter Four I address the methodological choices utilised in approaching the research question. I will begin with a brief discussion of practical theology's significance in attending to the complexity of lived experience in theological reflection and locate the challenge of reflexivity within research. From here, I situate my methodology as being informed by a phenomenological feminist perspective which pays attention to experience as lived and embodied, gender as constructed, and experience as shaped by dualistic and hierarchical social forces which function to legitimate dominant paradigms of knowledge. I then move to a discussion of methods, outlining my use of life stories (memoir, life story interview and my own autoethnographic life writing) as the means through which I will illuminate the particularity of autism mothering as an occluded lived experience, articulating my conviction that life narrative based research can provoke a generative and illuminative theological response to complex issues arising from everyday experiences of struggle.

In Chapters Five and Six I employ these life stories to reflect on and critically engage with my own and other mothers shared experiences of living with autism, analysing how the dominant themes which emerge from our narratives relate to contemporary literature on maternal experience, and revealing significant aspects of our experiences which are currently occluded in research. In these chapters, I develop a new account of maternal experience which is complex, conflicting, and enduring and argue this necessitates a distinct theological response.

Part Three
In Chapter Seven I will critically engage with traditional theologies of disability, examining the relationship between such theologies and the models of disability examined in chapter one. I will examine the impact of liberation disability theologies in situating disability as a theo-political issue in which accessibility and inclusion emerge as key theological concerns. I will then consider the utility of communitarian theologies of disability in attending to the relationality of disability as a social issue, evaluating how this model could inform the kind of social support which may be beneficial for mothers of children with autism. From here I will look to the emergence of 'autism theologies', which I propose can be shown to draw respectively from the preceding theological models to explore the theological particularity of autistic experience. Lastly, I will discuss the paradigmatic turn towards theologies of 'limits' in respect to disability. The theologies of limits I will examine acknowledge the embodied nature of human limits, moving beyond paradigms of lived experience as rooted in bodily impairment towards a more inclusive theological model of difference which may resonate more deeply with the multiplicity of challenges represented by autism.

In Chapter Eight I re-articulate my position that our lived stories have revealed a distinct form of maternal experience, critically engaging with theologies which attend to the importance of motherhood as a theologically generative (and currently neglected) site of knowledge. I will consider the themes which have emerged within chapters five and six in the context of theologies which look to the complexity of the everyday as a potential site of struggle and resistance.

In Chapter Nine I conclude this thesis by attending to the gaps and silences I have encountered in theologically reflecting on our lived experiences. Considering the limitations of current theologies in responding to experiences which are resistant to categorisation, I

propose a theological response attentive to lived experiences which are ambiguous, uncertain, and unresolved.

Chapter 1) Disability

In this chapter I will present disability as a contested concept, examining dominant paradigms of disability which have emerged in response to the marginalisation of disabled experience. I will explore how competing discourses situate disability as variously; medical, social and embodied; highlighting that even within disability studies, there can be seen to be epistemic incongruity as to exactly whose lived experiences might fall under the designation 'disabled.' In examining these conflicts, I explore key concerns in disability theory in respect to embodiment, adaptation, and accessibility, situating the central paradigms which will later be shown to inform dominant theologies of disability (see chapter seven). I will examine how the 'othering' of disability has been shaped by social, cultural and historical forces; identifying how these forces have operated to influence our understanding and attitudes towards disability, and, by extension, autism.

1.1) Dys-functional Definitions

> 'Disability' is a commonplace term. Its meaning, at one level, is beguilingly obvious –
> not being able to do something. In lay terms, referring to people with impairments -as
> disabled signals that they belong to that group of people who cannot engage in
> 'normal' activities because of their 'abnormal' bodily or intellectual 'deficit' or
> 'incapacity'. (Thomas 2002, 38)

Historically, the term 'disability' was used to refer to those who fall outside the parameters of what we consider 'normal'. This categorisation, while seemingly straightforward, however, has come to raise more questions than it answered. What do we consider as 'normal'? Where did those parameters come from? Who gets to decide who is normal, and who is not?

The term 'disability', much like autism, is thus a simple designation for what is anything but a simple concept. If we are to consider the multiplicity of individuals who identify as 'disabled' and the myriad of conditions and impairments which fall under this over-arching term, the possibilities of variation within this one classification appear infinite. A double amputee, for example, would be considered as an individual with a disability. Such an impairment would be visible, obvious, and would likely be accompanied by physical symptoms of pain or discomfort which would impact an individual's daily life and ability to perform everyday tasks to a considerable degree. However, we might also be likely to

consider someone with autism (who is able bodied) to have a disability. While the person with autism may not be physically impaired, their experience of the social world is often described as extremely disabling. Their disability, on the other hand, would to a large extent be 'invisible'; it would not be defined by their physicality or rooted in their body to the same degree, and would arguably go unnoticed by the casual observer. Thus, these such individuals experiences of the world would be wildly different, and yet they would be bracketed under the same 'catch all' designation for a group of people whose only commonality is arguably their 'otherness' to our 'normalness.'

In recent decades, the notion of disability has been increasingly challenged as homogenising a collective condition which does not, in fact, exist. There is no unitary group of the 'disabled' which can be seen to share the same characteristics. The framing of 'disability' as a collective noun for what are arguably un-collectable impairments has gradually begun to be problematised as overly simplistic, static, and discriminatory (Swinton 2012, 175). In what follows, I will discuss how these attitudinal shifts have been informed by and contributed to evolving social theories of disability, evaluating the impact of dominant discourses of disability on the lives of individuals with impairments, and their limitations in providing a meaningful account of disabled experience.

1.2) Disability and the 'Other': The social construction of normalcy.

> …disability is not a transhistorical, ubiquitous, social phenomenon, but is bound up with social relationships at specific historical junctures. This enables us to move beyond simplistic ideas about disability being a type of always occurring 'restricted activity'; disability is located spatially, temporally and economically (Thomas 2002, 46).

Disability has occupied a problematic space in our social history. Despite the fact that we all, at some point in our lives, will likely (at least temporally) incur some form of disablement, the role of the disabled individual has been that of the outsider, as peripheral to the successful functioning of society. Author Lennard Davis contends that 'the 'problem' with disability is not the person with an impairment; the problem is the way that normalcy is constructed in our society to create the 'problem' of the disabled person' (2002, 3). He suggests that 'when we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants' (2013, 8). Being subject to the dichotomy of the 'other' is one of the most enduring aspects of 'disability'. Disabled individuals, in the

absence of commonality in condition, are thus defined by what they are not; not able bodied, non-seeing, non-hearing, not normal. This distinction between 'normal' and 'abnormal' then, naturally functions to exclude, ignore, or devalue the experience of disabled individuals within society. As a consequence, the disabled story throughout history has been one of marginalisation, vilification and institutionalisation.

The reduction of disability to merely the dysfunctional body, and a body which, as Davis contends, is considered a site of deviance, also functioned to rationalise any stigma or discrimination faced by the impaired as being created, in effect, by their own body. Erving Goffman reminds us that 'stigma' has in its roots a deeply entrenched association with the body; its original use by the Greeks referred to physical symbols on the body to demarcate the bad or the amoral in society (1990, 11). Thus, bodily difference, such as disability, has been inherently associated with deviance, immorality, and shame (Goffman 1990, 24). The mind-body dualism developed by Plato enhanced the position that the mind was associated with culture, intelligence, progress; whilst the body was primitive, crude and tainted. In a society which favours bodily perfection, and yet which also considers bodily integrity as naturally predetermined and fixed, one's biological position dictates one's social. As a consequence, individuals with disabilities have historically found themselves in an impossible paradox in which merely occupying the body they were born with functioned to preclude them from being socially valued (Eisland 1990, 70). With the social position of the impaired so intrinsically linked to the body, disabled identities thus became inextricable from their impairment; by occupying an impaired body, an individual was, statically and unchangeably, disabled.

Paul Abberley, a founding member of UPIAS (Union of Physically Impaired against Segregation) and author of 'Disability and Oppression' reminds us that in attempting to chart the development of 'exclusion' in the history of disablement, we must also recognise that who we consider to be 'included' is also a contested notion bound by the same conflicting forces (2002, 121). Whilst the marginalisation of disabled lives was by no means a modern phenomena, Abberley points to the changing division of labour in the Industrial Revolution in constructing a society in which social roles, and therefore social value, became inextricably bound with production (2002, 125). With large scale industry demanding consistent and predictable levels of production, the notion of the 'perfect worker' became one in which 'average' was the ideal (Oliver 1990, 46; Thomas 2002, 61). This had significant implications for disabled individuals. In a society in which social value was intrinsically linked to

production value, being excluded from the labour market meant being excluded from active participation in society.

The economic changes wrought by the industrial revolution also significantly altered social relationships; with labour migration influencing the emergence of the nuclear family unit and the dissolution of wider familial ties. Advancements in medicine and the introduction of vaccinations brought increased life expectancy and the potential for individuals with disabilities to live beyond infancy. However, this was not an unproblematic development. While individuals with disabilities were now afforded a stronger chance at survival, they were also now dependent on a much smaller family unit, and much more visible to a society which increasingly considered them as superfluous (Thomas 2010, 37). This increased visibility of the disabled body within society made disabilities or any deviation from the 'norm' even more pronounced.

1.3) The Medical Model

With the additional economic pressures associated with increased life expectancy, and the stigmatisation of 'deviance' associated with individuals with impairments, the late 19th Century also gave the rise to the introduction of institutionalisation. Families of individuals with disabilities were encouraged to relinquish their 'financial burdens' to the state, who had begun the process of spatially isolating individuals with impairments from society. At the same time, biomedicine began to develop a model of care in which the primary concern for illness and impairment was 'detection, avoidance, elimination, treatment and classification' (Thomas 2002, 40). It is interesting to note that amongst these five options, only one concerns the practical management of symptoms; the remaining four are chiefly concerned with the cataloguing and eradication of 'abnormalities.'

Davis highlights that the same statisticians (Queletet, Sir Franics Dalton, Darwin) who promoted the concept of 'normalcy' in their social categorisations were also eugenicists. With this in mind, the statistical classification of humans takes on a sinisterly different function; one which is designed to mark, and subsequently remove, the flawed and imperfect (2008, 9). The disturbing growth in popularity of the eugenicist movement, coupled with the introduction of institutionalisation, meant that individuals with impairments were not only sequestered from visibility, but that this invisibility also functioned to conceal the practices which occurred within institutions. With elimination rather than amelioration the aim in respect to impairment, institutional life brought with it practices such as enforced sterilisation

of impaired individuals to prevent the continuation of hereditary conditions (Hauerwas 2005, 151).

Michael Foucault defines this phenomenon as 'biopower', one that is enacted by authoritative (medical) forces who exert physical and social control over 'deviant bodies'. Bodies, he argued, rather than naturally pre-determined organic entities, were sites upon which external social forces such as discipline could be enacted (1978, 144). Indeed, it is only within the last few decades that such institutionalised models of care have being abandoned within the UK. I have personally supported individuals with impairments who had been institutionalised at an early age on the recommendation of medical professionals; individuals who have, respectively, been both over and under medicated to the long-term detriment of their conditions, and had even had their teeth removed for 'convenience of care.' In this context it is not surprising that some disability and human rights activists argue that despite de-institutionalisation, we remain subject to the legacy of an 'elimination model' of medicine, with elective abortions associated with neonatal screening for disabilities still commonplace in contemporary society. As recently as 2017, actor and special Olympian Frank Stephens spoke powerfully at the United States Congress on the issue, asserting,

> People pushing their particular 'final solution' are saying that people like me should not exist…. I am a man with Down's syndrome, and my life is worth living[10].

The moral and social implications of such practices, particularly in neonatal contexts in which the health and well-being of the mother is balanced against that of the foetus, remain highly emotionally charged and controversial subjects. Such controversies are clearly beyond the scope of this thesis. They are useful, however, in highlighting that the distribution of power in the relationship between impaired individuals and medical professionals, can in some cases, be literally one of life or death. In the following chapter, I will examine how such issues of power would go on to have a pivotal, and disastrous, role in the development of autism research.

The unequal power relationship between the individual and the practitioner remains a complex and controversial issue. Whilst we are moving away (albeit only in the last few decades) from institutional models of care, individuals remain hugely dependent on the diagnosis of a medical professional for access to resources, treatment and support. The

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[10] https://www.lejeunefoundation.org/powerful-speech-down-syndrome-goes-viral/ accessed 28/08/19 12.41pm.

eugenicist legacy of 'amelioration or elimination' is arguably still strongly resonant in restorative models of medical care. These rehabilitative models of medicine were strongly influenced by the work of medical sociologist Talcott Parsons, who considered the ill or impaired to occupy a position of deviance within society which he termed 'the sick role' (1951, 439). Parsons suggested that the creation of the 'sick role' functioned to create a (temporary) space in which individuals were exempt from their social duties under medical advice; which, after being dutifully followed, would re-instate them to their full participation in society. Central to this model was the importance of the role of the medical professional, in both legitimising a person as 'sick', and in providing the tools with which one could 'become better.'

However, for individuals with impairments, this was particularly problematic. Once diagnosed with an impairment, one thus occupied the position of the 'sick role.' However, if such an impairment was permanent, the secondary obligation to rehabilitate could not be fulfilled, and therefore the reciprocal social exchange is broken. Without the hope of rehabilitation, the impaired individual remains stuck in a position of deviance, dependent on medical professionals for legitimisation. Carole Thomas suggests, however, that it was in part Parson's re-invigoration of 'deviance' which shone a post-structuralist spotlight on the social inequalities which emerged from such a label, with the 1960's marking a shift in sociological inquiry towards a critical analysis of the 'social processes involved in the discursive construction and regulation of deviance' (2010, 40). This marked a significant turning point in the history of disability studies, with disability being considered for the first time as something potentially dis-embodied and socially constructed.

1.4) The Social Model

Despite the fact that, as we have seen, impairment had (and arguably continues to have) profound and far reaching social consequences for the disabled individual, the relationship between the social body and the impaired one was not considered until the late 1960's and early 70's. Influenced by the critical lens of theorists such as Foucault[11], 1970's Britain witnessed an emerging movement which challenged how we consider disability, and what this meant for disabled lives. The Union of the Physically Impaired Against Segregation

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[11] As touched upon in the preceding section, Foucault's discursive analysis of 'bio-power' explored the constructive and coercive influence socio-political institutions exerted on individual bodies. Identifying that our bodily experiences were also fundamentally shaped by external social forces, Foucault arguably contextualised the social construction of disabled bodies later developed by social modellists (Hughes 2002, 60).

(UPIAS), comprised of individuals who were themselves disabled, proposed that in contrast to the medical model which considers disability to be causally linked to impairment, disability is in fact the consequence of a disabling environment; one which creates social, spatial and financial barriers to impaired individuals leading full and inclusive social lives (Oliver 2002, 12). Proponents of the social model, most notably disability theorists such Mike Oliver and Paul Abberley, contended that the most debilitating effects of disablement were not symptoms of impairment, but rather social attitudes.

The infantilisation of physically disabled individuals (sometimes referred to as the 'personal tragedy model'), they argued, consigned the impaired individual to the role of victim, preserving disability as something unfortunate, pitiable, and reliant. The assumption that physical impairment naturally implied mental impairment strongly influenced public policy, with political, civil, and sexual rights paternalised by the state (Campbell and Oliver 1996, 28). Further to the social barriers they perceived were constructed to exclude individuals to impairments, disability theorists also challenged the perspective that bodily impairments limited mobility. Rather, they argued, participation in work and leisure activities were inhibited by inaccessible buildings, poor public transport links, and public spaces which were designed purely for the able-bodied.

This shift in consciousness away from disablement being something inherently flawed and inescapable in the individual, to being something external and socially constructed, was transformative for many impaired individuals. Carol Thomas observes that 'when disabled individuals encounter the social model, the effect is often revelatory and liberatory; enabling them, perhaps for the first time, to recognize most of their difficulty as socially caused' (2002, 38-40). Whilst some adopted the ethos of the social model at solely the individual level, utilising it as a tool to alter their self-perception and outlook from a 'disabled person' to an 'individual with impairments'; the social model also operated at the socio-political level, applying pressure for legislative changes. This was not a simple undertaking. If we are to assume, as the social model proposes, that society, rather than the individual, is the problem for disabilities, one is left with the huge problem of changing society.

Recent decades have witnessed a dramatic shift from the paternalistic model of welfare towards policies which centre around inclusivity and equal access to all areas of public life. Though arguably hard won, the social model can be seen to have had some success in contributing towards these shifting attitudes towards disability. The World Health

Organisation's ICIDH schema (International Classification of Impairments, Disabilities, and Handicaps) has altered their definition of disability, reflecting the importance of changing the language we use to describe disability:

> The term 'disability' has been replaced with 'disablement', with a focus on limits to activities, and 'handicap' is superseded by considerations of participation; impairment remains as before – loss or abnormality of psychological, physiological or anatomical structure or function (Thomas 2002, 42).

In 2013, the Scottish Government introduced the 'Keys to Life', a policy strategy influenced by the UN Convention of rights and adopted by both public and private social care organisations. This strategy is designed to promote a commitment to ensuring individuals with physical or learning disabilities have equal access to health care, education and housing; and are supported to have choice, control, and independence in their lives as active, fully recognised citizens.[12] The divide between 'mainstream' and 'special' education is becoming increasingly permeable, with local authorities encouraged to make learning adaptations rather than separations. Such changes mark a dramatic turn in history from the situation for individuals with disabilities a century ago. The social and structural barriers designed to conceal, marginalise and victimise individuals with impairments have begun to gradually be dismantled.

Proponents of the social model and organisations such as UPIAS have reframed disability as a form of social oppression, speaking of 'disablism' in the same context as 'racism' and 'sexism'. In considering themselves as an oppressed group, rather than victims of personal circumstance, disabled individuals are arguably able to assert some agency over how they consider their impairment. This, however, is not unproblematic. Whilst, as I have discussed, the social effects of disability are profound and often far reaching, some argue that the social model has gone too far in attributing the challenges faced by impaired individuals to social forces alone, neglecting the physical and bodily experiences which too are disabling (Bury 2000, 75; Hughes 2002, 59-60).

1.5) Lived Experience: Embodiment and Impairment Effects

In many ways, the social model can be seen to be the antithesis of the medical model in which disability is considered consequential to impairment. The social model introduced a

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radical way of considering disability, bringing into focus the social inequalities which constrained the lives of the disabled individual. This focus, however, has been criticised for overshadowing what is arguably the starting point for the question of disability rights; that of the disabled body (Hughes 2002, 59). Whilst liberatory on the one hand, the social model's rallying call against disabling social forces relegated the impact of bodily impairment to the side lines, considering that disability could be largely 'overcome' with equal access to public spaces, education and employment. Adaptation, in contrast to the Parsonion paradigm of rehabilitation, was the watchword of the social model.

Chair of Disability Studies at the University of Glasgow Nick Watson, and sociologist Tom Shakespeare suggest that as admirable as the goal of adaptation may be, the early social model advocates' claims can arguably be seen to be somewhat blurred by their own ontological position. UPIAS in particular has been criticised as comprising a very narrow representation of disabled experience; composed largely of white, heterosexual men with predominantly physical impairments (often the result of accident or injury). Watson and Shakespeare propose that such organisations lacked the diversity and breadth of experience to elucidate a more nuanced and representative understanding of disabled lives (2010, 58). Furthermore, the social model's premise of adaptation can be seen to be more concerned with adjustments to accommodate physical disabilities or sensory impairments such as blindness; whilst the experience of individuals with learning disabilities, which are arguably more social in both presentation and in effect, is largely absent. Shakespeare and Watson issue this challenge,

> What would it mean to create a barrier-free Utopia for people with learning difficulties? … What about people on the autistic spectrum, who may find social contact difficult to cope with: a barrier-free Utopia might be a place where they did not have to meet, communicate with, or have to interpret other people…Barrier-free enclaves are possible, but not a barrier-free world (2010, 63).

As Shakespeare and Watson articulate above, the experience of disability for individuals with learning difficulties is often profoundly social, and arguably also profoundly different in many respects to individuals with solely physical impairments. With such different ranges of lived experience, can we assume that by mere juxtaposition to the 'normal' social body, that their experiences of disability are the same? It is precisely this question which underpins much of the criticism levelled at the social model. To what extent does it acknowledge lived

experience, and can there really seen to be a universal lived experience of disability which can be reduced into a unitary group of the socially oppressed?

If disability is social, then impairment is bodily, and as such remains within the remit of medicine. Thus, in attempting to move past disability being defined by the body, towards a paradigm in which disability is the shared experience of inequality, critics suggest that the social model preserves the biomedical discourse it seeks to supersede. Mike Bury proposes that the social model treats the disabled body as a taken for granted assumption, when in fact it is the body which is the site on which our reality becomes perceptible, particularly in relation to chronic conditions (2000, 75). That disabled experience is shaped by bodily experience seems too obvious to ignore, and yet a narrative of impairment is often conspicuously absent from the social model.

1.6) Feminist Approaches to Disability: Deconstructing Body Dualisms.

Feminist approaches in disability studies have highlighted the need for multi-sectional approaches that account for race and gender and attend to how structural hierarchies create positions of subordination (Hall 2001, 6; Morris 1992, 166). In her volume 'Feminist Disability Studies', Kim Hall suggests that many of the issues raised in disability studies are in fact issues which feminism has been attempting to unravel for decades; such as the issues of bodily difference and the regulation of 'different' bodies (2001, 6). Writing on the integration of feminist theory within disability studies, Rosemarie Garland-Thompson proposes that a feminist analysis offers a particularly strong critique of the material practices, such as medicine, which function to control and 'discipline' bodies of difference (2001, 17).

However, despite being strongly placed to attend to issues of bodily difference, it has been suggested that within feminist theory the experience of disabled women is often conspicuously absent from the debate (Samuels 2002, 55). Whilst non-disabled feminists such as Judith Butler might contend that the gendered body is itself a social construct and propose a feminist perspective which moves away from the body as the site of difference (1990, 47); many feminist disability theorists continue to advocate for a disability theory which attends to issues of gender and embodiment (Thomas 2002, 45).

Consequently, there is now an increasing shift towards a phenomenological reading of disability which posits that disability is defined by neither the social nor the medical, but that both conditions are in fact mutually reinforcing (Bury 2010, 1074, Merleu-Ponty 1962, xvi–

xvii). Heidegger has asserted that the normative body is a taken for granted reality, and as such is unquestioned. It is only when the interruption of this reality, or of our body, by disease, injury or disablement calls into question what we thought we knew, that the 'phenomenon' of our embodied selves in the social world becomes visible (1996, 49). These insights become fundamental to my own research (see chapter four, section 4.3b) in which I pursue a phenomenological methodology.

1.7) Missing Children: The invisibility of children's experience in the disability movement.

In their volume 'Approaching Disability,' Rebecca Mallett and Katherine Runswick-Cole suggest that the myth of a unitary collective of experience is particularly evident in the treatment of disabled children in disability studies (2014, 39). If we are to consider that disability theory attends, as we have discussed in the preceding section, firstly to male experience, with the female experience existing on the margins; then the experience of children is largely missing from the page altogether. While normative assumptions of the (adult) body have been critically challenged in sociology inquiry (Goffman 1990, 11; Butler 1999, 47; Davis 2013, 8), children's bodies remain measured against universalised and taken for granted assumptions of 'normal' development. Strongly influenced by developmental psychology, children are assumed to follow a linear, staged pattern of development (Burack et al 2001, 11; Zezalzo et al 2001, 49). This assumed process of 'normal' child development thus inevitably functions to situate anything out with this conventional paradigm as 'abnormal'; immediately pathologising such a child as 'disabled'.

Erving Goffman posits that for children with disabilities, the experience of childhood is complexly and precariously dependent on how their impairment is socially perceived. He suggests that, 'a child with a stigma can pass in a special way. Parents, knowing of their child's stigmatic condition, may encapsulate him with domestic acceptance and ignorance of what he is going to have to become' (1990, 113). He argues that children already occupy a position of partial social invisibility; thus, it is easier for parents and caregivers to shield their child, for a short time at least, from realising their difference from their peers. This opportunity for 'passing', however, is usually temporary, and can arguably present more problems than it solves. The moment when the glass shatters, so to speak, and an individual suddenly becomes aware of their difference may be even more psychologically harmful for the child who has been sheltered from an understanding of such difference.

This potential danger was brought into sharp focus for me when utilising a childcare provider for additional support needs. With my son unable to attend 'mainstream' childcare, this service was a lifeline. Not only could the provider cope with the challenges he presented, allowing me to complete a working day without desperate phone calls to retrieve him; they picked him up and dropped him off. I remember standing on the doorstep, waving him onto the bus with children of varying abilities and impairments, and being viscerally assaulted by the memory of children at school mocking what they would call 'the special bus.' Silent tears streamed down my cheeks; I was at once relieved for the help and devastated that we needed it. That same day, Micah returned home, troubled. While he loved the activities and the staff, he could not reconcile his own identity with that of the other service users.

'Those other children aren't like me, Mumma. Why am I there?' He asked. He had until then, for all intents and purposes, 'passed' as 'normal'. His discomfort at being confronted with the reality that he in fact might share something in common with these children (although their impairments were, admittedly, much more profound) was palpable. Balancing his need to feel 'normal' against my own need for support, I consequently gave up the brief respite this service had afforded us both. This anecdote raises another particular difficulty of childhood disabilities; the question of disclosure. For children with impairments, disclosure is a significant challenge and one which is perhaps unique to the experience of children. There is rarely a question of how or if an adult will or should be informed of their impairment, and yet for children, their knowledge and understanding of their own condition is often largely dependent on adults to construct. Perhaps reflective of this interdependency, children in disability studies are rarely discussed in isolation of their relational ties to adults.

With some considering this relationality as further functioning to oppress the lives of disabled children, there is an increasing call for disability studies, and indeed practitioners and educators, to consider the voice of the child themselves. Emerging bodies of literature suggest that children's agency in articulating their own experience and contributing to their own support is crucial to their equal status as social beings (Mallett and Runswick Cole, 2010). Research suggests that disabled children experience significantly unequal access to educational attainment and leisure activities, profoundly impacting their opportunities for social inclusion (Mallet et al 2014, 40). A 2017 study from the University of Cambridge found that children with additional support needs were considerably more likely to experience bullying and abuse, and 9 times more likely to be excluded from 'mainstream' schools. Undoubtedly, further study is required to explore the experience of children with

disabilities from their own perspective, particularly as this subject raises significant ethical challenges in respect to the capacity, susceptibility and reliability of children in making informed decisions on important subjects such as healthcare (Prout 2003, 1).

However, extensive studies have shown that society's disablement of children extends to the family, in respect to employment opportunities, access to resources and support, and the social lives of care givers (Dowling and Dolan 2001, 23). As such, the experience of disabled children is intricately, and arguably inextricably, bound with the experience of their care givers. This (inter)dependency impacts not only how the impaired child is socially valued, but also their parents. Increasing attention is being given to the complex emotions and pressures faced by parents of children with impairments, and how these can similarly be seen to be shaped by social constructions of disability. Despite studies suggesting that the well-being of parents can profoundly impact the well-being and development of children with disabilities (Giallo et al 2011, 466; Zhang et al 2015, 29); the potential positive 'trickle down' effect on children by appropriately supporting parents has yet to be adequately explored.

1.8) Summary

In contrast to other areas of study, disability studies is still arguably in its infancy, emerging as an academic interest and area of social inquiry only within the last few decades. As such, the ways in which disability is considered and experienced both by and within society remains an area in which there is much exploration to be done. In considering current discourses in disability studies, I have explored the ways in which dominant models of disability can be seen to significantly impact the experience, lives and opportunities of individuals with impairments. Despite often being considered dichotomously within disability studies as being *either* medical or *social,* I would contend individuals with impairments experience their disability as being mutually formed by these seemingly opposing forces. In the subsequent chapter, I will explore how the complex and competing issues examined in this chapter can be shown to problematise the emergence, diagnosis, and attitude towards autism as a condition within society, in ways which can still be seen to be enduring.

Chapter 2) Autism: An Enduring Enigma.

2.1) Difficulties in definitions and diagnosis.

Perhaps one of the most defining characteristics of the condition commonly known as autism, is its difficulty to define. While there can be seen to be a series of shared characteristics, the ways in which these characteristics present in any given individual are unpredictable and varied (Burack et al 2001, 11). Why one set of symptoms may be present in one individual with autism, yet not with another is a mystery which we are no closer to solving. Dr Stephen Shore, a professor in special education and himself autistic, once famously declared, 'If you have met one person with Autism…you have met one person with Autism[13].' Having had the privilege and opportunity through both my son and my work to meet other children, and adults, on the autism spectrum, I can say this to be true. I have never met another Micah, nor have I met any individual with autism who I could say was just like another. They are all brilliantly, curiously, inexplicably different. This is perhaps one of the most simultaneously wonderful and problematic features of autism; that one could spend years charting the behaviours and peculiarities of one autistic individual, only to discover their findings have little to no relevance to another.

The inconsistency and unpredictability in symptomology could undoubtedly be seen to contribute to the decades of confusion, misrepresentation and conflicting theories surrounding the question of autism as a diagnostic category. Despite first being documented as a distinct category of observable symptoms in the early 1940's, there continues to be debate as to whether autism can be seen to be a psychological, biomedical, or environmental condition (Wing 1997, 33; Loveland 2001, 17). Furthermore, increased visibility and understanding of autism notwithstanding, there remain some who continue to question whether autism, is in fact, even a 'real' condition at all[14]. The ambiguity in the causation, symptomology and presentation of autism has resulted in it being a condition which is notoriously difficult to diagnose, with no current uniformly agreed upon methods of management or support.

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[13] 'Interview with Dr Stephen Shore: Autism Advocate and on the spectrum'https://ibcces.org/blog/2018/03/23/12748/ Accessed 12/03/19 12.49
[14] 'Ignorance, Autism, and the things People say.' 25th February 2013, and article by John Elder Robinson for Psychology today. https://www.psychologytoday.com/us/blog/my-life-aspergers/201302/ignorance-autism-and-the-things-people-say. Accessed 13/05/2019 13.34pm.

The apparent spike in autism diagnoses in the last century has given rise to a myriad of competing, conflicting and often controversial theories as to why such an acceleration has taken place, confounding much of the confusion that already existed regarding autism as a condition (Silberman 2015, 6). In order to unravel some of this confusion, understanding how autism presents itself and how it came to emerge as a diagnostic category may shed considerable light as to why, decades into our collective awareness of autism, it continues to be such a misunderstood and misdiagnosed condition. In what follows, I will explore the development of autism as a contested condition, charting the historical turbulence and conflicting research agendas which have complicated autism research, and consequently, autistic experience.

2.2) Emergence of Autism: A Legacy of Confusion.

2.2a) Kanner's Syndrome.

> These characteristics form a unique 'syndrome,' not heretofore reported, which seems rare enough, yet is probably more frequent than is indicated by the paucity of observed cases…
>
> …To satisfy the need for some terminological identification of the condition, I have come to refer to it as 'early infantile autism.' (Kanner 1943, 242)

In 1943, Dr Leo Kanner released his seminal paper, 'Autistic Disturbances of Affective Contact,' which would later form the blueprint of clinical understandings of autism for generations to come. De-camped from Germany during the Second World War, Kanner had become a respected Child Psychologist working out of John Hopkins Memorial Hospital in Baltimore in the early 1940's when he began to receive children who were, at such point in time, considered 'lost causes.' Many had exhausted other diagnostic avenues, most had been declared respectively: schizophrenic, mentally retarded, psychopathic, even deaf and mute. Some had confounded diagnosis, yet all shared a distinct commonality- their parents were desperate for answers to the enigmas that were their children. For such children, prognosis was often lifelong institutionalisation, and so the significance of Kanner's diagnosis cannot be understated for these families. For some, he was quite literally their last chance of having some semblance of a 'normal' family life.

The children brought to Kanner for assessment were afflicted by a myriad of unusual and distressing symptoms. After observing 11 such children, Kanner was able to identify common

characteristics amongst those referred to him which differed from the characteristics presently defined as childhood schizophrenia, with which many of his subjects had been previously diagnosed. At times, we can discern an almost poignancy to Kanner's observations of the children in his study. He describes one boy, Richard, thusly:

> He did not communicate his wishes but went into a rage until his mother guessed and procured what he wanted. He had no contact with people, whom he definitely regarded as an interference when they talked to him or otherwise tried to gain his attention.

> The mother felt that she was no longer capable of handling him, and he was placed in a foster home near Annapolis with a foster woman who had shown a remarkable talent in dealing with difficult children. Recently, this woman heard him say clearly his first intelligible words. They were, 'Good night.' (Kanner 1943, 226).

What was relatively unique about Kanner's approach to Psychology in the United States at the time was his belief that family history, in particular family dynamics, were significant factors to the diagnostic process. He argued that the family history presented by his patients clearly indicated that this was as an innate, developmental condition, one which in many of his patients was described as being present from birth. Kanner, however, faced criticism from his peers as to the reliability of charting the development of children from birth retroactively, particularly when relying on a clinically accurate timeline of development from parents (Silberman 2015, 210). Furthermore, the uniqueness of his diagnosis was challenged, with others in the field suggesting it was almost indistinguishable from the popular diagnosis of early childhood schizophrenia. Kanner maintained, however, that these children did not appear to be afflicted or distressed by their reality, but rather it was ours which these children found perplexing.

The children who were presented to Kanner all presented with the diagnostic criteria for atypical early development, in varying forms. The most prevalent atypicalities amongst the children were development of speech, response to external stimuli or affection and personal independence. As a consequence, some of the children had been diagnosed as deaf or mute, as it was perceived that their inability to vocalise, respond to commands or instruction or express their needs was a consequence of their inability to hear and therefore engage with the world around them. Kanner, however, believed that the children's inability to respond was

not related to their inability to recognise speech, but rather their inability to infer any meaning or significance from it which was relevant to them (Kanner 1943, 225). Kanner observed that,

> The children's relation to people is altogether different…people, so long as they left the child alone, figured in about the same manner as did the desk, the bookshelf, or the filing cabinet. (1943, 246).

This, coupled with the lack of speech development, severely inhibited the children's ability, or seeming desire, to communicate. He observed that in instances where speech had developed in his patients, their speech pattern was unusual. Some of his patients could recite complex poems, lists or historical facts; however, they could not initiate spontaneous discussion or respond appropriately to questions put to them. The children displayed a literalness in their understanding of language; they were unable to infer meaning from speech (1943, 244). In addition to repetitive patterns of speech, the children all shared repetitive behaviours or preoccupations with objects, often simply spinning their object of choice for hours rather than engaging in creative or imaginative play. Repetition could also be seen to reinforce the children's concern with routine, with many unable to cope or function with any deviation from their perceived 'norm.' Although it would be years before Kanner's paper would gain recognition amongst his peers, the detailed observations on his patient's unusual idiosyncrasies would in fact, as we have seen, go on to inform the diagnostic model utilised today.

2.2b) 'The Refrigerator Mother'

The complex interrelation of social impairments presented by their children was undoubtedly extremely difficult to navigate for the parents seeking Kanner's assistance. Arguably, it was this desperation which led them to Kanner in the first instance. What they had likely not anticipated, however, was the extent to which they themselves would feature in their children's diagnosis. Kanner's reliance on comprehensive family histories in his diagnostic process distinguished his work from that of his peers and solidified his place in history as 'discovering autism'. However, it would be Kanner's casual observations of the parents themselves which would arguably form the basis of one of the most enduring, and damaging claims, in the history of autism:

> I have dwelt at some length on the personalities, attitudes, and behaviour of the parents because they seem to throw considerable light on the dynamics of the

children's psychopathologic condition…patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only…They were kept neatly in refrigerators which did not defrost (Kanner 1949, 425).

Kanner's nuanced observations of his patient's complex behaviours were punctuated by very personal (and arguably clinically baseless) observations of the psychology of their parents. The association between high intellect in parents and these children were ones which were to be echoed by Hans Asperger as an unusual commonality, however Kanner's perception of the link between parental intelligence and autistic traits were much less favourable. While such descriptions would arguably fail to pass as legitimately credible clinical observation today, Kanner's depiction of these mothers was unquestionably accepted at the time. Bernard Rimland, author of 'Early Infantile Autism' and parent to an autistic boy himself wrote of Kanner's assertion:

> To add a heavy burden of shame and guilt to the distress of people whose hopes, social life, finances, well-being and feelings of worth have been all but destroyed seems heartless and inconsiderate in the extreme (1965, 65).

Whilst this arguably hampered any deeper investigation into the causality of autism, it also served to retain autism within the field of psychiatry, and consequently, Kanner himself. Thus, autism was regarded as a psychological condition, and therefore one which could be treated. Furthermore, in associating autism with mothering, Kanner tapped into a popular social anxiety at the time, that of women entering the workforce. Psychologist and leading researcher in autism Uta Frith observes that,

> This caricature of bad mothering overlaps with the caricature of the career woman, in particular the 'intellectual' type. An abnormally detached child- a child who is unable to relate lovingly- is a fitting punishment for the woman who neglected to be a full-time devoted wife and mother! (2003, 30).

Bruno Bettleheim, psychologist and contemporary of Kanner, popularised this perception of the refrigerator mother with publications such as 'Why Mothers feel guilty' and 'The empty Fortress'. Capitalising on the fear that further education and economic independence of women during the war would destroy the traditional family, Bettleheim propelled Kanner's theory in the mainstream media and created a damning culture of blame which cited women as the cause of their own family's demise. This created an impossible situation for mothers; if

they sought help for their children, they were subjected to blame and stigma, if they did not, they were forced to ignore their concerns and forgo any possible assistance they might have accessed for their child.

2.3) Asperger: Parallel Histories

2.3a) A different kind of hospital.

One of the enduring curiosities relating to autism is that it was first 'discovered' almost concurrently, by two separate individuals who had never met, at opposite sides of the world. Whilst Leo Kanner is widely credited to have first observed autism as a distinct condition; in a serendipitous turn of events Dr Hans Asperger, a leading paediatric psychiatrist in Vienna, also found himself immersed in a similar world of bewildering and beguiling children a year later in 1944. Although Kanner's paper had already been published, it initially received little professional acclaim, and so it is generally accepted that it would have been highly unlikely to have crossed Asperger's path prior to his own publication. It is interesting to note, however that one of Asperger's primary diagnosticians, George Frankl, also worked under Leo Kanner as a psychiatric paediatrician after fleeing Vienna in 1937, and, despite failing to be credited by Kanner, arguably contributed much to his research (Silberman 2015, 180).

Asperger's patients similarly presented with delayed development, and an extreme detachment from the social world. The children, like Kanner's, were preoccupied with objects or routines but seemed to have little or no interest in pleasing or bonding with their care givers, to the extent that they were also often peculiarly violent towards others and seemingly without remorse (Asperger 1944, translated in Frith 1991, 77). Both men, however, had distinctly different approaches to their practice. Rather than rely on retrospective accounts of their condition, or subject these children to standardised tests (many of which they had already failed to measure on); Asperger and his colleagues at the Vienna clinic instead attempted to observe the children in as natural and comfortable an environment as they could create for them within a hospital setting, and instead painstakingly documented the minutiae of idiosyncrasies which formed each individual child as they naturally presented themselves (Frith 1991, 7).

Modelled after Erwin Lazaar's compassionate therapeutic approach, the Vienna clinic was unparalleled at the time in its unique and innovative approach to therapy. Rather than adopting a purely medical model of intervention, the clinic combined biomedical treatment with education and play therapy in an 'intuitive synthesis' which accepted, rather than

condemned, the children's differences (Frith 1991, 7). The children were allowed to indulge in their respective proclivities, with Asperger and his team seemingly intuiting that allowing such obsessions to be explored could potentially break down some of the barriers that adults typically had in engaging with these children. Perhaps one of the earliest examples of person centred and inclusive learning which we are only now, in very recent years, showing a shift towards in education; Asperger believed that it was the environment that the children were forced to learn that was flawed, and not the children themselves.

2.3b) Asperger's Little Professors.

One of the most marked differences between Kanner's and Asperger's syndromes, which still distinguishes them today in the D-ISVM criteria, is Asperger's association with autistic traits and intelligence. Asperger, like Kanner, had observed similar traits in both his patients and their parents, and had also documented that the children came from unusually intelligent families for the time. However, where Kanner saw the children as a product of an un-nurturing environment, Asperger saw a potential biological link, raising the possibility that autistic 'intelligence' could be genetic in nature.

Whilst the children on Asperger's ward were unable, or unwilling, to produce such knowledge in clinical tests, the environmental observations of the Vienna clinic proved invaluable in identifying that the children did, in the right setting, show a nuanced understanding and acumen on specific subjects. Asperger noted that despite some children being able to engage in general communication or behaviour appropriately in social situations, their expressive language when speaking about a subject of their choosing was quite exceptional. Indeed, he commented with clear fondness that in such contexts the issue was rather bringing the conversation to a close, as their reserves of knowledge on their given subject was seemingly endless- this, I am personally and fondly familiar with (Asperger, 1944; in Frith 1991, 53). In taking the time to speak to these children, whom Asperger affectionately dubbed 'his little professors,' Asperger was able to identify another unique facet to the autistic condition; the 'Special Interest.' The preoccupation with a particular topic remains arguably one of the most easily recognisable traits of Asperger syndrome, or what is now typically referred to as 'high functioning autism.'

For Asperger, however, these special interests were of greater significance than merely establishing commonality in behaviours. He believed that the children's ability to understand

and articulate their passions and hobbies in such a way demonstrated beyond refute that they were, indeed, not only educable but socially valuable:

> This ability…can in favourable cases lead to exceptional achievements which others may never attain. Abstraction ability, for instance, is a prerequisite for scientific endeavour. Indeed, we find numerous autistic individuals amongst distinguished scientists (Asperger, 1944; in Frith 1991, 74).

This perception of autistic intelligence has been both celebrated and criticised for 'romanticising' the image of the genius savant (Frith 1991, 32). Asperger himself admitted the maladaptive behaviours associated with autism were indeed much more common (Asperger, 1944 in Frith 1991, 74). However, Asperger had reason to portray what was perhaps a rose-tinted view of the condition. For children who had, to all intents and purposes, been deemed lost causes, the significance of Asperger's words could mean the difference between life and death.

2.3c) The Lost Boys

During the time of Asperger's research, Europe was deeply in the throes of the Second World War. Vienna, whilst home to many notably prominent scientists and intellectuals of the time, was also home to significant Nazi entrenchment. This presented a very real danger to research being conducted at the time; financially, morally, and physically. The expectation was undeniable; any valuable contribution to science or the arts was to be made under the banner of Hitler's regime, and be representative of their agenda. Building upon ideas espoused in earlier decades by catholic theologian Josef Mayer who believed that the mentally ill, poor and handicapped were 'life unworthy of life'; Hitler's position on genetic and racial superiority, which had hitherto been raised as purely theoretical debate, were fast in danger of becoming social policy. One of Hitler's doctors, Theo Morel, produced a paper in 1939 detailing the financial burden on the state of individuals with disabilities and introducing a bill which required the registration of all births with diagnosed defects or disabilities. Within a few short years, this bill had been utilised to facilitate the 'therapeutic euthanasia' of 336 children in Am Spiegelgrund, the Austrian hospital to which Asperger's Heilpadagogik clinic was attached (Silberman 2015, 143).

By the time he presented his paper on autistic disturbances in children in 1944, Asperger was facing an audience of peers who had adopted this model of a 'national socialist medicine.'

Asperger was forced to walk a precarious tightrope between appearing to toe the line with his Nazi benefactors and fighting to save the lives of his 'little professors'. His decision to present only his less severe cases, and stress their unusual capacity for intelligence, was arguably driven by his desire to portray his patients as socially valuable, protecting them from what would undoubtedly have been a grim fate. This decision to misrepresent the demographic of patients he had observed, whilst likely well intentioned, left a lasting impact on his research. While arguably promoting inaccurate expectations of the Asperger condition, Asperger also obscured many of the commonalities with Kanner's children: who in fact, were far more representative of Asperger's patients than those he chose to admit. In suppressing some of the more maladaptive symptoms in his patients, Asperger unwittingly distinguished his research from Kanner's and deprived himself from being associated with the discovery of what was, in essence, the same condition.

2.4 The Spectrum Model

The dualistic discoveries by Kanner and Asperger of two separate, yet hair splittingly similar conditions highlighted potentialities of autism which could not be ignored. As the notoriety of both papers grew, and their similarities became apparent, research began to question whether these men were in fact documenting the same phenomena. Nonetheless, there were sufficient differences that one could, as Asperger did, draw a distinction between the symptomology of his patients and Kanner's. How, then, does one account for the existence of two distinct conditions whose symptomology overlap so significantly?

Some decades later, Navy Psychologist Bernard Rimland raised the question that perhaps Kanner may have been somewhat exclusionary in maintaining such rigid criteria for his diagnosis, potentially excluding children who portrayed enough, but not all, of Kanner's autistic behaviours (Rimland 1963, 21). [15] For his part, Kanner criticised what he termed 'the dilution of the concept of early infantile autism,' believing that his condition was being diagnosed too readily by other practitioners (1958, 110). However, increasing attention was being given to the possibility that autism existed as a condition which varied considerably in

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[15] It is worth noting however, that Rimland would go on to create his own exhaustive diagnostic checklist which would be adopted by practitioners for some decades, and which was arguably more specific and meticulous (and therefore potentially exclusionary) than Kanner's.

severity and symptomology, often presenting in distinctly different ways depending on the individual. Rimland considered that such differentiation represented not different conditions, but in fact suggested the existence of 'sub-groups' of symptomology and ability within the same condition (Rimland, 1963, 60).

This theory was later developed by British Psychiatrist Lorna Wing (again herself a parent of an autistic child) into what we now refer to as 'the spectrum model.' Wing concluded that the variation in the children she observed, and multiplicity of their symptoms could not feasibly be considered to be separate conditions, but rather pointed to a continuum within the autistic condition. Furthermore, she argued that autism was not a static, unchanging condition, but that the patients she observed could be seen to move along this continuum, in either direction. She described some patients who initially presented with 'classic autism,' who later following maturation presented as more firmly within the Asperger category (Wing 1996, 29).

Wing's contribution not only impacted autism research in highlighting that autism could be a fluid and changeable condition, but also changed the way in which we speak of autism. Today, practitioners and parents typically favour the term 'Autism Spectrum Disorder', often abbreviated to 'ASD' rather than the traditional terms of 'Autism' or 'Asperger's', which arguably perpetuated narrow diagnostic criteria. Indeed, in recent years I have personally witnessed a shift in the dialogue with my son's doctors from 'Asperger's' to the more inclusive category 'ASD.' This development highlights that the diagnostic process has now become much more flexible as a consequence of the spectrum model, opening doors to children who may previously had narrowly missed a diagnosis due to the rigidity of traditional autism criteria.

2.5) Causes for conflict- Theories as to the origins of Autism

Perhaps one of the most challenging aspects of autism, for individuals and practitioners alike, is that 70 years later we are no closer to a definitive answer as to exactly how it comes to be. In contrast to the perceived 'invisibility' of children in disability studies raised in chapter one; autism has become inherently and inextricably linked with childhood development. Perhaps as a consequence of this, autism is still very much a condition which is significantly stigmatised for both the autistic individual themselves, and their families. With the shadow of 'toxic parenting' still looming over autism, the absence of a cause often compels parents to search more fervently for answers. That we still cannot say with any degree of certainty that

autism is a neurological, psychological or biological condition leaves the condition vulnerable to misrepresentation and misunderstanding. Whilst there is currently no accepted causality of autism, several theories have been presented over the years, of varying merit.

2.5a) Psychological

Initially associated with childhood schizophrenia, autism was first documented within the field of psychiatry, where it remained for several decades. Both Kanner and Asperger considered autism to be a form of psychiatric disorder. Today, this theory is considered controversial, as it implies that autism is form of mental illness, which can be stigmatising for the autistic individual. Nonetheless, psychological explanations of autism have arguably retained their popularity, as many of the characteristic associated with autism are considered to be relational and behavioural, and therefore more strongly associated with personality.

One of the most prevailing psychological theories of autism is the theory of mind approach, proposed by psychologists such as Michael Rutter (1983) Simon Baron-Cohen (1995) and Alan Leslie (1985). In their 1985 paper 'Does the Autistic child have a theory of mind?' Baron-Cohen and Leslie found that autistic children consistently failed tests designed to gauge an individual's awareness of the thoughts and motivations of others, in comparison to the neurotypical children and children with Down's Syndrome used as controls. This, they reasoned, accounted for many of the social relational difficulties often found in autistic individuals (Baron-Cohen 1985, 40).

Whilst this theory is useful in attempting to understand the social deficits experienced by the autistic individual, it has faced criticism in recent years for failing to account for the myriad of other symptoms associated with autism which are not social relational (Tager-Flusberg 2001, 186). Katherine Loveland furthers that such an approach confines autism as located within the person; 'when viewed this way, autism tends to be reified as a thing (a static syndrome or deficit) that afflicts a person and remains throughout life; thus, the person is said to 'have autism,' rather than to have autistic characteristics or behaviours' (2001, 19).

2.5b) Environmental

In Kanner's seminal study in 1944, he positioned autism as a mental health condition, brought on by the absence of a warm and loving family environment. Kanner proposed that these parents busied themselves with instilling information, rather than love, in their children: which accounted not only for their unusual feats of intelligence, but also their social

relational difficulties. In echoing the parental fears ignited by Freud's oedipal complex, autism was reduced to a 'psychodynamic conflict' which placed the blame, and consequently hopes for recovery, squarely on the parents (Frith 2003, 30). This hypothesis was enthusiastically adopted by contemporaries such as Bruno Bettleheim, Rudoph Ekstein and Lauretta Bender and became fundamental in shaping treatment and intervention strategies for decades to come (Evans 2013, 9).

This theory has now thankfully been almost universally dismissed; however, the ramifications of this controversial hypothesis were considerable. In positioning autism within the realm of child psychology and family therapy, it arguably discredited autism as a lifelong, developmental condition, hampering any multidisciplinary research for several decades by implying that autism was a mental state from which one could recover. Furthermore, the notion that autism was located within the family was an insidious one. Despite this theory being largely discredited, there is still a very real sense of culpability and shame felt by parents following a diagnosis (Frith 2003, 30).

2.5c) Genetic

Hans Asperger also noted peculiarities in the parents of his patients, particularly in relation to their unusual level of education. In contrast to Kanner, Asperger believed that rather the similar traits observed in families implied a genetic component to autism, observing 'related incipient traits in parents or relatives in *every* single case where it was possible to make a closer acquaintance' (1944 in Frith 1991, 84). He also suggested that the overwhelming prevalence in males reinforced the hypothesis that autism was a condition with a strong genetic component, and one which was potentially linked or inherited through gender. This theory has stood the test of time, as it is generally accepted today that autism is a developmental condition that is likely genetic in origin (Tsanis et al 2001, 81).

However, exactly which genes contribute to autism remains an area of research which requires considerably further inquiry. Catherine Tstanis and Fred Volkmar in their examination of neurobiology and genetics in autism observe that,

> …latent class analysis methods have been used to estimate that probably 2 to 5 genes act in concert to produce an autistic phenotype. However, as many as 10 to 12 genes may be implicated, and it is not predicted that the same genes would consistently be involved (2001, 82).

Recent research from Edinburgh University has succeeded in linking specific genes associated with autism and increased cognitive ability in the general population, particularly in relation to problem solving tasks (Clarke et al, 2016). However, the multivalency of autism presentation is characteristically problematic when attempting to successfully chart a genetic map of autism. Silberman observes that even the most common markers associated with autism were found in less than 1% of a recent sample study of children, citing neurogeneticist Stanley Nelson, 'If you had 100 kids with autism, you could have 100 different genetic causes' (2015, 15).

2.5d) Neurological

With the psychological theories of autism failing to account for how such cognitive differences arise, research has in recent decades shifted towards a developmental psychological approach, combining the fields of psychology with neurobiology to attempt to find causality between biological neural difference and the cognitive processes of the mind (Loveland 2001, 17). In contrast to the 'Top down' theories of psychology equating symptomology with behaviour; neurobiological theories offer a 'bottom up' approach, suggesting that rather behavioural and sensory symptoms are a consequence of impaired brain structures (Loveland 2001, 18). A study into the electrical patterns of the brain of autistic individuals of varying symptomology versus neurotypical controls, and found that in two thirds of their sample the autistic individuals showed differential activity across the brain in comparison to controls, and a reduction in activity in the frontal lobe particularly (Tsanis et al 2001, 90).

This correlates with similar studies which have drawn links between impaired executive function in autistic individuals and the temporal limbic and limbic frontal regions of the brain responsible for decision making, perception and behaviour (Frith 2003, 179; Tstsanis et al 2001, 90; Loveland, 2001, 28). Frith reinforces a neurobiological theory of autism, proposing that considerable commonalities can be drawn between the behavioural effects following damage to the frontal areas of the brain, as in acquired brain injuries, and those commonly found in individuals with autism, for example emotional regulation and repetitive behaviours (2003, 179). In current research, neurobiological theories have gained significant traction and credibility in assuming an underlying causality for the development of autistic behaviours.

2.5e) Biological

Biological models of autism have sought to locate the root of autistic behaviours within the body, medicalising autism as a condition with biological causality, and therefore, potentially, biological treatments. In the 1960's, psychologist Bernard Rimland began to receive correspondence from parents of autistic children with alarmingly similar and curious gastrointestinal issues, ranging from diarrhea, constipation to vomiting. As a result, Rimland began research into elimination diets with complex regimes of high dose vitamins, which many claimed to have ameliorated their children's more maladaptive behaviours. Such tests, however, were viewed with scepticism and failed to achieve FDA approval (Gabriels and Hill 2002; 77).

The potential link between GI symptoms and autism was to be revisited with some notoriety in the late 1990's with a controversial study in the Lancet by UK Gastroenterologist Dr Andrew Wakefield, which linked 'onset' symptoms of autism with levels of mercury in the blood following receipt of the MMR vaccine (Wakefield et al 1999). This study has since been widely discredited, with Dr Wakefield having his licence to practice revoked for failing to obtain ethical review and for accepting payment in giving evidence in civil suits pertaining to MMR liability (Holton et al 2012, 691). Although this theory was swiftly and frankly refuted by the medical community, the impact of the study was manifold. Despite no credible scientific data linking autism to digestion or vitamin deficiency, the association between autism and potential gastrointestinal issues caught public attention, particularly amongst parents who were proactively seeking curative interventions for their children.

In suggesting that autism was a biomedical condition which could be managed, the study revived credibility in many untested, costly, and arguably dangerous intervention therapies for children (such as induced vomiting and chelation) (Silberman 2015, 80). It also sparked widespread fear and 'anti-vax' movements surrounding the provision of the MMR to children, with many parents continuing even now to opt out of vaccinating their children for fear of 'giving' them autism. This potential link became a focus of fund raising and activism amongst certain parent groups, most notably 'Autism Speaks' [16] Whilst such movements which focus on curative interventions have arguably benefitted some families in providing

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[16] Autism speaks define their organisation as being '...dedicated to funding global biomedical research into the causes, prevention, treatments and cure for autism' (Autism Speaks (2012) cited in Waltz 2013, 138.

access to resources and perhaps a sense of community; they have also been widely condemned in pathologising and 'othering' autistic individuals by locating their condition within the body as something which has to be overcome and normalised (Waltz 2013, 162).

2.6) A Gendered Condition?

Autism has, traditionally, been considered a condition which predominantly impacts males. The ratio of boys with autism to girls is generally accepted to be 4:1, with high functioning autism (or Asperger's syndrome) being even higher at 15:1 (Frith 2003, 64). Asperger himself initially considered the condition which he observed to only affect boys, although later conceded its rarity amongst females (Frith 2003, 64). This perception has arguably endured over the last century, with girls being largely invisible from the autism narrative.

So pervasive has this gendered assumption been that some researchers have suggested that is in fact a biologically gendered condition. Dr Simon Baron-Cohen, experimental psychologist and autism researcher, has claimed that autism is 'an extreme form of the male brain' (2002, 248). The propensity towards analytical and systemising thought processes over those which are emotion driven, he argues, are indicative of a higher level of 'male traits', suggesting that autism is the consequence of increased levels of testosterone and other androgens prenatally (Baron-Cohen 2002, 248). Similar studies have suggested a link between testosterone levels in childhood in autism symptomology (Auyeung et al 2009, 20; Knickmeyer et al 2006, 830), however no large-scale medical research has been conducted into this potential association. It is also worth noting that prevalence of autism in girls has not been shown to correlate with stereotypical 'male' behaviours.

In the context of this research, the sample presented by my participants shows a ratio of 2 girls to 3 boys: notably, with one girl and boy being siblings. While this is a particularly small sample, and therefore cannot be generalised, the ratio does suggest that autism prevalence amongst girls is more common than is assumed. Emerging research (and accounts from autistic women themselves) have suggested that the diagnostic differential observed between boys and girls could be misleading, with girls potentially being more conscious of 'masking' their maladaptive behaviours in order to fit in than their male counterparts. Thus, girls may display better compensatory learning than boys and may consequently be more difficult to diagnose (Frith 2003, 60). Some of the characteristics of autism, such as increased focus on a particular subject matter and emotional aloofness may be characteristics which,

particularly in education settings, are perceived as simply poise and concentration and are therefore behaviours which are praised in girls rather than stigmatised. While the reasons for the gender discrepancy is unclear, the suggestion above highlights that binaried and stereotyped 'gender' characteristics pervade much of the literature, arguably hampering a more nuanced understanding of the autistic experience.

2.7) Contextualising the Conundrum: A summary

In this chapter, I have shown how the historical context of autism has strongly influenced how it has been understood, both in the field of research and in society more broadly. Emerging from a period of social tumult, in a climate where research was heavily laden with political agendas, autism arguably had an inauspicious and rocky start in its definition as a diagnosis. These implications served not only to hinder the research process, meaning autism today is still frustratingly ambiguous for researchers and families; but also perpetuated conflicting narratives of what autism is and what it means for the person. In this chapter, we can see how considerably the damaging and harmful constructions of normalcy depicted in chapter one can be seen to impact the development of research and social care policies.

Despite increasing multidisciplinary attention in the last 30 years, the cause of autism and its disciplinary home has still yet to be established. That there is no consensus as to the origins of autism has meant that some of more stigmatising psychoanalytical theories, particularly those rooting autism in family dynamics or mental illness, still have roots in the autism debate. Similarly, the indeterminate nature of the condition has left the field open for intervention therapies to focusing on curative treatments to continue to persist, medicalising autism as a condition which can be overcome. In the following chapter, I will turn to a discussion of how autism is currently understood in terms of symptomology and presentation. I will highlight that such symptomologies are varied and often incongruent with one another, making autism particularly difficult to diagnose. I will further highlight how this multiplicity and ambiguity in symptomology and their impact on everyday life create a particularly challenging and distinct parental experience, and one which mothers are disproportionately affected by.

Chapter 3) Symptoms and Stigma: A distinct maternal challenge.

Autism is a considerably complex and multi-valent condition in which individual outcomes are unpredictable and uncertain. It is also a condition which is inextricably and complexly rooted in various social, historical, and political sites of turbulence; what we know about autism has been informed by research shaped by dominant political ideologies which served particular interests. As I have charted in the preceding chapter, such ideologies can be seen to be shaped by wider attitudes to disabilities and have functioned in various ways to complicate and inhibit understanding and support for children and families with ASD. Although there can be seen to be some commonality in the symptomology displayed by individuals with autism, the ways in which these symptoms present and develop are so varied and multitudinous that attempting to describe common characteristics of autism is almost a contradiction in terms. Nonetheless, certain shared characteristics are generally seen to be present, and have informed the criteria currently used to provide a diagnosis of ASD.

The World Health Organisation has separated these into three, arguably quite broad, sets of diagnostic criteria which is commonly known as 'the triad of impairments.' For a diagnosis to be made, behaviours from all three criteria have to be observed. In what follows, I will outline the behaviours which are currently considered to fall within these categories, with the aim of demonstrating the breadth, ambiguity, and conflicting nature of autism symptomology which makes diagnosis particularly challenging. I will reflect on the impact of these symptomologies on the everyday lives of both the individual with autism themselves and those who care for them, highlighting that the social attitudes of disability described in chapter one strongly influence how symptoms of autism are perceived, making it a particularly stigmatising lived experience. In concluding this chapter, I will propose that ambiguity in symptomology, difficulty in obtaining a diagnosis, and deeply stigmatising attitudes to autism coalesce to form a distinctly challenging experience for parents; and an experience which, as Kanner has situated, remains much more closely associated with mothers.

3.1) 'The Presence of Abnormal or Impaired development that is present before the age of three years.'

Although autism continues to be a curiously unpredictable condition in its manifestation, it is now generally agreed that autism manifests very early in infancy and will present in what the

World Health organisation terms 'abnormal development'. Childhood development is considered to follow a somewhat linear pattern, albeit there will be some fluidity and fluctuation to development. The attainment of verbal expression, independent mobility, reciprocal actions, and object recognition are generally reached by the age of three years in typically developing infants. A child may reach each of these milestones at different stages or at a different rate within this three-year window. For example, a child may begin their first attempts at speech at 9 months, yet not begin to walk until 16 months, and go on to develop perfectly typically.

It is expected that initial concerns would be raised if children are 'not babbling or gesturing by 12 months of age, have no single words by 16 months, have no two-word phrases by 24 months of age, or if any loss of language or social skills is noted.' (Schulman 2002, 29). My own son had begun to form words at 9 months and walked at 11 months. He could hold a crayon; he had a healthy appetite. His toilet training was frustrating, but typically so. His delay in receiving a diagnosis was, in retrospect, in large part hindered by his developing too typically. That such variation can be seen even in typically developing children makes it extremely challenging to diagnose autism at this crucial early developmental stage.

3.2) 'Abnormal functioning in at least three areas of psychopathy: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour.'

<u>**3.2a) Communication and Reciprocal Social Action**</u>

This second diagnostic category consists of perhaps the most easily definable and recognisable characteristics of 'classic' autism. It is in this section that the delay in speech acquisition is generally compounded by an apparent lack of interest or ability in responding to social communication, in addition to unusual speech patterns or inflection. Our desire to communicate with our children, to hear their thoughts and witness their personality develop through verbal actions is likely to cause parents to be especially vigilant to a lack of social interaction in their children, leading this to be a common early indicator of autistic characteristics.

It is also these particular characteristics which inspired the term 'autism.' Coined by Swiss psychiatrist Eugene Blueler in 1912, the term conjoins the Greek word 'Autos', meaning 'of the self', with 'ismos', meaning action or state of being. Literally, it translates as 'being of the self' (Evans 2013, 4). Although originally used to describe a withdrawal from social

interaction and self-preoccupation observed in patients with schizophrenia, Kanner adopted this term to describe what he perceived to be a disinterest in the social world and desire for aloneness amongst his patients (Kanner 1943, 242). This representation of autistic individuals as *choosing* to avoid social contact or being indifferent to other's emotions or attention has pervaded perceptions of autism for generations, leading to autistic individuals being considered cold, unfeeling or incapable of emotion (Swinton 2012, 275; Lawson, 2008, 47). This has been a very hurtful and damaging stereotype to the autistic community and has arguably contributed to the many barriers autistic individuals face in respect to social inclusion.

However, with the increasing interest in autism in the last few decades, recent studies and indeed accounts from autistic individuals themselves (Grandin 1996; Shore, 2006), have suggested that the deficit in reciprocal social action present in autistic individuals is not a consequence of a desire for solitude, but rather an inherent difficulty in inferring meaning or context from social actions and understanding other's facial and verbal expressions (Lawson 2008, 103). Context is particularly important to individuals on the autism spectrum, as it is often relied upon to form 'social rules' or expected outcomes to particular situations so that one may anticipate the correct social response. Wendy Lawson, a psychologist who herself is on the autism spectrum, has described her difficulty in engaging in conversations with others which are outside of the context of her particular set of interests or range of experiences (2008, 59). It has also been observed that individuals with autism struggle with figurative language, in particular metaphoric language, and have a tendency to interpret speech literally (Kanner 1943, 244). Thus, the difficulty in understanding reciprocal social action could be arguably be seen to be one of the most problematic aspects of the autistic experience (Grandin 1996, 50).

3.2b) Restricted, Stereotyped Behaviour

Further to difficulty in social interaction, another symptom of autism is a preoccupation with routines, specific objects, movements, obsessive interests and ritualistic behaviour (Frith 2003, 14). Temple Grandin describes her preoccupation with the repetitive action of spinning. Spinning, or ambulatory motions, are commonly described characteristics of autistic individuals and are generally described as self-stimulatory behaviours or 'stimming':

> Spinning was another favourite activity…self-stimulatory behaviour made me feel
> powerful, in control of things…I realise that non-autistic children enjoy twirling

around in a swing, too. The difference is the autistic child is obsessed with the act of spinning (Grandin 1996, 18)

Like Temple, winding up a swing and allowing it to turn ferociously is one of my son's most beloved past times. He has always delighted in any motion which propels him, and spinning is his particular favourite. Such repetitive behaviours may also include movements such rocking, hand-flapping, finger motions and other such gestures[17]. It is considered that these repetitive movements serve to please, calm, or even excite autistic individuals.

Autistic behaviours are consequently often distinguished by their inexplicability to others, and their all-consuming nature to the autistic individual themselves. Indeed, it is the intensity with which autistic individuals adopt certain behaviours which seems to differentiate mere hobby from obsession. At times, this may take the form of a 'special interest' in a particular area. These will vary from individual to individual, although they are often comprised of a subject or object which is quantifiable, predictable, and easily systematised (Lawson 2008, 83). While my son has had a few 'special interests' over the years, the most enduring has been dinosaurs. He has memorised the types, locations, and eras of any dinosaur you would care to mention, and in fact he would be quite delighted if you would. Their size, their diet, their habits have all been carefully catalogued in his brain and are ready to be whipped out at a moment's notice, with the most tenuous, if any, connection to the conversation at hand. I know of another boy who is equally fascinated by trains: their engineering, their weight, speed, fuel. Still another is fascinated by sugar packets, and fervently collects packets he considers to be unique or interesting to him.

Attention to a restrictive interest falls under the category of 'repetitive behaviours' as it often becomes ritualistic in its manifestation, for example collecting, cataloguing, or memorising information or objects pertaining to the subject (Kanner 1943, 245). Whilst the impetus towards this behaviour is unknown, a recent study into restricted interests in children with autism has suggested that such behaviour, like stimming, is perhaps a functional tool to inhibit anxiety, and can be seen to be used as both a means of distraction for autistic individuals and as a means of attempting to order or control one's own environment (Spiker et al 2012, 314). Order, routine and an averseness to change is also a pervasive theme in autistic pathology. Leo Kanner's early observations of autistic behaviour described his

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[17] https://www.autism.org.uk/about/behaviour/obsessions-repetitive-routines.aspx
Accessed 18/03/19 10.06am

patients as having 'limitation in the variety of spontaneous activity' and an 'anxiously obsessive desire for the maintenance of sameness' (1943, 246).

Lawson suggests that in fact every individual is reliant on routines. The problem, she considers, is that autistic routines may appear different or unusual to other people's (2008, 87). Whilst Kanner considered his patients routines to be almost arbitrary and insignificant, numerous studies since have stressed the importance of consistency and routine to the autistic individual in managing their sense of emotional stability (Gray 1997, 1100). Indeed, structured schedules, visual timetables and social rehearsal have been found to be incredibly useful for autistic individuals and are often used to underpin many parental and educational strategies for supporting children and young people on the autism spectrum (Howlin 1997, 46; 172).

3.3) 'Non-Specific' problems

The third and final category of the autistic phenotype is the undoubtedly the most obtruse and problematic area to navigate, for both professionals involved in the diagnostic process and parents themselves. 'Non-specific' problems, while helpfully grouping an alarmingly wide myriad of characteristics under a single umbrella, also serves to muddy the waters of exactly what characteristics are, or are not, seen to be autistic. This ambiguity is particularly difficult for care givers, as it opens the realm of possibility that any or all behaviours could be arguably defined as 'autistic.' Due to the breadth of symptomology this category could encompass, it would be an unrealistic and fruitless endeavour to attempt to chart all the possible characteristics which could potentially fall within this area. Instead, I will look to discuss aspects of autism which have been seen to find commonality within the murky waters of 'non-specific' symptomology.

3.3a) Personal Independence

Whilst this is perhaps a rather broad and ambiguous heading, it is helpful in grouping together common characteristics which, whether present singly or collectively, may have a profound impact on the daily acts of personal independence which a neurotypical individual may take for granted. In early development, the ease with which a child acquires fine motor skills is often an indication of autistic characteristics. Autistic children have often been found to struggle with developing the fine motor skills or hand eye coordination required for tasks such as writing, tying shoes and fastening buttons. This may have a significant effect on a

child's learning, self-esteem and in some cases may provoke considerable anxiety relating to dressing and other personal care (Howlin 1997, 174).

It is commonly reported that individuals with autism may have continence issues, particularly in childhood. Other's may struggle to form a sleep pattern or may require certain conditions be met before sleep can be achieved. Issues with diet and eating habits are also commonly reported amongst children with autism, with some individuals tolerating very restrictive interests in foods (Schaff et al 2011, 381). Whether or not these behaviours manifest in their own right as distinct symptoms, are symptomatic of stereotyped behaviours or are a consequence of underlying sensory issues is unclear. Certainly, they can be seen to have a profound impact on the personal independence and general physical health of the autistic individual, and consequently a profound impact on the demands of care givers.

3.3b) Sensory Sensitivity

A common theme in autism symptomology, whilst varying in severity and presentation, is sensory sensitivity (Grandin 1996, 12). In 2016, the National Autistic Society released a video entitled 'TMI', depicting a young boy with autism experiencing sensory overload during a shopping trip. Described as a virtual reality experience for neurotypical individuals to understand the challenges faced by those with autism, the short video immerses the viewer in an onslaught of competing noises which gradually increase in volume, along with the young boy's clearly distressed breathing[18]. This video, it would seem, so accurately portrayed the experience that it prompted my son, who at such a time was unaware of his diagnosis, to ask, 'Mum, do I have autism? That's what I feel like!'

What is interesting about auditory sensitivity among autistic individuals is that it has not been shown to correlate with any physical difference or impairment in hearing. Lorna Wing, author of 'The Autistic Spectrum', observes that some individuals may be unresponsive or appear deaf to some even loud noises, whilst other noises prove to be extremely agitating or distressing (1996, 50). The unpredictability of noise sensitivity is compounded by the fact that it is often unavoidable, as shown by the video's decision to highlight the necessary and routine act of shopping as an almost insurmountable sensory challenge for someone with autism. Temple Grandin describes her own struggles with tactile sensitivity, which was at times overwhelmingly unbearable for her to manage. In 'Emergence: Labelled Autistic', she

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[18] https://www.autism.org.uk/about/family-life.everyday-life/shopping-strategies.aspx
Accessed 11/06/19 11.49pm

recalls one particular incident in which she causes her mother to crash their car over her inability to tolerate the sensation of a sun hat on her head:

> My ears felt as if they were being squashed together into one giant ear. The band of the hat pressed tightly into my head. I jerked the hat off and screamed. Screaming was my only way of telling Mother that I didn't want to wear the hat. It hurt. (1996, 12).

This example is particularly useful as it highlights that something seemingly innocuous and harmless to Temple's mother, a simple sun hat, is utterly devastating to Temple. When a neurotypical individual chooses clothing, we typically will select our garments based on style, colour, or aesthetic. While we may have a preference of fabric, our decision to wear or not wear a particular item is rarely determined by whether or not our skin can tolerate the sensation of it. For someone with autism, the sensation of the wrong garment can be almost incapacitating. Such sensitivity to tactile sensations can also be seen to account for the reported reluctance of autistic individuals to engage in physical contact such as embraces or physical intimacy with others, rather than a perceived lack of affection or emotion. Conversely, similar to the sensory self-stimulation we have discussed, certain sensory inputs can also be shown to be soothing for individuals with autism; deep pressure techniques such as weighted blankets and vests are now widely recognised as beneficial for tempering sensory difficulties.

For my son, sensory sensitivity scored particularly highly in his diagnosis. Competing background noises distressed him, and he could not tolerate anything loose or baggy on his person. To this end, his clothing had to be tight to the point of marking his tiny body, leaving grooves, indents and often bruises. Consumed with an irrational fear of laces coming undone or Velcro snapping causing him to trip (this had in fact never happened, but the possibility of it was enough), coupled with the need to have his clothing grip his body, Micah rejected every pair of shoes we attempted to put him in until eventually deciding on a pair of leather buckled sandals. This, in the beginning of spring, we considered a success. However, by the December, and on our 8th pair of what had to be the same brand and model of sandal (which had long been discontinued and which we now had to source by ever more creative means) this seemingly small victory had become the focus around which Micah orientated the success or failure of his, and consequently our, day. Now that he is older, he can reminisce with good humour about what has gone down in family infamy as 'The Year of the Sandal.'

The causation of sensory sensitivity amongst autistic individuals is also unknown. Whilst early theories suggested a compensatory model, proposing that individuals with autism favoured certain stimuli such as taste, touch and smell to the detriment of others; this was dispelled as increasing evidence observed sensory difficulties amongst all five senses, with no discernible trend or pattern (Frith 2003, 169). Rather, Frith offers that rather there is difference in the *way* that autists process certain stimuli, rather than necessarily the stimuli themselves. She suggests a hypothesis of 'stimulus over selectivity', which posits that 'autistic children cannot attend well to simultaneously presented information and therefore select one narrow aspect of this information' (2003, 170). It has also been suggested that external stimuli are often unpredictable and difficult to control, and therefore can be a source of anxiety for individuals with autism. Certainly, in a world in which we are confronted with unexpected and often competing stimuli, the experience of the autistic individual is one of constant external assault.

3.3c) Temper/ Aggression

Aggression, as a characteristic, is difficult to quantify or measure in terms of prevalence or severity. However, studies have shown that in relation to other developmental conditions, and indeed the general population, prevalence of aggressive, self-injurious or violent behaviour is considerably higher amongst individuals with autism (Stirling et al 2015, 115-116). A 2016 study into behavioural and emotional problems associated with autism found that 68% of individuals with autism related conditions reported aggressive or violent behaviours, which was considerably higher than controls (Lecavalier 2006, 1110).

In 'Autistic Psychopathy in Childhood', Hans Asperger offers a detailed description as to what he termed the 'autistic acts of malice' of his patients towards their caregivers, peers, and environment. 'These acts,' he muses, 'typically appear to be calculated. With uncanny certainty, the children manage to do whatever is the most unpleasant or hurtful in a particular situation' (1944, trans in Frith 1991, 77). This description is particularly jarring. It assumes not only an inherent cruelty in the autistic individuals observed but also an *awareness* of the cruelty of their acts. On their worst day, parents and caregivers of children with autism may sometimes feel the resonance of Asperger's words and attribute intent to the autistic aggression they are experiencing. This can consequently have a profound and severely damaging impact to relationships and family life, with parents facing the additional stress of being at risk of being injured by their child, and also in preventing their child from harming

themselves. Such behaviours can also be deeply stigmatised and may result in social isolation for both the individual and the family (Gray, 1997; 1999).

However, since Asperger's bleak portrayal in 1944, research has increasingly refuted the association between aggression and malice described in individuals with Autism. Patricia Howlin, in her guide for parents and practitioners of children with autism, considers that there can be observed to be a perfect storm' of environmental and developmental factors which coalesce to create aggressive outbursts in autistic individuals; difficulties in expressive language leading to communication difficulties and miscomprehension, sensory over stimulation, or even under stimulation leading to boredom and frustration are increasingly considered to be causes of anger and aggression in individuals with autism related conditions (1999, 211). As a means of de-stigmatising such behaviours, in recent years a distinction has been drawn between 'tantrums' and the outbursts of extreme emotion exhibited by individuals with autism now popularly termed a 'meltdown.' The National Autistic society describes a 'meltdown' as,

> …an intense response to overwhelming situations. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be expressed verbally (e.g. shouting, screaming, crying) physically (e.g. kicking, lashing out, biting) or in both ways. [19]

Whilst extremely upsetting for both the individual themselves and the people around them, it is generally considered that such outbursts become less frequent as children develop (Howlin 1999, 211). Whilst it is uncertain whether children simply 'grow out' of such expressive outbursts, as typically developing children do with tantrums, it has been suggested that the acquisition of greater expressive language and increased awareness and avoidance of potential triggers, particularly environmental ones, can significantly reduce the frequency of meltdowns.

3.4) Co-morbidities

A challenging feature of autism is that it is often found to accompany other co-morbidities, which can lead to a frustrating and elusive 'chicken or the egg' search for answers. Is it that certain health conditions lead to autism, or does autism make one more susceptible to other

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[19]19 https://www.autism.org.uk/about.behaviour.meltdowns.aspx   Accessed 18/06/19 12.32pm.

health conditions? No one is quite sure, however there are certain conditions which show markedly more prevalence amongst individuals with autism.

The relationship between autism and mental health has been an enduring one. Studies have shown that up to 70% of individuals with autism also have a co-occurring psychological condition (Simonoff et al 2008, 921). Particularly in school age children, ADHD is found to be three times more common amongst those with an autism diagnosis. Whilst many of the diagnostic criteria for autism and ADHD can be found to overlap, Mayes et al found in a study of 847 children with autism, over half displayed 30 or more symptoms of ADHD, in contrast to the control group of 158 children with a primary diagnosis of ADHD only (none of which displayed symptoms of autism) (2012, 278). Tourettes syndrome (or what is now commonly referred to as tic disorder) categorised by involuntary movements is also associated with autism; however as with the similarities in characteristics associated with ADHD, researchers are in disagreement as to whether such movements could instead be described as the ritualistic or repetitive behaviour (Baird et al 2006, 211). Similarly, epilepsy and seizure disorders are found to be present in 30% of individuals with autism (Silberman 2015, 199), with rates of the general population falling in the region of between 4 and 10 per 1000 people[20].

Whilst no large population studies have been completed to validate this hypotheses, researchers and practitioners as early as the 1970's have also raised concerns over the increased susceptibility of autistic individuals to anxiety and depression (Rutter 1970, 441; Macaskill 2019, 130; Stewart et al 2006, 103). It is thought that increased sensory anxiety and difficulties in social communication may contribute to individuals suffering from increased levels of stress and social isolation, leading to depressive symptoms. However, this is difficult to quantify for a number of reasons. Firstly, issues in communicating and articulating feelings are common amongst individuals with autism, making it less likely for individuals to speak openly about depressive symptoms. Furthermore, many of the symptoms of depression, such as withdrawal from social contact, decline in personal care and sleep issues can also be seen to overlap with the symptoms of autism itself, making it hard to differentiate. To this end, there is no current diagnostic model for depression that is autism specific, and so the model used for the general population may not suitably reflect the subtle differences between depressive behaviour, and autistic behaviour (Stewart et al, 2006, 109).

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[20] https://www.who.int.news-room/fact-sheets/detail/epilepsy   Accessed 18/06/19 14.08pm

3.5) Stigma

As I have touched upon in the preceding chapter, the association of autism with psychological disturbance has left an indelible mark on how autism is perceived socially. In chapter one, I illustrated how constructions of 'normal' (and consequently 'abnormal') behaviour have functioned to position difference as inherently suspicious, deviant, or pitiable, particularly in relation to cognitive difference. More significantly, the influence of the eugenic beliefs examined in chapter two on social attitudes and policies towards difference made 'normal' a particularly dangerous category to be excluded from when autism was first identified. Whilst we have mercifully moved beyond the devastating reach of social eugenics, as I have examined in respect to autism and popular culture, attitudinal shifts are much slower to transform.

Autism is, by nature, an invisible condition. In contrast to the differences which are often visually recognisable in the case of physical disabilities, intellectual or developmental conditions such as autism present by their difference in behaviour. Erving Goffman posited that stigmatising conditions which are 'invisible' (such as autism) allow for the phenomenon of 'passing' as 'normal' in social situations; therefore mitigating other's awareness of their stigmatising characteristics and allowing for greater opportunities for social inclusion (1990, 92). From this, we could infer that the 'invisibility' of autism leads it to be a much less stigmatising, and therefore less marginalised, lived experience.

However, as Asperger's attempts to shape his research to protect his 'little professors' has shown, the invisibility of autism far from translates into social acceptance. The behaviours associated with autism are often inexplicable and perplexing to others. Repetitive behaviours and restricted interests can appear 'odd' or peculiar', often drawing unwanted or negative attention and marking persons with autism as distinctly different from their peers (Lawson 2008, 31). Schaff et al noted that self-stimulatory behaviours in children with autism can also be particularly challenging for care givers and educators, as not only are they often stigmatised behaviours, but can also be potentially (if unintentionally) disruptive to particular social contexts such as family events or the classroom environment (2012, 374).

David Gray observes in his paper on stigma perception in addition to the individual with autism themselves facing stigma, families also experience stigma as a consequence of their relationship to the stigmatised individual, in this case, their child (1997, 103). This research is consistent with what Goffman refers to as the phenomenon of 'courtesy stigma'. 'Stigma

perception', or the intense awareness of other's and their potentially negative opinions of both the child and the parent is considered to significantly impact not only maternal well-being, but also the likelihood of participating in leisure activities outside the home, attending social situations, and seeking social support (Duerte et al 2009, 217). Gray also noted that parents of children with more aggressive characteristics (such as the temper and aggression detailed above) were considerably more likely to experience such stigma than children whose behaviours were 'passive' (2003, 2007). This may be a particularly relevant and interesting area of further study in relating to parenting as a unique experience of courtesy stigma, as parents arguably experience stigma both in terms of their relationship to the child, and also, as we have learned from Kanner, in terms of their perceived responsibility in the behaviours their child displays.

3.6) A Distinct Challenge to Motherhood

Despite it being commonly accepted that children with autism are considerably more likely to develop successfully the earlier diagnosis and potential intervention takes place (ideally prior to the child turning 3); it remains frustratingly difficult for parents to obtain a diagnosis for their children (Zelzazo 2001, 41). Research conducted by Howlin and Asgharian found that of the 770 parents they interviewed concerning the diagnostic process, 60% were not diagnosed until a third diagnostic consultation, with more than 25% being told 'there was no problem' or 'not to worry' at the first appointment (2007, 836). Sansosti et al noted that the majority of children in their study, despite their parents first noticing differences in their development between 9 and 12 months, were not officially diagnosed until they were of school age (2012, 86). This is alarmingly consistent with my own experience. Initial concerns regarding my son's behaviour were raised in the last 18 months of his pre-school nursery placement, and a diagnosis was not formally obtained until June 2015, 14 months after beginning his assessment and 2-3 years after his development presented as atypical.

There can be observed a tendency to adopt a 'wait and see' approach to development so as not to misdiagnose and potentially mislabel a child before they have had the chance to 'outgrow' particular behaviours (Sansoti et al 2002, 87). In this respect, the heterogeneity of autism may often function to inhibit its own disclosure, as a very young child may meet some yet not all of the diagnostic criteria at the point of assessment, or simply be too young to accurately assess in terms of language and cognitive ability, despite showing other indicators of early autism presentation. Schulman et al attribute several reasons to the prolonged

diagnostic period associated with autism, highlighting the significant impact such delays may have on families:

> The onset of autism is insidious, not usually marked by the appearance of abrupt or dramatic symptoms. Typically, families experience an awareness that a problem exists, adapting to their child's difficulties without even being aware that they are changing their behaviour and expectations…The difficulties in diagnosing autism are manifold, as there are no clear or specific biological markers (Schulman 2002, 25).

The diagnostic process can therefore be seen to be hindered two-fold. In one respect, the diagnostic process can be seen to be impeded by parents themselves, who may be reluctant to admit that their child is not developing in the same way as other children. In some cases, this may simply be due to lack of comparable experience. My own son is an only child, therefore I had no control measure of typical development to gauge him against. The characteristics associated with early indication of autism are often behavioural, and therefore often stigmatised as merely symptomatic of poor parenting. Consequently, individuals of children presenting such behaviours may be reluctant to draw attention to them, for fear of being seen to be merely 'bad parents' of 'bad children.'

Over recent decades, a huge amount of research has investigated the impact to parenting of an autism diagnosis in comparison to neurotypical control groups, and, also, in comparison to other developmental disabilities in children; typically Downs Syndrome, Fragile X Syndrome, and Pervasive Developmental Delay (Dumas et all, 1991; Estes et al; 2009; Howlin et al, 1999; Sansoti et al, 2012; Zhang et al, 2015). While current research pertaining to autism care giving predominantly utilises the relatively gender-neutral term of 'parenting,' the literature itself paradoxically reflects that the experience of parenting even typically developing children remains strongly gendered. Marshall and Bonita suggest that research indicates the care giving demands of parenting a child on the spectrum are more consistently occupied by the mother in comparison to the father (2005, 105).

Nicholas et al observe that throughout the literature, the stereotype of what makes a 'good mother' and the strict conditions under which one may adhere to this category remain a cause of significant stress amongst mothers of children on the autism spectrum (2016, 927). As I have touched upon in the preceding chapter, Kanner's damning indictment of the 'refrigerator mother' arguably fuelled this assumed dichotomy between 'good' and 'bad' mothers, contributing to a damaging culture of maternal guilt. Whilst awareness and understanding of

autism has increased in recent decades, discrediting notions that autism is a psychological disturbance caused by mothers; the painful legacy of these paradigms can arguably continue to be seen in the way mothers experience the diagnostic process, access support, and are treated socially.

Investigating fatigue and self-efficacy amongst mothers with children on the autism spectrum, Rebecca Giallo et al reported that further to maternal stress, their respondents experienced considerably higher levels of fatigue than mothers with typically developing children as a consequence of additional care demands (2011, 466). By this we can infer that the challenges faced by mothers of children with autism are not merely located in the social world but have very real implications on both physical health and emotional well-being. It has been suggested that in addition to heightened parental stress, mothers with children on the spectrum may experience lower perceived quality of life, or develop psychological conditions such as depression, anxiety and in severe instances PTSD (Zhang et al 2015, 29). A recent study by Kocabiyik et al investigating the emotional impact to mothers of an autism diagnosis suggested that many mothers experienced an emotional journey similar to that experienced during the grieving process:

> At the first stage that they faced with the diagnosis; they might undergo shock, denial, grief or depression in most of the times. The reactions of families experienced in the second stage were anger, guilt and shame... Sometimes they might think that they are punished by the God. Sometimes they think that this has happened because they are not good parents (Kocabiyik et al 2018, 33).

Examining the coping processes of mothers with children on the spectrum, Marshall and Bonita observed that the research suggests that in fact 'few disorders in children pose a greater threat to the psychosocial well-being of parents than autism' (2005, 105). Whilst this seems a bold, and perhaps controversial statement, the literature surrounding the family experience of autism overwhelmingly supports this assertion. Estes et al concluded that 'no study to date has found a group of mothers with higher distress levels than mothers of children with ASDs' (2009, 376). Mothers who are also care givers of children on the autism spectrum can be seen to be caught in a 'perfect storm' of mutually reinforcing difficulties; they are at once challenged by their child's symptomology and the daily unpredictability of managing such a condition; yet also profoundly affected by policies and attitudes which

socially and materially disadvantage them. Thus, the experience of mothering a child with an ASD diagnosis can be a particularly obscured, lonely and challenging one.

Despite the highly relational and experiential nature of this particular subject, much of the research to date has remained strongly quantitative; distilling participant responses on criteria such as mood and child symptomology into observable trends in experience (Estes et al, 2009; Kissel et al, 2014; Tomeney, 2017; Adams et al, 2019). Whilst this is extremely useful in providing a concise overview of the commonalities experienced by parents, what is largely missing from the research is the voices of the parents themselves, articulating the lived experience of their parenting journey.

3.7) Summary

In this chapter I have sought to clarify some of the ambiguity in respect to autism by detailing symptomologies which are currently accepted to be diagnostic indicators. However, as I have demonstrated, the symptoms themselves are varied, unexpected, and often incongruent to one another; making autism a distinctly difficult condition to diagnose. I have problematised these symptoms as profoundly stigmatising for persons on the autism spectrum, with characteristics of autism variously impacting personal independence, social communication, and often defying socially accepted norms of behaviour. This presents a particularly challenging lived experience, not only for the individual with autism themselves, but by extension their families and caregivers. Whilst Kanner theorised that mothers were deeply implicated in the development of autism and, by extension, the mental health of the child; recent research suggests that conversely, autism is rather more significantly implicated in poorer mental health outcomes for mothers. Such research provokes insight into the relationality of autism as a condition whose impact extends beyond the individual.

I have also argued that an over-reliance on quantitative approaches within this research context serves to dilute the authenticity of the experience it seeks to illuminate. Philosopher Ian Hacking has suggested that the ambiguity and complexity of autism makes it particularly resistant to quantitative methods, proposing that rather much of what we currently know about autism (even within medical contexts) comes directly from the lives of those experiencing it; often through life stories, biography, or creative fiction. He furthers that in fact how we choose to write about autism can deeply impact the lives and experiences of living with it (2009, 1467). With this in mind, in the following chapter I turn to a discussion

of methods, acknowledging the resistance of autism to quantitative inquiry and developing a qualitative approach sensitive to the complex, multivariant and occluded nature of autism as a lived experience.

Chapter 4) Research Methods and Methodology

In this chapter, I will engage in a discussion of how practical theology responds to the complexity and ambiguity of lived experiences; exposing the disciplinary conflicts as to how we attribute theological significance to such experiences, and considering how practices of reflexivity respond to the challenge of authority in respect to knowledge production. I will then turn to a discussion of methods, identifying the methodologies I have used to underpin this research. These are shaped and informed by practical theology as a knowledge making system which seeks to locate the sacred, spiritual and the revelatory in the embodied 'tragipassions' of the everyday (Walton 2014, 86). As I have sought to illuminate, the experience of autism, and of those mothers who love an autistic child, cannot be easily or neatly slotted into any single framework. While shaped by similar external forces, each experience of autism is different. It is in the complexity and ambiguity of these lived experiences which I propose will expose profound sources of knowledge.

4.1) Practical theology as a knowledge making system

Practical theology could be considered to occupy the space on the border between what is thought and what is known. It revels in the blurring of boundaries; in revealing the tensions between theory and practice, the sacred and secular, faith and praxis (Veling 2005, 5). Heather Walton considers that,

> … Perhaps our ragged ranks have always been assembled in a disputed territory on the borders of worlds and disciplines. It may be that our uneasy suspension between practice and theory lends us a different vantage point? We are the people whose vocation is to deal with the fact that in life is complicated, ambiguous, and impure – and our challenge is to respond to this in *faith* (Italics original) (2018, 224).

Rather than a discipline whose knowledge making forms a linear path between theoretical work and practical application, Terry Veling considers practical theology an attempt to 'heal the divisions' between the apparent otherworldliness of theology, and the everydayness of the real world in which our experiences are located (2005, 6). However, in rejecting dualisms which seek to separate earth from heaven (Veling 2005, 5), practical theology has also occupied a space of tension within academic discourse. If it is neither theory nor practice, but somewhere in between; might it also be neither sufficiently academically authoritative, or even sufficiently theological to justify its position as a discipline?

Such frictions between objectivity and legitimacy have led some to suggest that it is often too easy for practical theologians, whether consciously or unconsciously, to default into accepted patterns of knowledge making in an attempt to re-assert the discipline's credibility and validity as an academically credible theological discourse. Developing this critique, Courtney Goto argues that,

> …in a group of researchers, individuals implicitly research according to accepted, underlying patterns that presume and extend what is taken to be true. …I suggest that one can readily appreciate how privilege, epistemic violence, and historic communal injuries are insinuated in a community's patterns of knowledge production (2018, 221).

As I demonstrated in chapters one and two, exactly who is conducting research, how, and to what end can have significant material consequences on the results generated and, indeed, the lives of the researched. Goto observes that it can be difficult for those who occupy a marginalised position, and particularly those who occupy multiple marginalised positions, to speak within practical theology without their voice being assimilated and adapted into taken for granted paradigms of knowledge (2018, 32). In the context of this research, the voices represented are 'othered' in many overlapping and conflicting ways. In the light of such criticisms we must be aware that while practical theology has been considered to offer a response to theological inquiry which lends itself well to diverse methodological approaches, it is increasingly being challenged to broaden its disciplinary boundaries to accommodate inter and intra-faith perspectives (Veling 2005, 4; Swinton and Trevett 2009, 4).

4.2) The Challenge of Reflexivity

In responding to this move within practical theology, Goto proposes that reflexivity is crucial to the self-interrogation required to begin to recognise, pay attention to, and develop new ways of practice around the dominant paradigms and assumptions from which our knowledge is formed (2018, 216). Reflexivity is described as the process of making explicit the reasons behind particular modes of engagement, the choices of methods, the reasons for looking at a given population, individual, or theological issue, and the impact of the researcher's personal history and presuppositions on the issue being researched (Swinton and Mowat 2006, 61). Within the research process, reflexivity is a tool which can be employed to ensure that personal subjectivities and presuppositions are acknowledged, checked, and rechecked,

throughout the research process. In this respect, it is often described as the process of 'writing oneself in to the text' (Graham et al 2018, 22). Reflexivity, in this mode, can be considered a means of creative self-expression, of sharing life events in imaginative and engaging ways which contribute meaningfully to a subject.

When first encountering this approach, it seemed almost too easy that I, as the writer, could become my own source of data, and that this data could be something academically credible. I now know all too well that there is nothing easy about self-reflection. Indeed, to conduct it well, one requires intense discipline, critical self-analysis, and a 'thick skin' as the process can render the writer particularly exposed. It also requires a lot of practice, as Walton further states; 'it is assumed that theological reflection will develop organically from a life of faith and find its way unmediated onto the page. In my experience, this is never the case' (2014, xi). Goto acknowledges that the practice of reflexivity is often at risk of being considered 'self-indulgent navel gazing;' and is consequently practiced hesitantly, conservatively and all too inconsistently (2018, 216). Miller-McLemore cautions that within the field of practical theology, whilst reflexivity is perhaps more readily practiced than in other theological disciplines, we are still far from consciously interrogating our own deeply hidden subjectivities, and she laments, 'We analyse hegemony and hierarchies of knowledge almost everywhere else but our backyard' (2016, 204).

My own academic 'backyard' is interdisciplinary. I am influenced by a sociological academic training and tradition which values critical analytical inquiry, a 'value free' position in which the researcher is a neutral observer of an external locus of concern; and yet I am also influenced by a theological tradition which extols the value of reflexive and reflective engagement with issues which are not so easily abstracted into neat conceptual frameworks. This research has been formed from the 'epistemic advantage'[21] of my lived, embodied experience of motherhood firstly, but also by being the mother of a child with autism. This distinction may perhaps seem insignificant, but the experience of mothering an 'atypical' child produces its own particularity of motherhood; one which is inherently shaped by distinct historical, social, and political sites of discourse.

Whilst I may be considered to occupy many 'minoritised' positions; as a woman, as a single mother, and as a person whose life is closely intertwined with someone who is considered as

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[21] In this context I use the term 'epistemic advantage' as defined by Courtney Goto as a 'critical perspectival edge created by experiencing oppression personally or empathically, enabling a knower to stand in multiple places, discern what others might not, and to challenge ignorance or violence.' (2018, 68).

a person with a disability, as someone outside of the Christian tradition of my field; I am aware that I also occupy many positions of privilege. I am a white woman, who has been educated within a white, middle class, predominantly Christian academic setting. My research is being conducted in the West of Scotland, which is a similarly largely white, Christian demographic. Research which investigates the experience of autism in BAME[22] communities is limited, however a 2014 study by the National Autistic Society suggests that diagnosis and access to support may be significantly more difficult for individuals who are non-white: as a consequence of potential language difficulties, access to resources, or indeed biases from professionals themselves [23]. Thus, I cannot neglect to acknowledge that my experiences may be significantly different and shaped by my own epistemic advantage. A reflexive awareness of these challenges recognises that my epistemic standpoint may influence, and potentially limit, the ways in which my ontology (or perceived ontology) shapes the research process.

4.3) Methodology

Reflexivity as defined above also affords us an awareness that our epistemological perspectives also strongly influence and inform our methodological decisions. By methodology, we typically refer to the ways in which research is conducted through the collation and representation of data, the research 'tradition' in which the researcher chooses to situate their analysis, and the significance of the researchers own ontology in shaping these choices. Often described as the 'research paradigm', the term methodology identifies the particular 'stance' through which the researcher will present their research. Swinton and Mowat define the term as 'a family of methods that have in common a particular philosophical and epistemological assumptions' (2006, 75). Such 'epistemological assumptions' are considered useful in situating research within particular conceptual frameworks which have commonly defined parameters. However, as I have illustrated above, there are inherent dangers in assuming research can be produced from unproblematic epistemological contexts.

Problematising the very nature of terms such as 'paradigms' and 'contexts;' Courtney Goto shares her unease with practical theologies uncritical acceptance of dominant theoretical

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[22] 'BAME' is an acronym used to refer to 'Black, Asian, and Minority Ethnic' communities. It has become increasingly utilised in discussions relating to socio-political inequalities, however it is worth noting that its usage is contested, with some considering the amalgamation of these distinct communal identities arbitrary. http://www.bbc.co.uk/news/amp/uk-53194376. Accessed 17.07.20 20.20.
[23] https://www.autism.org.uk/about/BAME. Accessed 17.07.20 20.13

frameworks as established and unquestionable sources of knowledge. She proposes that what we consider to be 'paradigms' or 'contexts' are themselves constructed and therefore contested concepts, emerging from particular social and cultural milieus. Naming these milieus as 'rhetorical spaces', Goto furthers that 'within rhetorical spaces, members of the guild decide the degree to which the work of individual scholars contributes meaningfully to the field, conferring legitimacy where they deem it to be deserved' (2018, 47). As I have explored above, such 'spaces' are often colonialised, functioning to minoritize and marginalise voices which do not fit within the dominant paradigms established as legitimate knowledge (Althaus-Reid 2000, 119; Beaudoin 2016, 11; Goto 2018, 28-31). As someone who has similarly found themselves hovering on the borders of such established spaces, considerations of methodology can often feel like a litmus test of academic legitimacy.

Bennet et al observe that 'a methodological awareness reminds us that we do not come to the creation of knowledge as innocent inquirers. Our practice is creatively enabled and critically constrained by the methodologies employed' (2018, 143). As I have demonstrated with the particular representations made by both Kanner and Asperger in the development of autism research; methodological decisions can be shown to actively contradict, misrepresent and hinder research towards particular aims or agendas. I have asserted that autism as a condition is ambiguous, complex, and significantly mis-understood, and can be shown to be located, shaped and constrained by multiple conflicting 'paradigms.' Thus, the lived experience I am seeking to present of mothers with children on the spectrum is similarly complicated and distinct. Indeed, my decision to research this particular issue is rooted in my assertion that it is not currently located within accepted theological discourses. It cannot be found to neatly fit within any single methodological context without privileging one facet of experience over another.

Furthermore, as this research project is based upon life narratives and draws upon the emerging rubrics of autoethnography, my epistemology is inextricable from and deeply embedded within the subject I am seeking to explore. Consequently, whilst this section situates itself as a discussion of methodology, it does so with a recognition that the nature of this research necessitates that my methodology will not form a stable, determined location from which an objective researcher observes an external subject or object (De Certeau 1998, 36); but rather is fluid, ambiguous and deeply interwoven in the processes and knowledge it seeks to produce. In what follows, I will thus consider my methodological choices in terms of 'perspectives', acknowledging the spaces in which accepted paradigms of knowledge may

resonate with the experiences I am seeking to illuminate, whilst also recognising the unsettled nature of these lived realities as ambiguous, transformative, and resistant to being tamed (Walton 2014, 162). As this research centres around issues such as motherhood, the family, and disability, I will be drawing from feminist and phenomenological perspectives which support my consideration that mothering a child with autism spectrum disorder is a phenomenon which is gendered, embodied, experiential and occluded from current discourse.

4.3a) A Feminist Perspective

Utilisation of a feminist perspective in this research context will seek to bridge the gap of experience between the normative, essentialist, and androcentric paradigms of disability explored in chapter one, and instead highlight the more complex and multivalent realities of the lived experience of autism I am looking to observe. A feminist perspective offers a paradigm which enables us to consider the experience of the 'other' as something valuable and meaningful, demanding a 'critical analysis of structures and ideologies that rank people as inferior or superior according to various traits of human nature, whether gender, sexual orientation, class, colour, age, physical ability and so forth' (Miller-McLemore 1999, 79). This recognition of the voice of the other has been one of the overarching strengths of utilising a feminist methodology in representing the experiences not only of women, but of other similarly marginalised groups (Goto, 2018, 67). In its rejection of 'otherness', a feminist perspective lends itself well to disability studies as people with disabilities, much like women, have often found their voices disregarded as a consequence of their embodiment.

Womanist and liberation theologians such as Ada Isa-Díaz, Nancy Eisland, and Althaus-Reid have utilised their distinct epistemic advantage as out with a white, heterosexual, or able bodied male experience to give voice to women of colour, individuals with disabilities, and those who are marginalised and oppressed by dominant social orders. Goto observes that in this way feminist theologies subvert our perceptions; de-familiarising what we assume we know to be familiar (e.g. the lives of mothers) whilst making familiar the lives of those who are perceived to be different from our own. She cautions, however, that 'as feminist theology slowly transforms awareness, what once needed translation can become assimilated by the dominant discourse' (2018, 67). In this sense, we must be wary that of the 'conceptual trap of 'solidarity'' in assuming a universal, hegemonic (and usually white) category of women whose experiences and struggles are easily transferrable with others. It can be all too easy 'to

fall prey to this,' and to neglect our own sites of privilege and power in representing the voices of other women (Althaus-Reid 2000, 90).

Recognising the theoretical tensions as to exactly how we define the category of 'women', some also suggest that feminist theology has shifted too far away from the particularity of the body as a locus of experience. In contrast to perspectives such as Butler's who rejects notions of bodily difference as essentialist (1990, 47); there is criticism from within feminist inquiry that such positions neglect the experience of women as one which can be powerfully embodied (Graham 1995, 170). Supporting a recognition of the value of embodied epistemology, Walton asserts that attention to embodiment does not imply that we consider women's bodies as naturally imbuing them with an inherently 'feminine' theological perspective; but that rather our bodies are socially, culturally, and historically located, and it is this distinct location which offers a distinct voice (2018, 7).

Feminist theologies have received further criticism, particularly from empirical theologies,[24] for their evocativeness; that they are too influenced by emotions, and consequently not sufficiently critically analytical to be a credible method of inquiry (Bennett et al, 2018). However, the disclosure of strong and conflicting emotions by female writers, which are often so carefully censored due to fear of judgment or criticism, are arguably what serves to give voice to the silenced experience of others. In sharing my own autoethnographic reflections throughout this thesis, and in sharing the often painful stories of others, I do not seek to merely create dramatic effect. Rather, I aim to reveal aspects of lived, everyday experiences which are often too difficult to share.

4.3b) Phenomenology: Everyday Insights

Whilst an awareness of the socially constructed nature of issues such as gender, the body, and impairment are essential in recognising the complex and competing forces in which our identities and perceptions are formed, we must also be careful not to neglect the lived, embodied experience of the social conditions in which we exist, and the meanings which we attach to these experiences. Michael de Certeau reminds us that 'theoretical questioning, on the contrary, does not forget, cannot forget that…it is linked to the pollution of that which does not speak (does not yet speak) and which takes the shape (among others) of ordinary

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[24] Empirical Theology, emerging from the Netherlands in the 1970's is a form of theological reflection which proposes that there is a logical order and observable systemisation to human experience, beliefs, and practice which can be quantified, analysed, and evidenced to produce theological 'results.' (Van der Ven 1993, 2).

practices'(2011, 61). In an attempt to circumvent this potential pitfall this research is also informed by a phenomenological perspective, in that I consider mothering with autism as rooted in the phenomena of everyday lived, embodied, and enacted moments and practices, and that these practices can also be considered sites of resistance against experiences of marginalisation.

Phenomenology itself is something which is not easily defined and can be employed in many different ways in many different contexts. Clint Randles in his literature analysis of phenomenology describes the research paradigm as 'a meaningful way to describe something which is not easily quantified' (2012, 12). This aptly articulates that the difficulty in defining phenomenology is that the definition itself often raises more questions than it answers. Put simply, we can describe phenomenology as the 'study or science of phenomena' (Cerbone, 2006, 1). Developed in the academic tradition of philosophy by writers such as Husserl, Sartre and Merleau-Ponty, phenomenology rejects the principles of naturalism, empiricism and intellectualism which assert the position that objects, or phenomena, have a definable, static, observable or 'true' state of being, and instead looks to the phenomena of experience, perspective, and intentionality as fundamental components of our reality (Merleau-Ponty 1962, xvi–xvii).

Within the scope of this project, it can be described as the analysis of particular moments or experiences, and the meanings elicited from these particular sites of experiential knowledge. As my question is rooted in experience, this is a significant methodological tool as it positions experience as the generative source from which we create our meanings. David Cerbone, in his volume *Understanding Phenomenology* (2006), explains that the focus of attention in phenomenology is not the 'what' or the 'who' of the experience, but rather of the experience in its own right (2006, 3). De Certeau proposes that any analysis of experience is inherently and inextricably social and is rooted in daily practices. He argues that 'many everyday practices (talking, reading, moving about, shopping, cooking etc) are tactical in character', and that the wider social meanings to which we attach our experiences are rooted in the banalities of such seemingly unremarkable everyday tactics (2011, xix). Walton observes that,

> Recognition has grown that the ofttimes neglected sphere of daily living is where most people exercise agency and construct selfhood. It is the plane on which our most

meaningful life experiences unfold and also where the impact of economic and political forces are most keenly felt – and, in some cases, resisted (2020[25])

Phenomenology asserts that perspective is central to experience- that experience is more than it appears to be. As I have problematised in the previous section, perspective cannot be extracted from the narratives of our experience. It is not the 'thing' we are experiencing; it is a merely a perspective of the subject, which may be different depending on the angle from which we are viewing it. However, Randles furthers that 'researchers who use phenomenology as a research methodology do not shy away from some otherwise 'messy' subject matter, rather, the messiness intrigues them, informs them, and guides them to draw conclusions that are logical for them and quite possibly others as well' (2012, 18).

When describing the experience of mothers with autism and the complexity of the emotions which may emerge from this experience, no two mothers will have the exact same experience, at the same time, in the same way. Rather, they are presenting different perspectives of the same subject. Consequently, while I will develop common themes of experience in the following chapter, this thesis is underpinned by a methodological awareness that the issue at hand is experiential, subjective, and located within our own diverse and distinct personal histories. In exploring the maternal experience of autism, I do not seek to generalise or universalise, but rather reveal what has hitherto now been hidden within the everyday realities of mother's lives, and theologically reflect on what insights or meanings these revelations may provoke. My choice of methods draws from these everyday lived experiences, affirming my position that the phenomena of the everyday can provide profound and generative sources of theological thinking.

4.4) Research Methods

In the previous chapter, I have described autism as unwieldy; defying our attempts to categorise its experience. I have problematised the fact that research into autism which relies on quantitative data is often tentative, speculative, and conflicting. I have sought to illustrate that the experience of autism is deeply enmeshed in conflicting sites of knowledge, and yet is also rooted in everyday living in ways which are ambiguous, indistinct, and complex. This research is, in essence, an autoethnographic project. However, this research journey is a process in which I am not only interrogating the meaning behind my own experiences but

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[25] Unpublished paper.

also those of others; developing an ethnographic analysis into how such experiences are understood in the social context in which they occur. In what follows, I will outline my assertion that a utilisation of life stories as a research method offers the potential to reach the ambiguous, conflicting, and mutable nature of autism as a distinct facet of maternal lived experience in ways which would difficult to obtain through other means.

4.4a) Life Stories

Informed by a recognition of the significance of reflexivity in research practice, life writing has developed as a method of narrative based inquiry in which the researcher reveals elements of their own life in a narrative format in order to produce insight into particular lived contexts (Atkinson 1998, 9). While there is a wealth of genres which fall under the category of 'life stories' it is generally accepted that life stories (or 'life writing' as it is often referred to in research contexts) are accounts of lived experiences and the thoughts, feelings, and meanings we attach to such experiences (Wolfteich 2017, 19).

Ruard Ganzevoort suggests that we all understand our lives in terms of stories, of which we are both the author and the protagonist. Describing this process as 'enplotment', Paul Ricoeur considers the construction of narrative as the way people are able to make sense of life's intricacies which would otherwise be 'chaotic, obscure and mute' (1991, 115). As a form of narrative, life stories are thus necessarily fictive; they are plotted from our recollections of significant moments in our histories and understood within the context of what has been told before (Ganzevoort 2012, 216). Heather Walton reminds us however that 'enplotment is not a creative act that takes place ex nihilo (2018, 2). Rather, all stories can be seen to have similarly 'enduring elements…made up of beginnings, conflicts, and resolutions, with many repetitions of this pattern' (Atkinson 1998, 3).

Life stories have gained increasing traction as a research method able to reach experiences which are often deeply silenced and difficult to name (Walton 2014, 100). Walton considers that 'although our use of life writing is still often cautious and circumscribed, there is also growing recognition of how fruitful an epistemic resource personal experience might become' (2020). One of the strengths of life stories in this particular research context is that they afford a depth of understanding of the uniqueness of this situation which would be difficult to produce by other methods. With so many unknowns as to what autism actually is, what has become clear is that perhaps the richest and most reliable source of data in respect

to autism comes from an analysis of autistic lives. Consequently, much of what we currently understand about autism comes from the stories of those who have lived or are living with the condition (Hacking; 2009, Grandin; 1996, Claiborne-Park; 1997).

In contrast to objectivist research paradigms which assume knowledge to be nomothetic, fixed, and generalisable (Swinton and Mowat 2006, 43); this thesis draws on methods which demonstrate that rather knowledge is subjective, contextual, and dialogical. Attentive to the limitations of the research explored in the previous chapter, I engage with life stories as a research method responsive to the enigmatic and vivid nature of the lived experience of autism. I will draw on three creative forms from within this genre namely:

- Autoethnography
- Memoir
- Life story interviews

These will be employed in order to generate insight into an issue which I have proposed is currently theologically occluded. In what follows, I will demonstrate how a 'telling, reading and hearing' of life stories can help to reveal the complex, embodied, dialogical and relational nature of lived experiences in ways that challenge our theological thinking.

Autoethnography: Telling our own stories

As a feminist practical theologian, mother to a child with autism, and friend to other women who share this lived experience; I am not only deeply implicated within the subject I am researching, but live and embody the experiences about which I am writing. I am not a neutral observer of an objective reality; rather, I am critically engaged in the process of researching my own experiences and their meanings through interpretive communication with others. Whilst the potential for bias from such an 'insider position' has been treated with methodological unease (Anderson 2006, 387; Sotirin 2010, 5), it is my conviction that my embeddedness within this subject instead offers the potential for a rich and authentic production of knowledge. Describing this process as 'situated knowledge,' Donna Haraway asserts that our epistemic location inevitably influences our epistemic making (1988, 581). Naming this epistemic advantage as 'standpoint epistemology', Sandra Harding has argued that our perspective, particularly when that perspective comes from a social location of marginalisation, affords us a privileged understanding which enables us to creatively engage with and share the insights of other marginalised voices (1992, 138).

Recognising the generative potential of personal experience in revealing deeper understandings of complex issues, I undertake an autoethnographic approach in this thesis which utilises my own lived experiences as both significant sources of data, and epistemic resource, in the production of this research. Often described as the process by which the researcher writes his or herself within the text (Graham et al 2018, 22), autoethnography draws upon the researcher's particular social context and history in order to produce deep, vivid and meaningful descriptions which would be arguably unattainable from an outside perspective (Spry 2011, 54). My experiences will be utilised as something generative, something which can profoundly inform other's understandings. However, this autoethnographic project is also a reciprocal process. I approach this research with an awareness that the act of producing this project in dialogue with the voices of others may also challenge my own meanings and understandings. In dialogical engagement with the voices of others speaking from their own respective locations, Goto reminds us that our own 'situatedness' is tested and re-tested, affording us the potential to see things which otherwise may have escaped our attention (2018, 69).

Synthesising autobiography and ethnography, autoethnographic research has a long tradition within research as a method which draws on the researcher's personal experience as an epistemically generative method of reflecting on social, cultural and political issues (Ellis and Bochner 2003, 213). Despite it often being perceived as mere 'decorative flourish' (Behar 1996, 14) intended to evoke artificial emotional responses in the reader, autoethnography has its roots in the analytic research processes of fieldwork, note taking, and interviews utilised by notable social anthropologists such as Malinowski (1848), Levi-Strauss (1964) and Durkheim (1912) (Walton 2014, 3). Whilst we can identify elements of autoethnography in these methodological processes, what we now understand as autoethnography is a fairly recent development in research. Conflict remains as to whether autoethnography is a family of methods (Butz and Besio 2009, 1661), a singular research method, or merely an acknowledgement of researcher perspective (Smith and Sparkes 2008, 6). However, autoethnography's defining characteristics are generally accepted to include; the visibility of the researcher within the text and a reflexive engagement with the subject (Anderson 2006, 374), authentic, emotive, and vivid descriptions (Ellis and Bochner 2003, 212), and a challenge to epistemic norms (Denzin 2003a, 105).

Autoethnography has become attractive, particularly within feminist, post-colonial, and liberation theologies, precisely because it allows for voices to be heard which may otherwise

be silent (Althaus-Reid 2000, 119). Walton observes that 'as feminist scholarship has creatively reassessed the significance of gender difference, women practical theologians and practitioners are becoming increasingly confident about articulating insights from alternative positions' (2018, 11). Norman Denzin in particular has advocated the liberatory potential of autoethnography in 'unsettling' and 'criticising' taken for granted socio-cultural and socio-political scripts (2003a, 105). Stacey Holman-Jones considers that in this sense autoethnographic writing allows us to reveal '…a palpable emotional experience as it connects to, and separates from, other ways of knowing, being, and acting in/of the world' (2005, 767).

The intention for this particular autoethnographic project is that it will challenge commonly held beliefs about autism and what the experience of autism means to the family. My own autoethnographic texts have taken the form of life writing in which I have reflected on particularly strong memories which have emerged as shaping my lived experience of mothering, utilising these to precede and contextualise themes I later develop in each chapter. It is my intention that by offering an honest, sometimes painful, retelling of these moments, I will produce a meaningful and authentic engagement with an issue which is troubling silent in current discourse.

However, that I am presenting my own story in this research is not without its own ethical considerations. Martin Tollich caution that 'like an inked tattoo…the marking is permanent. There are no future skin grafts for autoethnographic PhDs (2011, 1605). Some of the challenges which I have chosen to write about were so all-consuming; emotionally and physically in being exhausted and overwhelmed by our life, that there have been points in this process in which they have simply been too raw and too painful to write about. Some of this research, consequently, has been written back to front, or from the middle out, during times when the more emotionally charged issues were simply too much to undertake. Tollich furthers that in autoethnographic work 'The word auto is a misnomer. The self might be the focus of research, but the self is porous, leaking to the other without due ethical consideration. Topic choice can inadvertently harm the researcher' (2011, 1608).

How much to share, and to what extent the sharing will cause potential hurt or embarrassment to my child and our wider family is a deep concern. My son is 11 now but articulate beyond his years. I am aware that he could, and very well may, read this thesis in the not so distant future. Throughout this process, he has often sat beside me in the writing of it. He will at

times peer over my shoulder as I type or ask me what I am working on. It has been important to me to be honest with him about what I am writing, and why. I have been fortunate that he has a remarkably pragmatic understanding of the challenges his attempts to navigate his autism has created for others, particularly myself. As the researcher, I have had to make my own informed consent, and continually weigh the potential benefit of the information I am choosing to share against its potential harm to myself and my family. In undertaking this research project, I am making the decision that the potential benefit to others in sharing our story will outweigh the potential harm in telling it; encouraged by others who have made this same decision, and chosen to share their lives on the page.

Using Memoir: Reading other's stories

The sharing of life stories is by no means a new phenomenon. From Augustine's Confessions to Maya Angelou's memoirs, the literary tradition of writing our lives has shaped what we know of each other, what we know of ourselves, and what we come to know about God. Autobiographical writing (or memoir) is often utilised as testimony, as confession, even as acts of resistance through the intentional practice of revealing significant elements of the author's life to an audience. Leading practical theologian Clare Wolfteich asserts that, 'reading another person's life is not merely an act of curiosity, however. Rather, it is a 'parallel process of transformation'; what the author reveals may resonate with, challenge, or inform the meanings we attach to our own experiences (2017, 23). In research contexts this reciprocity can afford a collaborative potential, whereby the researcher gains insight into a particular issue through the insider perspective shared by the author. In memoir, the author's positionality is typically explicit; allowing them to share their observations, judgements and perceptions of the particular contexts in which they are writing in a way which highlights the inherent biases and subjectivities they bring.

For the purposes of this research, I am utilising memoir both to situate the issue I am seeking to explore in its wider critical context, and as a form of data from which commonalities in experience can be identified and analysed thematically. In recent decades, emerging literature has critiqued the reluctance of academia to engage with autobiographical writing as a legitimate form of research, particularly in relation to experiential topics such as motherhood (Sotirin, 2010). However, within practical theology, the practice of autobiographical writing has already shone important light on the lived experience of motherhood as a potentially revelatory, challenging, and generative form of knowledge (Miller-McLemore 1995; Bons-

Storm 1999; Moschella, 2016; Wolfteich, 2017). Nicholas et al note that in the context of mothers of children on the autism spectrum, 'lived experience emerged as a form of mothering that was deemed unique to the extent that 'You have to live it to understand it.' (2016, 930).

Given the paucity of research into autistic experience, memoir's written by mothers of children with autism have become a significantly vital resource in furthering our knowledge and understanding of autism as a condition and offering insight into their often hidden lives. I have chosen to look specifically at narrative excerpts from two important memoirs: those of Clara Claiborne-Park (1995, 2001) and Jenny Lexhed (2008). Both are mothers to children on the autism spectrum, and their works are widely considered to have contributed significant insight into autism. By articulating their stories vividly and with candour, these authors name the often conflicting feelings and emotions associated with mothering a child with autism, affording us a glimpse into this particular lived experience of mothering which often remains hidden within research using other forms of data. Through their memoirs, Claiborne-Park and Lexhed reveal their private, and often painful stories, evocatively detailing their journeys both prior to diagnosis and their subsequent struggle to adapt as parents of an autistic child.

In examining their experiences, I have been able to identify parallel processes which suggest that there is a particularity to mothering a child with autism which can be seen to be shared. While my own research has emerged from a particular geographical, temporal, and social location; a comparative analysis reveals that there can be seen to be a thread of shared maternal experience in respect to autism beyond these contextual boundaries, legitimising its significance as an area which requires deeper theological reflection. Attempting to categorise the experience of two women, whose only commonality is a child with a condition which I have already problematised as defined by its diversity, arguably seems risky. Further consider that these women are from completely different countries (The U.S and Sweden, respectively) with different health care and education symptoms, writing from different points in time, and the categorisation seems perhaps overly simplistic. However, despite these apparent limitations, I argue that their incongruence in circumstance in fact serves to highlight that there are resonances in the experience of mothering a child on the spectrum which traverse geographical, temporal, and political contexts.

One of the inherent dangers in reading the stories of others, however, is that they are composed of memories. Memories, as we know, are not always linear, logical, or reliable. In

this particular context, the subject matter is particularly emotive, and thus the memories of the authors may be significantly influenced by their personal responses to the events they choose or object to share. Claiborne-Park in particular details her memories with an almost pragmatic detachment, and so while her emotional struggle is intimated, perhaps the depth of her emotion is such that it is unreachable to the reader.

Problematising the use of biography as data, Wolfteich reminds us that life writing, like any other form of writing, editorial decisions have to made in which the author 'both reveals and conceals' what they wish others to know (2017, 22). In this sense, what the author chooses to leave out can often be shown to be just as revelatory as what they leave in. Heather Walton cautions that while life stories are an incredibly rich and generative epistemic source, 'life narratives are unwieldy and difficult to tame to our own ends' (2014, 14). In an attempt to bridge these silences, I have chosen to augment this research by turning to the voices of other mothers with children on the spectrum. Undertaking interviews with three women with children of differing genders and ages within my own local context, I seek to interrogate the gaps and silences of the literature through a hearing of other's stories.

Life Story Interviews: Hearing other's stories

The interview process has a long tradition in research, and is an established method of gathering, interpreting, and presenting the experiences of others to produce rich and valuable data (Denzin and Lincoln 2005, 16). Interviews can be described as a dynamic process, allowing the participant an active and collaborative role in shaping the meanings and understandings brought to the research. As a contribution to ethnographic research, interviews are particularly useful in obtaining insight into the everyday lived contexts and practices of particular communities. With this in mind, how we define who or what is representative about the particular community we seek to research is an important methodological consideration in the interview process (Robinson 2014, 25). Given that I am seeking to offer insight into a particular and deeply personal maternal experience and not looking to validate a pre-conceived, generalisable hypothesis, I have chosen to adopt an idiographic approach to interview selection.

Utilising a small sample of three participants, this approach allows for the authenticity and distinctness of individual voices to be heard, whilst affording sufficient scope to identify similarities between their accounts (Robinson 2014, 29). In order to define the parameters for

this small selection of participants, purposeful sampling was utilised to establish the inclusion criteria for interview participation[26]. The particular voices represented in this research were selected based on the following criteria; that they are all mothers of children with an autism diagnosis, sharing the particular social context of the West of Scotland, with children of similar ages, supported by the same local authority.[27]

Naomi*, is a married mother of three, with a son diagnosed with Aspergers, ADHD, and Tourettes. Naomi was forced to give up work to accommodate the additional caring demands of her son's condition while her husband works away to support the family. Scarlet*, divorced, has two children: a son, and a daughter with an ASD diagnosis. She also was unable to continue working due to the demands of being a single parent, frequent appointments, and her daughter's disruption at school. Abigail*, married, also has two children, a daughter and a son both on the spectrum. Abigail was able to complete further education and continue her career, however she observed that this was a delicate balancing act with her husband's career. Although their personal circumstances and histories were varied and diverse, their children were diagnosed, educated and supported by the same local authority. Given that I have highlighted the experience of autism as profoundly shaped by social, medical, and economic forces; their shared context offers insight into the potential impact particular social policies may have in producing experiences of struggle and marginalisation for mothers with children on the spectrum in Scotland.

In beginning this research, I had intended to conduct semi-structured interviews, signposted with some basic 'opening' questions in terms of background context, for example age of diagnosis and duration of assessment. In considering a semi-structured format, I intended to avoid leading and limiting questions, mitigating the potential danger of influencing my participants towards a predetermined outcome, yet provide enough structure to focus the conversation on the issue at the heart of the research question. However, whilst I had entered into the interview process with predetermined questions, I found that we had little need of them once we begun. The desire to break the silence that they had experienced was palpable. What emerged, rather, was a spontaneous telling of life stories. These women all, unconsciously or otherwise, communicated their experiences as rich and vivid life story narratives.

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[26] 'Purposeful sampling' can be defined as the process by which inclusion criteria is chosen prior to interview, based on what the researcher considers significant to the research outcomes (Swinton and Mowatt 2006, 69).

[27] Further detail on the selection process, the participants and the interview process can be found in appendix 1.

In exploring the history, life events and beliefs of these women, life stories emerged as an unanticipated but particularly useful tool in revealing their 'situatedness'; offering a depth and context to their observations which perhaps would have been difficult to ascertain through other forms of interview. The detail afforded by this method has made life story interviews a particularly attractive tool in feminist and womanist theory. Susan Geiger asserts that the sharing of women's life stories 'must constitute our most critical and complex data' about the social experience of women (1986, 335). Avowing that it is not enough to include women's issues in 'the scholarly agenda', she stresses that women must be included in the production of such knowledge. Peter Atkinson observes that in contrast to other forms of interview, life story interviews enhance the agency the interviewee has in the production of knowledge (1998, 8). The central themes which emerge in life story interviews are thus not in response to a given set of questions but rather unfold in accordance with what the interviewee themselves consider to be significant to their own lives. Atkinson furthers,

> In a life story interview, the interviewee is a storyteller, the narrator of the story being told, whereas the interviewer is a guide…the two together are collaborators, composing and constructing a story the teller can be pleased with (1998, 9).

Through our conversations, these mothers shared their separate and distinct experiences of the challenges and complexities of mothering children of varying ages and genders on the spectrum. Although we were each very different women with very different lives, many of our experiences echoed with each other's, affirming my observation that despite the multi-valency of characteristics associated with autism, there are many characteristics of the mothering experience which can be seen to be shared across temporal, social, and cultural contexts. The process of collating different voices and allowing different perspectives to shine through, Isasi-Díaz asserts, allows an organic and authentic revealing of connections, 'creating a tapestry in which one can see the similarity of experiences much more than dissimilar experiences' (2004a, 142).

American practical theologian Mary Moschella, considering the therapeutic potential of sharing life narratives, observes that 'the opportunity to speak out loud, hearing one's own voice and being asked for one's own judgement, is an empowering experience' (2018, 373). It soon became clear that choosing to take part in this research process was not merely an altruistic gesture by my participants to assist me in the production of research by sharing common experience; but rather was an active, resistive and liberatory process of engagement

with issues which strongly shaped their lived experiences in ways they had previously been unable to share. The liberatory potential of sharing narratives, however, is one which requires a critical and thoughtful theological response:

> If listening to narratives is to become 'an act of resistance' or an act of community and solidarity, practical theologians must do the difficult work of reflecting theologically upon others' narratives without co-opting them, without writing over them, sanitizing and homogenizing them (Wolfteich 2017, 133).

In an ethnographic research process, the researcher must resist the temptation to generalise or universalise participant experiences in the aim of demonstrating specificity (Isasi-Díaz 2004, 84). Thus, the task of representing another's worldview or experience brings with it an enormous amount of responsibility. Who has the authority to speak on behalf of someone else, and how this authority is used (or abused) is a potential minefield of ethical considerations. As this research is looking at potentially difficult and painful experiences of mothering, from women who share a relationship with a vulnerable group (children with autism), there were many significant ethical challenges which had to be addressed. I was keenly aware that the sharing of personal, painful experiences may trigger negative emotions in my participants. There is an inherent stigma attached to sharing views of motherhood which do not conform to rose tinted stereotypes (Wolfteich 2017, 8); thus, how their narratives would be perceived by those close to my participants or the wider public, and the potential risk of distress or embarrassment to their children was a significant concern.

In being mindful of these issues, I considered the nature of what my participants consented to share as something which was dialogical, ongoing and changeable throughout the research (Olassen 2005, 236). My participants' consent was regarded as fluid and able to be withdrawn at any time throughout the research process (although no such withdrawals occurred). Given the sensitivity and relationality of this issue, an extensive ethical review process was undertaken to ensure that my writing process did not become one of colonisation, and that considerations of my participants well-being were situated as imperative to the research process. During this process, I established that:

- assessments of my participants vulnerability had been made during the selection process.
- my research aims, methods and intended presentation were made clear and transparent to my participants.

- pre-existing supports were identified and encouraged, and information for obtaining independent support was provided.
- issues of confidentiality had been addressed by offering full anonymity for both participants and those they referenced in their interviews by way of pseudonyms. (See appendices 2-5)

In undertaking this research, I sought to establish an interview process in which the stories of others emerged as organically as possible, and not in accordance with any pre-conceived agenda or intended research outcomes to mitigate my participants anxiety as to what was shared, and how. However, even the practice of 'letting participants speak for themselves' can have significant methodological limitations (Mazzei 2012, 745). Individuals bring with them their own interpretative frameworks through which they understand and make sense of their experiences. Whilst life story interviews are considered better placed to reveal these, the contexts of a person's experience are not always easy to reach. Drawing on Spivak's work on subaltern groups (1989), Kwok Pui Lan questions the role of researcher in 'the constructing of subjectivity of subaltern women, the representation of their voices by intellectuals, and the social conditions which enable these voices to be heard' (2011, 20).

Critiquing the romanticising of 'voice' in qualitative inquiry as something which is presented as authentic, stable, fixed and true, Mazzei challenges the simplistic reduction of 'complicated and conflicting voices to analytical 'chunks' that can be interpreted free of context and circumstance' (2012, 745). While we interrogate our own epistemological standpoint through reflexive engagement with the research process, we must also consider that our participants' epistemology is similarly not singular or fixed but constructed around their own multiple axes of gender, class, and social location. Such an approach acknowledges the relationality and complexity of our experiences, and a recognition that we cannot interrogate our own sites of epistemic privilege without acknowledging their relationality to other's epistemological standpoints (Goto 2018, 22). In this respect, I consider this research to be relational, dialogical, and transformative; recognising that the experiences of others may in fact challenge or subvert the meanings and understandings I attribute to my own experiences, and on the insights I expected to find.

Indeed, our stories emerged as mutually resistant to the archetypal pattern of 'beginning, muddle, and resolution' previously described (Atkinson 1998, 9) (Walton 2018, 2). In a very real sense, the women I spoke to were 'in the midst' of their particular experience. As I have

highlighted in chapters two and three, autism is problematic precisely because it does not appear to have a 'beginning', nor can it be seen to have an 'end'; but rather is surreptitious, unpredictable, and evolving. In contrast to memoir, life story interviews are accounts which can arguably be described as 'unfinished;' they offer reflection on issues which are current and ongoing. In the context of this research, life story interviews allowed real-time access into the 'everydayness' of this particular lived experience, yet also spoke to the unsettled and unresolved nature of autism as an ongoing and evolving condition. The unexpected evolution of the interview process also affirmed the fragmentary and disruptive power of life stories in challenging our theological thinking in unexpected ways (Walton 2014, 162).

4.5) Summary

In this chapter I have situated practical theology as a knowledge making system which is similarly relational and dialogical, identifying its creative ability to traverse the boundaries between theory and practice and engage in more fluid and diverse forms of knowing. I have considered the disciplinary challenges inherent in producing new forms of theological thinking which do not neatly fit within traditionally accepted paradigms of knowledge. Attentive to these conflicts, I have presented my methodology as informed by feminist phenomenological perspectives which recognise lived experience as embodied, experiential, and deeply revelatory.

Drawing together three distinct forms of life stories (autoethnography, memoir, and life story interview), the following two chapters will examine the shared motifs which emerged from our life stories as particularly significant to the lived experience of mothering a child with autism, developing these thematically to offer insight into the everyday realities of this maternal experience. Through the sharing of our stories, I intend to highlight the revelatory potential of maternal experiences which are complex, ambiguous, and which have hither-to-now been occluded from theological reflection.

Chapter 5) Reading Mother's lives: Uncertainty, Diagnosis, and Stigma.

Uncertainty

I tried to remember a time before. It had not always been this way, had it? It was in his last year of nursery that it all began, wasn't it? …Wasn't it? I tried to retrace our steps, all the while painting over the sleepless nights, the furious tantrums, with the rosy tint of denial. Yet those little moments stubbornly refused to be painted over and began to take on new vividness, new meanings, under my now critical gaze.

I remembered he had just turned one, and suddenly refused to wear the red dungarees I so loved him in. Every time I buckled the straps, he furiously tore them off, standing indignantly in his nappy shaking his head. At the time, I found his stubbornness amusing. He knew what he liked. I took pride in what I perceived to be his maturing personality; he was choosing his style. Looking back now, it was the beginning of a slow, insidious, and seemingly arbitrary rejection of anything he did not like the feel, colour, or fit of. By the time he was two, he could tolerate only a handful of items of clothing; those which he would tolerate he could not bear to grow out of and would continue to wear even after they had long since stopped fitting.

I remember one morning drinking coffee with his aunt, my childhood friend. She was my sister formed without blood, and she lived with us in his first few years. Micah was playing contentedly on the floor with his toy cars, lost in his own world. He was always content with him own company, he rarely demanded attention for the sake of attention. She was watching him, but her gaze had an intentness beyond the pride of a loving aunt. She quietly observed as he pulled his cars out of the box and lined them carefully and studiously up by colour in a row. He would put them all back, and then repeat the process again and again.

'He knows his colours,' I said brightly, if a little uncertainly. Something was wrong. She was unreachable in that moment. I could sense that something had shifted in her perception, but I didn't know what. 'He doesn't drive his cars,' she said softly. It was true. He didn't zoom his cars around the floor, simulating crashes or using the chairs as tunnels as her brother had done. The eldest of five siblings, she knew babies. Was he different from the babies she had nurtured before? We have never spoken about it. Looking back, I wondered if in that moment, she knew. It was to be many years from that moment before any of us would have an answer.

As I have sought to articulate in chapters two and three, autism is a condition which is characterised by ambiguity and uncertainty. Consequently, it is not a condition which is apparent at birth, or presents itself overnight, but rather often appears as a series of little irregularities during early development. Sometimes these may be very slight, innocuous even. Different enough to notice, however not quite so different to cause panic. These inconsistencies build up, gradually, however, into a picture of difference which can no longer be ignored. For this reason, I have situated the pre-diagnosis experience of parents as often one which is marked by doubt, uncertainty, and fear.

In 'Love is not Enough; A Mother's memoir of autism, madness, and hope' Jenny Lexhed, a first-time mother, shared her nagging dread that her son was different from his peers:

> Increasingly, I understand that that Lucas is not like other children. He has always been different…but now the differences are beginning to be so big that they're noticeable. Somewhere in the back of my mind: the word 'autism' is spinning … but I don't want to believe it's as serious, as terrible as autism (2008, 17).

Lexhed's account highlights the excruciating uncertainty of being at once aware that something is awry, and at the same time trapped in the uncertain limbo between concern, and diagnosis. For the women who have chosen to share their stories, myself included, our spectrum children were given to us as first-time mothers. Without a frame of reference or a context for appropriate development, the difficulty in reconciling gut feeling with action is a significant one. Despite subtle indications that development was not what it should be, the research examined in chapter three reflects that the doubt of having no comparison often outweighs the compulsion to seek external advice. Clara Claiborne-Park, writing of her journey with her autistic daughter 'Elly', describes the challenge of observing the differences presented by daughter in comparison to her other three 'beautifully normal' children. Her frame of reference would make each failed milestone all the more obvious, and all the more jarring in comparison to her siblings:

> So Elly grew, and though we look back and remember one incident or another, the onset of the condition was imperceptible. We perceived we had a child who, at twenty-two months, was not toilet trained- but neither were most of our neighbour's children. She did not walk, but the little boy down the street had sat contentedly in his play pen until he was two…She spoke only a few words- but the onset of speech in children is notoriously variable, and every parent of a slow talker is aware that

Einstein didn't talk until he was four. The various signs that now seem so clear then seemed easily attributable to individual differences (1995, 23).

These attempts to reconcile her daughter's difference reassured her, for a brief while at least, that her daughter too would 'catch up' despite all evidence to the contrary. She writes, poignantly, on her attempts to deceive herself that everything would be 'just fine'; 'She would grow and take her place in a family lovelier than anybody else's…' (1995, 29). However, as each milestone continued to pass without any indication that it was likely to be achieved, Claiborne-Park painfully admits to herself that her dreams of Elly catching up to her thriving siblings would not be realised:

> It is possible to learn humility…A year later, Elly would be examined again, in a bigger hospital with more refined techniques. And this time I would wait at night and hope and nearly pray that they would find a physical deficiency-something that could be controlled with a diet or a pill. And then my baby's perfect health would be a heartbreak to me and no source of pride (Claiborne-Park 1995, 29).

Despite the research indicating mothers are likely to experience an underlying anxiety, and to some extent dread, of receiving a diagnosis, our stories reflected that there is also significant anxiety that one will NOT be received and you will remain in the dark, unable to obtain answers for your child's behaviour. At my own son's diagnostic assessment, I remember vividly not knowing what outcome to pray for. Speaking with Naomi*, mother to an 11 year-old boy with ASD and other co-morbidities, she echoed Clairborne-Park's fear of being undiagnosed,

> You start doubting yourself. Before he was diagnosed, I thought no, maybe there's nothing wrong with him, there's definitely nothing…and then you think why am I doubting myself, you know there's something wrong. There's so much back and forth… and then I thought no, there is there's definitely something underlying. You always get that fear that they'll turn around and say there's nothing wrong and then you won't know.

I was equally afraid that we would have no explanation as I was of receiving a diagnosis; that the violence and rigidity and the tears we had grown accustomed to were nothing more than my son being inherently 'a bad boy'. His behaviours were increasingly erratic, unpredictable, and challenging both at home and at school. Pre-diagnosis, my crippling fear that my son was bad at best, 'crazy' at worst, led autism to be something which was a much less frightening

alternative. Often, as my participants describe, the judgement and stigma experienced by parents attempting to unravel their children's complex symptomology creates an unusual paradox in which a diagnosis is both a blow and a relief.

Diagnosis: A Spectrum of emotions

'During the first term of this academic year Micah appeared quite settled; his behaviour was not as challenging as it was to become…'

> *'disruptive'*
>
> *'shouting out, hitting and kicking others and spinning around'*
>
> *'extreme anxiety'*
>
> *'exhausted and overwhelmed'*
>
> *'unable to be contained.'*

These words were not unfamiliar to me. They were forever inked onto my thoughts in tears. The term 'Challenging behaviour' was a very clean and concise phrasing of a reality which was anything but. Our days were uncertain, unsettled, unexpected. There, on the page, was the reality that I was too afraid to speak out loud. If I didn't name those things…If I didn't speak them…it wasn't really that bad, was it? He isn't really bad, is he?

Being confronted with those words, in black and white, was a jarring assault on my carefully constructed denial. The last two lines of this report, written by an outreach worker drafted in to untangle the complex knots of behaviour my son had been exhibiting, would pull me out of the deep depths of confusion and despair I had been submerged in, whilst simultaneously setting me on an unfamiliar road, in the dark, without so much as a map or a torch to guide me.

> *'Having observed Micah over a period of 4 weeks these behaviours appear to be consistent with those described as a 'meltdown' in children with an Autistic Spectrum Disorder.' (Date of Report; April 2014).*

These last lines I read with an almost exuberant sense of relief. There was a reason, a tangible, medical reason for my son's inexplicable behaviour. It was not my fault. Someone

would help us. They would know what to do. Of course, as is so often the case in the complex narratives of an autism diagnosis, it was not that simple.

This remarkable woman, though insightful, was not a doctor. She was not qualified to make such a diagnosis. It was at once given, and at the same time swiftly taken away. I was firmly reminded that,

> *'There is a process to these things. He will need to be fully assessed by a team of multi-agency professionals to establish the veracity of this claim. This may take some time. Until such a point that a diagnosis can be given, we must continue as we are.'*

Continue as we are. So innocuous, those words. They evoke stability, sameness. Routine. The mundane. There was nothing mundane about our routine. Our routine had become a daily battle to even leave the house, it had become tears and anger and violence, daily phone calls from teaching staff who were as perplexed by his unpredictability as I was. How could we continue like this?

It was to be 14 months after this well-meaning report, that we would finally receive a diagnosis. Naomi described her son's diagnostic process as taking 18 months. The research explored in chapter three indicates that this is a far from uncommon experience. Amongst our accounts, and throughout the literature, it is clear that it is extremely common for parents to be referred from one professional to another, to still another, in the attempt to obtain a diagnosis. Sansoti et al noted that 'such a circuitous, redundant undertaking likely is frustrating and may contribute to feelings of uncertainty about the information received and which direction to take' (2012, 81). Whilst research consistently reports prolonged delays between reporting concerns and receiving a diagnosis, very little is said about the oscillation of emotions which occurs during this process. In sharing her own diagnostic journey, Naomi highlighted a peculiar bi-product of this prolonged waiting period; that the frustration and anxiety provoked by such delays may become internalised, leaving mothers questioning whether in fact it is they who have not done enough, or in time;

> Autism didn't even cross my mind to be honest, we just thought he was behind. I feel…not regret because the outcome wouldn't have been any different, but I feel like I should have picked up on it and I should have picked it up sooner.

She was not alone in struggling with the benefit of hindsight. Despite retrospectively being able to detail in surprising and nuanced detail the early indications of their children's autism,

the women I spoke to all expressed regret to some extent that they were unable to identify or act on the signs earlier. Such feelings of regret could also be seen to run heavily through the biographical accounts of Lexhed and Clairborne-Park, who questioned their own effectiveness in advocating strongly enough for their child's diagnosis.

Lexhed writes candidly, and often painfully, about her emotional journey during the diagnostic process. She describes her sorrow for the loss of all the experiences she fears her son may never have, and the helplessness of being unable to understand or to guide him in his self-imposed isolation from the world. So severe was Lexhed's emotional strain during this period that she was in fact placed under psychiatric restraint, hospitalised for several months before she was able to return to the challenges of caring for her son:

> Sometimes during the day, I can't hold it back and my sorrow takes over. Like a hurricane, it blows the door wide open and blackest sorrow completely
>
> Rushes in
>
> Washes over me
>
> Drenches me. (Lexhed 2009, 37)

Naomi similarly expressed an acute sense of grief and fear following her son's diagnosis:

> I had set myself up for a diagnosis, but it didn't make it any easier when it came…it really doesn't. I felt like my whole world had collapsed. They say Aspergers, ADHD and Tourettes Syndrome…it was like a punch in the gut…I was scared…not scared…no, actually I was scared because I thought, how am I going to deal with this. It is life changing. I didn't realise just how life changing it was. You fear for their future…their whole future flashes before you …The sense of grief when you get the diagnosis is huge because it impacts everyone, even his grandparents.

I too, shared Naomi's fear and sadness. I remember going home to an empty house after receiving my son's diagnosis and being flooded with all the things I thought I knew about autism. Mutism, dependence, inability to form relationships…the worst-case scenarios of spectrum severity, none of which actually represented my son at 6 (nor do they now) flashed before me. I remember sitting on the stairs, unable to stop the tears, mourning the loss of all the things I thought that he would do, that we would do, that now seemed so impossible. He was what I was most proud of in my life: his intelligence, his sense of humour. But what

would become of him as an adult, if he was indeed autistic? Would he retain the qualities that I so cherished, or would they fade away under the weight of his condition? Naomi spoke of her sadness, not for herself, but for her son, in considering the reality that he may not be able to achieve 'normal' milestones in life like driving, marriage, children:

> And that's okay if they don't…it's just they won't experience life in the same way that we did. Life won't be simple for them. You just feel like he should be independent and go on holiday with his pals and me not be worried sick about him. Not be able to go to mainstream…I feel so much guilt about that because he won't be able to go with his friends who he's so attached to. And that's another hurdle we're going to have to get over because it's a major change again….and then you've got puberty…as a family how do we deal with that?

Whilst current research into the emotional journey of parents assumes that 'grief' will be an expected but temporary outcome of diagnosis, Naomi's reflection highlights that in fact feelings of grief can be seen to be cyclical, with 'fresh griefs' often recurring years after diagnosis. Naomi's story strongly resonated with my own experience, reminding me of a sudden and unexpected recurrence of grief during a recent multi-agency review of my son's progress. I had entered that particular meeting armed with discussion points and evidence of my son's progress, which had been steadily improving. I held onto my belief that he would attend my former school, which I had experienced as a nurturing and supportive place. He would be fine. In sharing this belief with his review team, I was met with sympathetic, concerned faces. They gently reminded me that while he was indeed doing well, his progress was hard won, and a result of intensive one to one support that a mainstream high school would likely not be able to accommodate. While it was not set in stone, the possibility that he also may not be able to progress up to high school with his peers was a very real one.

I was blindsided. I thought he was doing well…we were doing well. And he was. So well, in fact, that I had allowed myself, not to forget, but to place his autism on the margins of our lives, rather than the centre. I had been deceiving myself that the tenuous equilibrium we had worked so hard to achieve was evidence that the battle was over. Slowly, insidiously, images of my teenage son had been invading my dreams… of laughing with his friends at the bus stop, worrying about girls, receiving an award at assembly. And in one sentence, that had again been ripped away. Again, I walked out of that meeting, arguably more grief stricken

than I had been the very first time. Hollow and devastated, that meeting was a reminder that things will perhaps never be how we had expected them to be.

To date, parental grief, when considered, is explored primarily in relation to terminal illness in children, sudden loss of a child, or issues concerning infertility and miscarriage. Emerging research is beginning to identify complex grief present in parent- carers of non-terminal children with conditions such as epilepsy and schizophrenia, although this research is still in its infancy (Eakes 2009) (Whittingham et al. 2012) (Brown, 2016). In contrast to the literature which suggests feelings of grief are a response to diagnosis, our stories indicate that in fact grief is more strongly related to expected 'milestones', which are continual throughout a person's life. In a study by Fernandez et al, it was observed that parents displayed an oscillation of coping mechanisms between 'loss' and 'restoration' following a diagnosis which were consistent with the 'Dual Process' model of grieving. They observed that parents were continuously adapting to the 'losses' associated with their child's development, whilst actively concentrating on daily tasks of understanding how to best support their child (2013, 319). In contrast to traditional staged process models of grieving which assume a linear path to a restorative outcome, Stroebe and Schutz make clear that in the context of their model:

> ''restoration'' does not refer to an outcome variable, but to secondary sources of, and coping with, stress...this analysis is focusing on what needs to be dealt with (e.g., social loneliness) and how it is dealt with (e.g., by avoiding solitariness), and not with the result of this process (e.g., restored well-being and social reintegration) (1999, 214).

Research by Brown et al support this finding, proposing that what is unique to parental grief in respect to childhood disabilities is the continuousness of it. She observes that over time, there are recurrent reminders that life will, undoubtedly, be more difficult for your child than it was for you and that this is a constant process of adaptation and adjustment (2016, 119). Our accounts reinforce the cyclical, ever- shifting, and unresolved nature of autism, highlighting that our emotional journeys are also similarly circuitous, conflicting, and not so easily resolved.

For Abigail, mother to both a son and daughter on the autism spectrum, the source of her grief was not her daughter's Aspergers, nor the fear that she may not reach independence as an adult. Rather, she experienced a very acute and anticipatory grief over her concerns that her daughter may not reach adulthood at all. In the chapter three, I touched briefly upon

violent and self-injurious behaviour being a symptom of autism, however the prevalence and significance of this for both individuals on the spectrum and their families is perhaps considerably underreported. My son, during his most challenging years, was particularly violent, most frequently towards me. I had been punched, slapped…bitten. At a particularly low moment, I admitted to a friend that it was almost like being in an abusive relationship that you could never leave. These periods were profoundly traumatic.

However, they paled in comparison to the periods when such aggression was turned towards himself. I remember sitting in A&E with my son, at around age 8, who had begun to smash his head against the wall repeatedly following the death of my mother. After days of this, and days of him furiously sobbing that he no longer wanted to live, I didn't know what else to do. He was thankfully unhurt, not concussed or bearing any physical damage. Due to his young age, the doctor, although well-meaning, dismissed the seriousness of my concern. I understood. What 8-year-old is serious about ending their life, one might ask? But yet, the nagging doubt that perhaps he might, was utterly, bone chillingly, terrifying. Abigail spoke of a particularly distressing encounter with her own daughter:

> There was one night I was bringing her home, I can't remember after what or what happened, but whatever happened she wasn't happy about what was said in the car and when we got home, she stormed up the stairs and said 'I won't be here in the morning,' and shut the door. We had to bust the door in…Children on the spectrum struggle to vocalise their emotions at the best of times, so asking her if she's going to be there in the morning…she's sitting there saying, I don't know. So we then had to take her to hospital, and we sat there till 4am to be told, well if we admit her it won't have a good outcome so the best thing you can do is take her home and sleep with her until morning. And you really feel at a loss. You really do. You really feel at an absolute loss. It's so hard.

Naomi shared that she had to move from a flat to a house because her anxiety of her son's suicidal threats was so acute:

> And I said something has to give because we were in a flat before, and he used to threaten to jump out the window. It was soul destroying. I couldn't sleep in case I woke up and he was gone.

Whilst the other women spoke of their efforts to keep their children safe, Naomi's fears in relation to her son's safety was so severe that it had actual, material consequences for the

family. To move home is a significant upheaval, and to do so in response to a perceived threat of safety to your child highlights the seriousness of the distress she experienced. Scarlet became particularly distressed when discussing her fears for her daughter's future well-being, and her anxiety over potentially being unable to protect her from herself:

> For better or worse, I do remember being inside my head as a child, so I try to be the person I would have wanted. But it's depressing, frustrating…really seriously upsetting. And despite all of that, she still hurts herself. It's difficult seeing her go through it and not being able to help. Maybe I am helping, maybe it would have been worse, and she'd have gone through with her plans if I hadn't tried...you just want to be able to find a way to help her. And sometimes on a bad day, you feel like there just isn't. You feel helpless.

Her choice of language is powerfully emotive ('depressing', 'helpless') and powerfully conveys how all-consuming and distressing this particular lived experience is for mothers. The thought of losing a child is unthinkable, but to have your own child threaten to take themselves away is a viscerally distressing experience. In contrast to anticipatory grief often researched in respect to palliative care, which, although not defined, has an expected end point; the anticipatory grief that mother's experience in relation to their children's self-harm is often continuous and unremitting. To my present knowledge, to date there is no study which explores the unique and complex relationship between self-harm and parental anticipatory grief, much less within the context of autism. For the mothers I spoke with, this issue emerged as a considerable source of grief and challenge in their mothering journey, and would warrant further, more in-depth study.

Stigma

He would not put his shoes on. He couldn't tell me why, other than that they were 'terrible.' As were the boots, the sandshoes, and in desperation, the trainers I attempted to wrestle him into. He would not wear shoes, EVER, he told me. His anger was sudden and disproportionate. We sat on the stairs, at an impasse; him, furious, me utterly bewildered. Eventually, I steeled myself. 'I am your mother, and you MUST go to school.'

He was only five. The shoe issue had arisen suddenly and unexpectedly. In those first days, I had spoken to him softly, reassuringly, attempting to distract him with tales of all the fun he would have at school once he arrived. When it became clear that my reassurances were

mistrusted, I tried games. Putting his shoes first on his teddies, then on our dog (this elicited a brief and bewildered repose from his rage), then, lastly, and unsuccessfully, on him. We had bought new shoes, with dinosaurs (his obsession) and flashing lights. While he appreciated these in the store, in abstract, he most certainly did not appreciate them in the context of his own feet. Day after day, he roared in fury. He threw things. He banged his head repeatedly on the floor. He sobbed, disconsolate. I tried everything.

Eventually, arduously, I managed to wrangle him into a pair of shoes, sweating, exhausted by the effort. While he clung to the banister, howling in rage, I repeated this mantra to myself 'You MUST got to school.' That's what good mothers did. They got their children dressed and they took them to school. I gripped his tiny hand and forced us through the door. We were fortunate enough to live only a few minute's walk from school. It's only along the street. We were out of the house, that was always the hardest part. We would make it.

Immediately, he flung himself to the ground, anchoring his tiny body to the spot, and screamed. In panic, painfully aware of the stream of other parents and children we would soon join, I scooped him up, his body contorting and twisting in anger. I staggered resolutely onwards, trying desperately to ignore the onslaught of blows as he writhed furiously in my arms. The bell had long since rung, and mercifully, only a handful of parents remained on the street, their chatting quietening to shocked silence at our approach. We pushed forward. He kicked, he punched. He twisted fistfuls of hair. He bit. He spat. And still, we were not yet there. Then one furious punch brought a turret of blood from my nose, the next tearing the flesh of my lip in two. I stopped, frozen. He froze, too, the sight of my blood jolting him out of his rage and dissolving him into complete devastation.

I sat down on the ground, enveloping his now sobbing limbs in mine. I held him, and I rocked him, tears streaming silently down my face. 'It's ok', I shushed. 'I'm okay, you're okay. We're okay.' Over and over. I rocked him. I don't know how long we sat there like that, he and I. I lost all awareness of the silent stares of the other parents; at some point they had abandoned our spectacle and returned to their day. By the time his sobs had quietened, and his body stilled, the street was empty. I lifted him to his feet, clutching his hand and walked finally, brokenly, to the school office.

The door opened and the secretary looked up from her desk. Her mouth fell open. She disappeared through a door. I looked up, staring at our reflection in the glass doors. My hair was a tangled nest, my face filthy and streaked with blood and tears. My son was ashen,

hollow eyed, exhausted. We stood there, broken, shattered by trauma. A minute later, she reappeared, teacher in tow. The teacher, though visibly alarmed, looked at us with a mixture of sympathy and concern. We stared back, unable to speak.

'Oh dear,' she said. 'I think mum needs a cup of tea.' She turned to the secretary, 'Can you take Micah to wash his face please?'

His little hand tightened on mine, and my mouth opened to protest.

'He is okay. Right now, you're the one who needs to be looked after. Come with me.'

I nodded, still unable to speak. My stubborn attempts to conceal my private struggle had been laid bare. There was no hiding anymore.

In chapter three I have identified that although autism does not have any outward physical markers, it is very difficult for individuals on the spectrum to 'conceal' their behaviour. Thus, we have individuals with 'normal' appearances who are behaving 'abnormally'. This may be arguably more stigmatising for individuals on the spectrum, who may face doubt as to the validity of their condition by virtue of their appearance. The reflection I have articulated above was sadly not an isolated incident but was to become a routine part of our morning for many, many months. What also became routine were the gazes of others who witnessed our daily battle, gazes which were a spectrum of shock, pity, and judgement. As recently as a few weeks ago, a neighbour of mine remarking on how much my son has grown, commented; 'I remember when you used to have to carry to him to school, you'll not be doing that now… What a hard time he used to give you.'

It was well-intended, but this encounter reminded me that whilst mercifully it has been many years since I have had to carry him to school, other's memories of that time, and their perceptions of us both, remain. Naomi described an encounter with another mother at the school gates:

> I even had one mum say to me I would love your life; you just swan about and do what you do and I'm like really? You have no idea that I haven't slept for two days and he's running out of school, sitting for two hours in the boot of a car trying to talk him into school.

> It's the hiddenness of autism that's difficult…the way he acts sometimes in public...I just let him get on with it, but you do feel people staring.

The characteristics associated with early indication of autism are often behavioural, and therefore often stigmatised as merely symptomatic of poor parenting. Consequently, individuals of children presenting such behaviours are very often considered to be 'bad parents' of 'bad children.' Scarlet felt strongly that the behaviours associated with her daughter were often inextricably linked by others to her own perceived failing's as a mother; 'Bad parenting,' she commented. 'I still get 'done' with bad parenting.' I expressed to Naomi my own reluctance to engage with other parents at the school gates or admit to staff that we were struggling, certain that what they had witnessed would be a cause for judgement. All of us were able to reflect on incidents in which we were ostracised or excluded from some form of social situation: birthday parties, school discos, after school clubs. Sometimes the stigma was covert, concealed by 'forgotten invitations', however it was sometimes also overt; being asked to 'deal with' our child, asked to leave, or being openly remarked upon were sadly not uncommon situations.

I recently reflected in conversation with a family member about one particular Christmas, in which an extended family member attended with their new partner. I remember being anxious that the busyness and excitement of the holiday would overwhelm my son, and that he would not be able to cope. Christmas was always a challenging day for us, the over stimulation almost inevitably resulted in agitation, aggression, or exhaustion. To my surprise and delight, he was excited and eager to tell everyone about his presents. That year his special interest was geology, and so he received a collection of gem-stones and fossils that he was particularly keen to show off to his cousins. I was incredibly proud, and admittedly relieved, by the lovely memory he created for us all that day. I later learned that following our departure, the guest of my relative remarked 'What a strange child. What kind of nine-year-old wants a bunch of rocks for Christmas? He's very weird, isn't he?' Upon being told of my son's condition, she brusquely replied 'Well, that explains it. I knew he wasn't normal.'

I had been used to stigma at the school gates, in the supermarket, at play parks. After so many years, I was steeled to the stares of strangers. This particular judgement, in a place where we felt safe and loved, came as an unexpected blow; in part because I had been so proud of his ability to have, at least what I perceived to be, a 'normal' Christmas day for the first time. I was at once furious and devastated that she had taken this achievement away from him…But yet there remained the nagging doubt, had I merely been lying to myself about how others see him?

Stigma perception associated with autism is a particularly challenging issue as autism is, by nature, an 'invisible disability.' Thus, the social recognition or empathy potentially evoked by a visible disability does not occur. In the case of our Christmas guest, she expected my son's behaviour to match his appearance, a 9-year-old boy she presumed would be into cars or football. For both Clairborne-Park and Lexhed, the schism between 'normal' appearance and 'abnormal' behaviour tainted both their own perceptions, and how they felt they would be perceived by others:

> For Carl and me, autism has a stigma. It feels abstract, scary, and awful. We didn't know much about it, and we have preconceived notions—that autistics are mentally retarded people who cannot speak, and sit and rock in a corner, doomed to live in their own isolated world. That was what we envisioned when we first heard the word 'autism' (Lexhed, 2008, 49).

Clara-Claiborne Park admitted her own terror that others may look at her daughter with barely concealed horror as a consequence of her habit of mumbling:

> Because there can't be mumbles. There mustn't be. I remember the middle-aged woman I encountered in a bus station, mumbling under her breath to nobody at all — the frisson I felt, of pity but also fear. Jessy was still young; my imagination leapt ahead. Would she be like that, grown too old to be charming, still mumbling? If I felt fear, what could I expect from others? (2001, 60)

Whilst the research examined in chapter three suggests stigma can be seen to correlate with more challenging behaviours; even 'passive' autistic characteristics, such as stimming, rocking, humming, or in my son's case, unusual interests, can be shown to attract negative attention (Lawson, 2008). Abigail reflected that the even the resources and tools she employed to manage her children's anxiety so that meltdowns were less frequent, for example ear defenders, Theraputty and other stimulatory toys, also attracted negative attention.

For the most part, the mothers I spoke with reflected they dealt with stigma by developing a 'thick skin' to the stares of others, steeling themselves to judgement. At other times, stigma was actively resisted by challenging negative attitudes, and attempting to educate others on our children's condition. Shortly after my son's diagnosis, I remember buying small cards which described autism so that I could provide those to people who showed strong reactions to his behaviour. Abigail observed that 'sunflower' lanyards were particularly helpful for her

children in subtly indicating to others that they had an invisible condition. Naomi commented that for her, providing others with the knowledge demanded greater sensitivity from them:

> I'm more vocal since his diagnosis…I have no shame in telling someone that he does have Aspergers or if he's going somewhere he does need to have an adult because he does need one to one support. We don't have to tell people why, but I think no, why should we pretend that he doesn't. I'm a believer that if the children are aware of what he's got and they understand, then if they put him in a situation where he has a meltdown, they're complicit in that and they can't get away with it. I don't let people put him in that position easily.

Scarlet and Abigail both noted however, that education does not always correlate to greater understanding. Both described engagements with health care professionals who, despite being assumed to 'know better', displayed the very attitudes they were expected to dispel. Describing her daughter's diagnostic process, Abigail commented that one particular professional remarked:

> 'She's just doing this to wind her mother up…If she has autism, I'll eat my hat.'

Scarlet reflected on a similar conversation with her daughter's Educational Psychologist,

> She said, 'I'm begging you please not to label her, if you push for a diagnosis she'll be held back and stigmatised in school and she's so clever…if you do this you'll cause her to miss out.'

> And I thought you're a professional! In my head I'm thinking I've worked with a lot of special needs children, and it really upsets me when people look at it as a stigma and a label. The only reason it could be is that people make it that way.

These reflections suggest that an inherent difficulty for mothers is that they not only experience stigma socially, but also institutionally: which has significantly more far reaching consequences in respect to diagnosis and support. Scarlet raises a particularly intriguing issue; that stigma can often be a self-fulfilling prophecy. She questioned whether the professional in her daughter's case was in fact perpetuating stigma by the mere fact of anticipating it. Burack et al raised similar queries in respect to the reciprocity which takes place in the context of autism. He suggests that by their very differences, persons with autism produce different social responses in others, thus inadvertently shaping their social experience:

…children with autism, therefore, experience a distinctly different social world than that experienced by other children from a very early age, as their unusual behaviour affords different sorts of interactions from those that other children usually experience. Not only do they experience or understand the world differently from other children, their world really is different from that of other children, simply because they are in it. (2001, 27)

Summary

In chapter three, it was anticipated that the delay in achieving diagnosis and the diagnosis itself would have a profound impact on the mental health of mothers. Whilst our accounts reflect these are indeed significantly challenging factors, it is clear that the diagnostic process, and the eventual diagnosis itself, are much more complex emotional processes than the literature suggests. Our accounts highlighted that the prolonged diagnostic period associated with autism generates a peculiar kind of medical authority on the lives of autistic individuals and their families; rather than a source of support, medical professionals often appeared as a gateway to obtaining social legitimacy for what is otherwise a considerably socially stigmatised experience. Rather than an advantageous ability to conceal, the invisibility of autism presents a particular challenge for traditional discourses of normativity. Individuals with autism appear 'normal', and yet their behaviours often present contradictions to normative expectations of the able-bodied. As our stories have reflected, this leaves both individuals with autism themselves, and us as mothers, open to particularly hurtful and stigmatising attitudes of others.

 In contrast to research which anticipated 'grief' to be the primary reaction to diagnosis, our accounts reflected that in many ways a diagnosis came as a relief to the uncertainty, self-doubt and judgement of pre-diagnosis. In reality, our experiences of grief, whilst significant, were fluctuating, periodic, and responsive to particular situational challenges. For mothers experiencing very real challenges to their children's mortality as a consequence of autism-related depression and anxiety, grief undoubtedly took on a very different and acute form. We lamented, were frustrated by, resisted against the lack of support, services, and understanding for our children, and for us.

These conflicts between symptomology, social attitudes, and social policy make the experience of autism itself, and the experience of mothering a child on the autism spectrum,

distinctly challenging. Whilst the literature often frames this phenomena as 'parental stress', each of us described a much more complex emotional journey than a narrative of 'stress' could adequately encompass. Thus, whilst many of the themes which emerged were consistent with the research examined in chapter three, there were many more experiences which could not be seen to be located within current research into the maternal experience of autism. In the chapter which follows, I will explore the realities of what has emerged from between the gaps in the research; articulating a distinct experience of maternal struggle, and resistance, which is currently occluded.

Chapter 6) A Mother's Struggle: Resistance or Resilience?

Everyday Struggles

The same room, a different year. A different Micah. This was our third multi-agency review, and perhaps the hardest one yet. In all of his previous meetings, referrals, and appointments, I had my mother by my side, his staunch defender; 'the Micah whisperer', I called her. She had left us 4 weeks earlier, finally succumbing to what had been a ferocious and determined battle with cancer. Before her passing, life with Micah had plateaued into a grinding, anxious, relentless struggle. All of the carefully negotiated strategies we had implemented at home, the stability of consistent routines, the ability to anticipate the next day's challenges by making sure the RIGHT jumper was clean…all of those had been thrown into disarray by the emergent necessity of my mother's palliative care. Gone were our Tuesday and Sunday night dinners, gone were his Friday sleepovers. Gone too was his mother, who was now shuffling hollowly through his days, struggling to maintain the façade that things were, or ever could be normal.

The door opened and a stranger burst in, visibly harassed. I don't remember much of the minutes before that, other than staring blankly at the table unable to meet the sympathy in the eyes sitting around me. This unexpected arrival cracked the defence of my numbness. 'Duty Social work. Apologies for the delay, Micah hasn't been re-allocated a social worker yet, so I was asked to attend at the last minute. Where are we at?' The stranger was keen to get straight to the point and avoid being late for his next appointment. The chair cleared her throat. 'Well, we didn't know you were attending…but it's very good of you to come. I'm not sure if you are aware but Eilidh has just experienced a significant bereavement, and a great loss of support to both her and Micah so it would be of benefit to them both to have some input from your department.' He nodded at her, turning to me. 'So, what can we do for you?'

'I….I don't know. We'd only just met a social worker, and she took Micah out to soft play so that I could look after mum or just get a break, she brought her dog to visit him when he was sad…we were just getting to know each other when she left so we so hadn't completed his needs assessment yet…' I pause, aware that he is expecting me to provide something, concrete, tangible for him to respond to. 'Our needs are… mornings are probably the hardest, he really struggles with dressing… and I'm missing a lot of work because he can't always manage the school day, I'm always being called away because he needs me…We had

a night once a week that my mum would take him, so that we both got some space from one another, and I could work or get some rest… I don't know what social work do…or can do but I just…we don't really have any support now.'

The stranger looked exasperated, abruptly shutting his notebook. 'I'm very sorry for your loss Miss Campbell. But if you don't actually know what you want, I'm really not sure how we can help you. It sounds to me, to be frank, like you need a babysitter. That's not something the local authority can provide. You have our number if you're really struggling but, in the mean time, perhaps it's best for us to withdraw until your needs become clearer.' With that, he excused himself, leaving a room of shocked expressions. It was to be 10 months before Micah was assigned another social worker. Months of desperately trying to soothe the grief of a child who doesn't understand what grief is, just that he is angry, and sad, and I am not his nanny.

Many of the issues which autistic individuals find challenging are often counterintuitive to the realities of social life, such as the need for routine and stability; along with other somewhat unpredictable challenges arising from sensory sensitivity to noise, busyness, strong smells. As such, the experience of predicting or pre-empting such challenges can be an all-consuming and often overwhelming task for parents of children on the spectrum. For my son, these anxieties often centred around dressing. This I came to regard with a degree of irony – of all the triggers we could potentially avoid, putting clothes on was not one of them. My son would only wear certain clothes; finding the right ones was an arduous process of trial and error, and once found they had to be bought in bulk, in various sizes, because his need for sameness was all consuming to him. His favourite things must always, always be carried in twos – for if one were to break, the consequences would be unthinkable. As a lone parent with a small baby, I had relied upon routines because it simply made things easier; as an older child, these routines became less convenient and more crucial to his well-being. Plans could not be deviated from, promises made must be promises kept.

In respect to impact to their personal lives, Both Claiborne-Park and Lexhed describe that the time demands of appointments, therapies and alternative education paths superseded their ability to maintain their careers. My son was unable to cope with organised childcare, or rather they were unable to cope with him, however I have been fortunate enough to largely be able to structure my job and studies around his schooling. That being said, every successful balance often comes as a consequence of sacrifice; my progression in both my academic and

working career has, in some respects, undoubtedly been impeded by my inability to commit to full time hours, attend conferences or be flexible in my schedule. Scarlet and Naomi both spoke of being unable to maintain their employment due to the frequency of appointments and high absences from school. Naomi reflected on the impact to her own life of her son's caring demands, citing exhaustion as being one of the biggest challenges to daily life:

> The lack of sleep. He doesn't sleep. That has a major impact, because it impacts school, it impacts my health because I don't sleep because he's not sleeping. He's okay, because he seems to get enough that he needs. But I'm constantly exhausted. And I have two other children. And a house to run and meals to cook and the meetings and dog walking and the meetings…everything you can imagine. It affects so many different parts.

> It's the same with taking his meds in the morning, he takes his meds with the same yoghurt every morning. But if someone else eats that yoghurt the whole day erupts. But it's their home too, so I can't tell the girls don't eat his yoghurts.

> I used to be so social…I used to play the piano. I thought I'd be a qualified nurse by now, but it hasn't worked out that way. But he comes first and that's the way it is. My feelings as a mother have never changed. I've never thought I'm not doing this anymore. I would never every give up on them.

Factors such as exhaustion and the additional demands of anticipatory planning emerged as significantly impacting our daily lives of mothers. Naomi gave the example of the seemingly unimportant number of yoghurts in the fridge. Whilst for many mothers, the matter of not having enough yoghurts could be considered a minor inconvenience, for mothers of children with autism, a simple yoghurt can be fraught with hidden meanings and far reaching implications that would seem impossible for anyone else to consider significant. Such narratives are often framed within the literature as 'care-giving demands' or 'disruptions to daily living.' Certainly, they are both. However what I consider significant about Naomi's particular reflection, is that it highlights that one of the significant challenges of autism is that the 'simple' is very rarely 'simple', the mundane is often interwoven with the complex, and tiny changes can result in profound impacts on how the day will transpire. Put simply, what is easy for others, can be a monumental struggle for us.

Nicholas et al found that among their respondents, parents described that, along with additional caring needs, they also had *anticipatory* caring requirements. Describing the

necessity of pre-empting potential triggers or difficulties with proactive and often ever-changing solutions, Nicholas et al note that autism was observed to be 'pervasive' in the thoughts, structures and routines of mothers:

> …unlike a job with delineated working hours and designated tasks, the roles of these mothers were described as broad-based and 'all encompassing,' and were thought to vastly exceed the demands associated with mothering a typically developing child. Participants described unending demands which required anticipatory planning for events in and out of the home, continual monitoring and adjustment, ongoing ingenuity and work in addressing the child's immediate and anticipated needs, and responding to challenges in proactive ways (2016, 926).

The pervasiveness of 'anticipatory planning' in my thoughts and routines is one which I have personally struggled with. I am not a natural planner. Organisation is something I enthusiastically attempt, only to abandon as everyday life gets in the way. In mothering a child with autism, you must not only be two steps ahead, but five. Once you learn to speak the complex language of all the anxieties your child may struggle with daily, which is in and of itself a long and often cyclical process, you then begin to pre-empt the myriad of potential triggers and situations which may derail their equilibrium. For my part, this was a considerable source of emotional disruption. Whilst some strategies could be relied upon to be consistent, I was regularly confounded by situations arising which circumvented my meticulous planning. When this occurred, it was often dispiriting and overwhelming, leaving me feeling like a failure for being unable to anticipate every eventuality. The ceaselessness of anticipating the possible multiple meanings everyday objects or activities may have for Micah was profoundly exhausting.

I vividly remember during the challenging period articulated in my previous reflection watching other mothers at the school gates, wondering what they would consider a 'bad morning'…what would it be like, I wondered, for my child to simply get dressed in the morning? Smile and wave at me at the school gates? Sometimes, I would be able to laugh at the absurdity of how traumatic the loss of a particular sock could be for us; at other times, I would weep with something akin to bitter injustice that such simple things were never simple for us. In admitting this to Naomi, she revealed that she had witnessed my daily battle of the school run and had shared much of it herself with her own son. Rather than the judging stares I had feared, she was in fact there, understanding of my struggle and comforted that she was

not alone in hers. Later in our conversation she confessed that she too felt burdened by daily life,

Every day is a struggle. Mainly on me but Ryan* has the financial burden...nobody realises the financial burden. I genuinely think if he didn't work away and earn a good wage I don't know where we'd be...it's so hard because it feels like a constant battle, you're up and down to the school, you're taking it home, and then my husband and I were just bickering as well…which didn't help the situation at all. Other people would always say how smiley I was, but people had no idea.

I think I did have depression…at his worsts. I remember getting up battling with him to get to school, and just going back to my bed until three o'clock. And then feeling the shame and guilt of having not done anything all day, but I just lay and felt sorry for myself and cried…ate. And that's how I dealt with it. But I was very personal about it, I didn't talk to anyone about it. But I was really depressed for a long time.

For Scarlet, while her daughter's symptoms were in and of themselves a significant source of difficulty, her struggle was made harder by social attitudes and barriers to diagnosis which challenged and trivialised her experience:

So they tested her and in their words…and this is something that has been a source of frustration with me for some years with my daughter…as far as the professionals are concerned, they tested her on all these various academic areas, maths, literacy etc and she tested at the highest range for all these areas so therefore, in their words, there couldn't possibly be anything 'wrong with her'.

And I have an issue with that 'Nothing wrong with them'…because either way there's nothing 'wrong' with them, but just because someone excels academically doesn't mean they're not having these other issues, doesn't mean they're not crying themselves to sleep or having these other emotional issues… the doctors say there's nothing wrong with her and again it was really, really frustrating for me…

She was being excluded from school every other day, I was getting the phone call and having to come down, she'd be excluded for a week. I would have to work out the childcare because I was a working parent, as well I was also a single parent from when she was 5 years old. And I was banging my head against the wall trying to get somewhere.

Scarlet's narrative reinforces some of the particular challenges autism presents for those advocating for support and understanding for their lived experience. As we have discussed in previous chapters, the invisibility of autism, coupled with the fact that it is a condition which arguably presents itself most acutely in daily experiences such as sleeping, dressing, eating and social interactions makes it all too easy for others to challenge the veracity of the struggles faced because they are often concealed within the private sphere of the home. In the opening reflection to this chapter, I have described how difficult it is for mothers to articulate the challenges and struggles we face, particularly when the sources of such struggles are often rooted in daily trials considered to be too mundane, too banal, too inconsequential to justify such a designation, much less support.

Between the meeting I described, and our eventual re-allocation of a social worker, it was to be 10 months. During this time, I called, wrote, pleaded and ultimately berated our local authority to re-engage with us. Eventually, after the intervention of a local MSP, we received a re-allocation, a support worker, and a formal apology from the department. Whilst we eventually obtained the support that we so desperately needed, the balance of time spent advocating for my son, against time which could have been spent with him, weighed heavily on me. I was not alone in feeling that the attempts to advocate for support were often equally as stressful as the circumstances for which we needed support. Abigail discussed similar experiences of struggling against institutional barriers, facing many denials and refusals in the diagnostic process as a consequence of being dismissed as a mother merely overblowing the challenges of parenting:

> You doubt yourself. You do, you doubt yourself. To some extent I felt a failure. I'm letting her down. And to some extent I couldn't cope because her behaviour as a teenager really did get excessive…And in the midst of it, you've got a psychiatrist saying she's just doing it to wind her mother up. So as a mother you think what am I doing that's causing her to want to wind me up this much? So it's really, really hard.

> We've had a long fight…I'm probably not particularly well liked within the local authority because I had to push for my son to get into his school but I felt it was my duty to get him the outcome he deserved.

Scarlet repeatedly echoed this imagery of 'fighting', often describing herself as 'battling', 'being up against a brick wall' and 'banging her head against the wall.' The use of such metaphors illuminates that mothers of children with autism are often forced to undertake a

very different role to 'care giver'; they are often required to fight and advocate for their child's healthcare, education, and inclusion against a culture which does not take seriously their experience. We were just as, if not more, impacted by the responses to autism from employers, family members, schools and professionals as we were from our child's symptomology. In reflecting upon both my own and my participants experiences of struggle, they were at once rooted in the frustratingly unremarkable activities and routines of our everyday lives and yet also waged at a much larger social and institutional level.

Each of the women I spoke to discussed the strain of an ASD diagnosis on relationships, however for many it was rather family members or those in their wider social circle who struggled to come to terms with a positive diagnosis, often preferring to deny the reality of the situation to the detriment of their own relationship with the child. Scarlet discussed that not presenting as 'autistic enough' can often lead to other's raising doubt over her daughter's diagnosis, which can often feel like a lack of acceptance of who her daughter is and the struggles that they share:

> My siblings feel the same way, my ex-husband doesn't acknowledge that there's an issue. And people who have known her for her entire life...even other children on the autism spectrum can be the same.

Whilst Scarlet has been able to maintain relationships with those in her life who reject her daughter's diagnosis, this has often been the result of her developing a 'thick skin' to their opinions and abdicating her own right to turn to them for support. However, it is not always possible to maintain relationships in the face of such rejections. Abigail spoke about the painful reality of her parent's refusal to accept her daughter's Aspergers:

> It's torn my family apart. It's absolutely torn it apart. My son was somewhat easier to accept in some ways because so many of the signs were there so early. But my parents are quite old fashioned.

> So far as my daughter is concerned, my parents were absolutely determined she wasn't on the spectrum, and if I even considered putting her forward for an assessment they wanted nothing to do with me. So, our whole family was torn apart last year, because I wanted my daughter assessed, my daughter agreed to it, and my parents forbade me from doing it. My parents also owned the house that I lived in, so we became homeless, because they decided that if I wasn't going their way, I was

being cut off. That was the reality of it. They just can't accept my children's diagnosis at all.

For Abigail, her parent's denial was not merely a symptom of their processing of the new reality of their granddaughter's condition, but had very real, material consequences for the whole family. At a practical level, important sources of support are withdrawn leading to further stress and isolation for the parents; at an emotional level, such a schism within the family can be devastating for all involved and is often difficult to repair once broken. Kearney et al observe that,

> Whilst sorrow seems self-evident, a great deal of pain derives from societal values and beliefs mirrored in the words and behaviours of friends, family and professionals. In a better world, this pain could be avoided. On the other hand, existential pain and grief (Stephenson & Murphy 1986) cannot be avoided, as it cannot be ameliorated by education and attitudinal change (2001, 588).

Coping and Adaptation: Resistance or Resilience?

We will of course, have him apologise to you. We do recognise the withdrawal of support has had an impact on Micah, which is deeply regrettable. You'll be pleased to know we have considered a support package appropriate to Micah's level of need.'

By this time, I was emboldened by our struggles. Furious and indignant.

'That is wonderful to hear. And I appreciate the offer of apology, which I will of course accept. However, what you fail to grasp is not only the affect it has on us in the present, but the impact it will have on the future. This 'mistake' has withdrawn support which could have significantly impacted his life. We have lost 10 months of progress. I also notice you state 'Micah's need.' I'm not sure what you consider Micah's needs to be, however I assume from your choice of phrasing that my own do not factor?'

'Well…'she stuttered. 'It is Micah's support package. It's all about supporting him to be independent. We considered a respite allocation, but it was agreed that it would be of no significant benefit to Micah in terms of socialisation or inclusion in the community.'

'Forgive me,' I interject, 'But the sign above the door says, 'Family Support,' not 'Child support.' Am I incorrect in assuming that you are duty bound to support families as a whole, and not just the child who is the subject of referral?'

'Well…I mean…yes, we are…however you must understand that we are at the mercy of the public purse. Funding decisions have to be made on a needs basis and in the best interests of the child. We always have to look first at what support family and friends can provide in our stead and perhaps this has been under-utilised…'

I did understand. I appreciated her predicament. Working within a charitable organisation, the support I would like to offer is often tempered by the financial realities of what I am able to offer. That notwithstanding, I am also painfully aware of robbing Peter to pay Paul; cutting costs in support in the short term creates bigger social problems in the long term.

In the intervening 10 months, out of our struggles, I had learnt to be creative with Micah's needs. Some of our old routines could be reinstated, others could be tweaked in such a way that it was still acceptable to him. Our tribe had rallied around us. My partner introduced him to the martial art of Muay Thai, finding an outlet for his anger, quelling his aggression and forging a bond out of shared interest. To our eternal gratitude, his school had worked hard to support his inclusion, gradually increasing his participation and channelling his interests into the learning outcomes he needed to achieve. I enrolled him in swimming lessons, art classes. As a result of significant hard work was, he was mercifully, eventually, coping. However, this delicate, intricate balance required constant thought, anticipation and effort. Every success was paid for with exhaustion.

'With respect. What YOU need to understand is that what you are offering Micah, I have already provided. His material needs are met, he is healthy. He is loved. He is included. He attends mainstream extra-curricular activities, independent of me. He has friends. I have done all that. WE have already done all of that. My son is without grandmothers, my father is 83 years old. My friends are scattered across the city and work full time. My partner works full time and doesn't live with us because Micah needs the consistency of our routine. They cannot, though they may want to, take on our day to day struggles. What we need from you is a recognition that while we mothers are killing ourselves to meet their needs, and killing ourselves to hide the fact that it is killing us, there is no one meeting OUR needs.'

In the preceding sections, I have highlighted the significant adjustments and adaptations that families must undergo in order to ameliorate an autistic child's experience of the world. The importance of this stage, adaptation, is considered crucial to mother's ability to cope with the demands and expectations of their reality. Parents are often required to be creative, resourceful, flexible and resilient to the ever-changing and often circuitous needs of the child.

Claiborne-Park writes extensively on the myriad of strategies, tools and adjustments her family employed both to mitigate her daughter's anxiety, and also to attempt to glean tiny glimmers of progress in her development and independence. This she undertook, despite, as she writes above, steeling themselves against expectation:

> Minuscule, apparently empty victories nourished something in Elly and in us. In Elly, perhaps some frail sense of adequacy, in us the necessary hope that our daughter had some mind hidden away inside her speechless incomprehension. Not too much. Hope was something against which we had to defend ourselves. Only enough to mount the next assault (Clairborne-Park 2001, 50).

Echoing Claiborne-Park's assertion that optimism must be tempered with a heavy dose of realism, Naomi observed that her husband's response to their son's diagnosis was one of pragmatism,

> In that wee space every thought goes through your mind…and then I thought don't feel sorry for yourself. You don't know what the future is going to bring. Every day is different with him. I remember phoning Ryan and he was like, well you know this a good thing because he'll get the resources he needs at school and at home and he won't have to struggle through life without support. And that's a great way to look at it.

Naomi's reflection resonates with the theme of 'loss and restoration' examined in the previous chapter, highlighting that mothers can be seen to cope and adapt with the realities of autism caring despite their own emotional turbulence. In the preceding chapter, I demonstrated that mothers become adept in adjusting to the ever-changing needs of our children. Rather than approaching these as problems to be solved, I suggest that mothers are able to maintain this intense and immersive level of care by being realistic about which challenges can be met and overcome, and which simply require acceptance. During a time when my own attempts at adaptation seemed like a very unsuccessful process of trial and error, I was advised to 'choose your battles.' Whilst this may seem like an empty platitude, it has stuck with me in times of intense frustration and self-doubt. In three words, this sentence conveys that some difficulties may never be fully ameliorated; rather, we must pour what energy we do have into battles we know we can win. The theme of 'battle' emerged as recurrent through our stories and illustrated that what is often defined as 'coping' is in fact an active, resistive, and liberatory process for mothers navigating their children's autism.

Nicholas et al observed that following diagnosis mothers often take on the role of 'researcher, advocate, and coordinator of services' for their children, immersing themselves in attempting to understand their child's condition and petitioning for appropriate support (2016, 926). After the seemingly interminable limbo often experienced pre-diagnosis in which families are paralysed from taking steps to improve their child's position, Scarlet felt liberated by the ability to take some control and responsibility for her children's future outcomes:

> I was happy to get the diagnosis. It had been a fight to get it…people say nothing will change but things do change. You get a voice. You can talk till you're blue in the face but without that piece of paper nothing gets put in place.

Scarlet's sense of empowerment from the agency afforded her by obtaining a diagnosis and undertaking her own research into how to best support her daughter was palpable:

> I fight in other ways. I fight on paper. I use my words. That fight...gives me something to focus on. I write a complaint and I follow it like a dog with a bone...I go on missions and if I run out of things to fight for for myself, I fight for other people if someone has an issue I'm like right, I'll sort this out! I keep myself busy, I never have a day where I don't have a dozen things to achieve and that's how I get through. I keep myself busy and I give myself fights to achieve and little things that I can win. And that gives me something to get away from the stress that's going on in my head.

Nicholas et al further that for some of their participants, the challenges of their child's autism became 'purpose defining' within their lives (2016, 929). Scarlet's account above highlights how important this sense of purpose is, both in terms of maternal self-perception and in ensuring positive outcomes for our children. Abigail, reflecting on her experience of motherhood in the context of her wider life experiences suggested,

> I know you don't get time, but when you do get time it's good to think about yourself the way you were before you had children, and the way you've had to change yourself for their needs and you realise, actually I'm a better person for this…I absolutely know 100% that I am a better person for having those two children. I am a better person for having those two children with different needs that I need to think about and accommodate. I'm a much better person for it.

Abigail felt very strongly that her experience as a mother had not only changed her personally but had shaped her vocation. As an educator, her experiences with her children

very much informed her practice, and positively so. In many ways, my participants considered themselves to have been made a 'better person' as a consequence of their child's autism, in their awareness and understanding of others and in the compassion and patience they found themselves capable of possessing (2016, 929). In being able to overcome some of the challenges they faced, or, as Claiborne-Park articulates, discovering just how much one can bear, the mothers I spoke with reported a validation of their personal strength as a consequence of their experience.

This led me to reflect on my own self-perception as a mother. Perhaps I am indeed a better person for being Micah's mother, and have learned things about myself, relationships and faith that I would otherwise may not have. In heeding Abigail's advice, and finding the time to reflect about these journeys, it is clear that my life has similarly changed direction following my son's diagnosis. I became a support worker for adults with additional support needs, and latterly, a mental health advisor for young children with emotional and developmental challenges. Without the experience I had with my son, I would arguably have been unqualified, and emotionally ill-equipped, to undertake these roles. I don't deny that the feelings of sadness, and frustration, and loneliness can be overwhelming at times, but slowly and over time they can become peripheral to a sense of accomplishment and strength we may feel when, as Abigail suggests, we think about what used to be.

Whilst the emotional journey associated with mothering a child on the spectrum can be acute, overwhelming and life impacting, research has shown, as have our stories, that mothers of children on the spectrum also demonstrate a remarkable level of resilience. Zhang et al found that the respondents of their study described having a 'new appreciation of life' and a 'greater sense of spirituality and strength' as a result of their experiences (2015, 30). King and Colleagues suggest that literature relating to parenting childhood disabilities has to date focused on a narrow model in which the child is seen to be the stressor, negating the possibility that parents may regard their experience as positive (2006, 1076). Critiquing the 'personal tragedy model' of disability, Sarah Green found that parents of children with autism were much more significantly impacted by the objective realities of exhaustion and financial struggles associated with daily care giving (2007, 161). The mothers I spoke with were at pains to reinforce that their children were not sources of sadness for them, nor even necessarily their condition; but rather the complex, unexpected and ever-changing challenges and social barriers that their condition brought to their lives.

However, while I find the premise of Green's article 'We're tired, not sad' particularly useful in challenging the personal tragedy stereotype of 'struggle', I am wary that it may neglect the multi-valency of the challenges associated with autism parenting. In respect to autism, and, I would counter disabilities more generally, our subjective and objective realities are very often mutually reinforcing, not mutually negating entities. This frames the challenge of mothering on the spectrum as a 'double burden' which is particularly difficult for women.

In reflecting on the shared experiences of these mothers, and on my own encounters with friends, family members, and professionals over the years, it became clear that what connected us, what emerged from the silence, was a shared experience of struggle. We were battle hardened, weary, exhausted from the relentlessness and pervasiveness of autism on the lives of our children, and of our own. We were tired, frustrated, lonely and embarrassed by the myriad of daily problems that the autism symptomologies of our children presented. However, we were also furious, indignant, and resolute in struggling for our children, fighting to obtain understanding, recognition, and access to appropriate health care and education. Our struggles were simultaneously small and domestic and huge and societal.

We struggled. Everyday. Materially, as a result of loss of income and expense, physically, from exhaustion or as a consequence of melt-down induced violence; emotionally, from the constant unpredictability of our children's emotions. We struggled in our relationships, in our attempts to gain vital support and services for our children, with the judgement of others. Yet this struggle has become so much a part of the fabric of our everyday lives, of our narratives, that my participants and I had often taken it for granted as simply life. I could only really see this clearly as distinctive to our lives, once it was on the page. Although 'struggling' is often conflated with 'suffering', implying a passive state of tolerance in the face of hardships; when considered within the stories presented in this chapter, 'struggle' can be seen to take on a much more active, responsive, and oppositional meaning. It is my hope that the agency and resilience demonstrated by the accounts presented in this section will perhaps help to challenge perceptions of mothers of children with disabilities as more than passive victims of a quirk of fate.

However, I am cautious about falsely representing our stories as redemptive. The love that we as mothers expressed for our children is undeniable, and yet all of us at some point in our conversations wept openly in recounting our memories. Our stories were not quest narratives in which we had overcome great obstacles to reach a happy ending. While we have been able

to find happiness, joy and indeed meaning in our experiences, I would contend that it is naïve to consider that these positives completely sanitise the hardships we have experienced along the way. Nor, I would argue, that there can be seen to be an 'ending' to our story, happy or otherwise. The challenge of autism is precisely that- it is ongoing, fluctuating, sometimes joyful, often crushing.

Summary

In this chapter I have sought to articulate the ways in which our lived experiences can be shown to be complexly shaped by challenges such as fatigue, fear, and lack of social and institutional support. I have demonstrated that mothers with children on the spectrum are thus required to adopt creative and adaptive practices and attitudes in responding to these difficulties. In the following section, I will explore how theologies currently respond to the complexity of autism as a condition which is variously and simultaneously shaped by medical, social, and institutional discourses. I will consider whether traditional models of disability can be seen to effectively attend to the issues of normativity, stigma, and resistance raised by our shared accounts. By examining these issues within the context of disability theologies, I intend to explore whether the lived experience I am seeking to examine is most strongly shaped by its relationship to disability, or whether there is something in our lived experience which has emerged as more theologically complex. I propose that the particular experiences of mothering which have emerged from 'between the lines' of our stories pose a distinct challenge to our current theological thinking, and one which may prove generative for new models of theological response.

Chapter 7) Theologies of Disability

7.1) Theology and Disability

> Disability is so much more than a medically diagnosed impairment, a social stigma, or political activism engaged in the fight against manifest injustice: it is an existential struggle. Foregrounding this personal struggle is theologically important because most people do not find disability disturbing in this deeper and more personal way... I write then for those who have for some reason found themselves forced genuinely to wrestle with disability. (Brock 2016, xvii)

In the preceding chapters, I have sought to articulate what this experience of 'wrestling' is like for those of us whose lives are touched by disability in such a deep and more personal way. I have situated autism as a condition which is strongly shaped by social and political attitudes and policies towards disability, and yet which simultaneously defies many commonly held beliefs about what it means to be disabled. It is both rooted in the everyday reality of autistic lives, and yet it is invisible to the lives of others until it disrupts and subverts our social expectations of what is considered 'normal behaviour.' I have also articulated how these complex and conflicting sites of discourse significantly impact the lives of mothers caring for a child with autism. I have proposed that this distinct maternal experience is a particularly significant and generative area for theological reflection, and one which is currently troublingly silent. In what follows, I will explore how current theologies of disability attend to the complexity of these competing issues.

Firstly, I will turn to liberation theologies of disability which draw on the socio-political models explored in chapter one to articulate a theology which offers resistance to oppressive and exclusionary theological structures. I will consider how autistic lives and the related experience of mothers can be informed by liberation theological approaches which resist the marginalisation and stigmatisation of individuals who do not fit normative ideals of personhood. Secondly, I will look to communitarian theologies of solidarity in examining their potential significance in informing a theological response which engages with the relational and interdependent nature of this maternal experience. I will then turn to emerging theologies which, whilst drawing on these pre-existing communitarian paradigms, seek to develop a theological response which specifically attends to the experience of autism. I will examine whether 'autism specific' theologies can be seen to offer an opportunity to develop

more nuanced and insightful theological reflection on the lives of those on the spectrum and those who love them.

Lastly, I will present theologies which seek to re-frame our conception of personhood as situated on a spectrum of vulnerability and human limits. Here I will propose that such models have the potential to move beyond paradigms of inclusion and hospitality which arguably still function to situate disability as 'other'; instead asserting that we are all, as embodied persons, defined by difference. While these modes remained closely associated with the body as the locus of reflection, I will argue that they, perhaps more significantly, subvert the damaging deficit models of disability identified by liberation theologies and move towards a model which more fully attends to the diversity and breadth of occluded lived experiences.

7.2) Liberation Theologies: Stigma, Accessibility and Inclusion.

A synthesis of Christian theology and socio-economic inquiry, liberation theologies emerged into prominence in the second half of the twentieth century, predominantly within a Roman Catholic Latin American context (Streck 2012, 526). Influenced by Catholic social teaching's 'preferential option for the poor', theologians such as Gustavo Guiterrez (1971, 1973) and Leonardo Boff (1985, 1993) proposed a shift to liberation theologies in response to issues of poverty and social injustice (Streck, 2012, 527). They have since been enthusiastically embraced in increasingly wider contexts (such as feminism and post-colonialism) as a form of theological thinking which particularly speaks to issues of oppression and marginalisation. In doing so, they position themselves as sites of resistance against structures of inequality (Eisland 1994, 28). Strongly influenced by the social model movement, liberation theologies similarly situate disability as a socially constructed discourse shaped by political and economic dimensions (Eisland 1994, 13; Betcher 2007, 11).

In upholding a social minority perspective of disability, liberation theologies of disability draw on the themes above to assert that theology has a problematic relationship with disability in a number of respects. The first, at a fundamentally practical level, is that religious institutions can be a particularly inaccessible place for individuals with disabilities, both physically and organisationally (Macaskill 2019, 41). The second is that disability has been pathologised, particularly within the Christian tradition. It is often represented through 'personal tragedy models of disability' in which bodily difference is considered something which defines an individual as 'lesser', 'other' or not 'whole' in their personhood (Eisland

1994, 92). Thirdly, these factors often coalesce into stigmatising attitudinal barriers to inclusion which (consciously or unconsciously) treat persons with disabilities as inferior or incapable (Swinton 2012, 444). As a consequence, disabled experience is not represented, and disabled voices are often silenced within theological contexts. Naming the absence of attention to the spiritual dimensions of people's lives within contemporary disability studies (Creamer 2006, 78), liberation theologies of disability traverse the disciplinary boundaries between disability studies and theology.

Liberation theologies of disability are often developed from the standpoint of an 'insider perspective' by those who occupy a body which, in one respect or another, has been defined as a site of difference. Drawing upon key emphases in disability studies, central concerns include issues of social recognition, accessibility and inclusion. In challenging the lack of representation of disabled experience, such perspectives have offered alternative theological symbols which speak to their own lived experience. We have been challenged to imagine a God with Down's Syndrome (Winston; 2003), a God who is blind (Hull, 2001) and a God who is 'crippled' (Lewis; 1982, Eisland 1994). Such representations seek to oppose the particular inaccessibility of religious symbols for disabled bodies, asserting the position that if 'If God is disabled, then exclusive and excluding practices cannot be tolerated' (Swinton 2012, 446). Providing a re-imagining of the symbolic tradition which she considers has been historically misappropriated to the detriment of disabled lives, Nancy Eisland proposes:

> …that a liberatory theology of disability must create new images of wholeness as well as new discourses. Furthermore, the bodily rituals of stigmatization and exclusion that are a significant form of oppression of people with disabilities must be supplanted by bodily practices of ordinary inclusion (1994, 92).

Eiesland here can be seen to echo feminist disability theorist Liz Crow in asserting that a recognition of the impaired body does not diminish the socio-cultural dimensions of oppression imposed on it (1996, 3).

Asserting the moral obligation of Christian communities to challenge the social oppression of individuals with disabilities, liberation theologies of disability are particularly concerned with issues of access, challenging the Church to make their structures and organisations more physically and intellectually inclusive spaces (Block 2002, 21). However, as I have demonstrated in chapter one, notions of accessibility are typically based upon physical definitions of disability, evoking images of ramps, lifts etc. This is inherently problematic

when considering the experience of autism. In the context of the Church, the busyness of the environment and competing voices (in differing tones and registers) coalesce to present a significant sensory challenge for individuals with autism. Speaking of his own experience as a member of the Church who is also on the autism spectrum, Grant Macaskill maintains that churches could introduce many simple adaptations to improve the experience for individuals who find them inhospitable. The fact that they are often slow to do so, he asserts, demonstrates that practical problems of accessibility and inclusion can arguably be seen to be secondary to the Church's attitudes towards difference (2019, 41).

Liberation theologies which focus on disability highlight that within the Christian tradition, disabled bodies are often constructed as 'deficient' or 'less valuable' than non-disabled bodies. In her introduction to Nancy Eiesland's 'Disabled God', Rebecca Chopp observes that despite the 'astounding fact…that Christians do not have an able-bodied God as their primal image,' (1994, 11), there remains a tendency to treat persons with disabilities with a mixture of pity, suspicion and aversion. Such positions assert that Christian theology has all too readily adopted normative secular, medical models of the body which exalt bodily perfection, and position the wounded, disabled or suffering body as deviant.

Disability theorists and liberation theologians have critiqued the influence of dominant capitalist ideologies in defining the ideal body as one which is economically valuable. Sharon Betcher, although herself rejecting the label of liberation theology, shares similar concerns to the issues raised above and offers a particularly strong post-structuralist perspective on issues of disability. Preferring to designate her analysis as post-structural and post-colonial, Betcher argues that post-colonial paradigms offer a 'pragmatic immediacy' in their ability to resist the 'socio-political stigmatization' of lives deemed economically un-valuable (2007, 4, 9). Drawing on Lennard Davis's description of disability as an 'economically generated category'(2002, 3), Betcher develops this position to suggest that the Church's idealism of the normative body betrays acquiescence to dominant capitalist ideologies, as critiqued by Marxian and Weberian perspectives (2007, 12).

Developing Rosemary Garland Thomson's critique of modernity examined in chapter one, Betcher argues that parallel to the construction of the ideal body as a healthy body; modernity has also constructed a damaging paradigm of suffering, emptying it of meaning and positioning it as something to be eradicated or cured. Highlighting the influence of political ideologies in shaping dangerously oppressive social policies towards disability, Betcher's

critique supports the observations I have made in chapter two; naming the very real and dangerous potential of normalcy to function as a form of social violence (2007, 160). As I have problematised, paradigms of suffering which rely on restoration, rehabilitation, and eradication present particular challenges in respect to life-long developmental conditions such as autism. Furthermore, they imply that autism is a condition which ought to be cured; which, for many, is a deeply hurtful rejection of something which is arguably inextricable to their personhood.

Rather than providing a response to disability which relies on elements of the theological tradition, Betcher asserts that rather it is the issue of disability which has the potential to fundamentally shift our theological perspectives. She considers that issues of inequality and marginalisation, such as disability, challenge our assumptions about God and the nature of human personhood and suffering. Asking us to consider if there is a different way to be human which accounts for imperfection, she proposes that 'cripping our figural maps may be among the ways to imagine a love of life which can cope with suffering, which will find beauty- beyond idealism- in the midst of life' (2007, 21). This resonates strongly with the reflections presented in chapter six. In contrast to 'personal tragedy' perspectives which situate disability as a 'problem' requiring 'response'; our accounts reflected that experience of autism opened us up to confronting our own, and others, expectations and beliefs on what it means to be valued.

Betcher's work, together with the liberation theologies explored above, represent a shift away from individual difference being considered counter-normative, towards a recognition that there are many different embodied lived experiences which require theological recognition. Such perspectives challenge our theological thinking, asking us to interrogate our own constructions of personhood and how these inform our theological convictions. Furthermore, they are particularly useful in highlighting the intersectionality of oppressive social, political, and economic forces at work in the creation and continuation of marginalised and occluded identities. Liberation theologies can therefore arguably be seen to offer a valuable lens through which to reflect on the lived experiences of mothers whose lives are shaped and constrained by their relationship to disability, and the oppressive structures and attitudes which function to stigmatise their experiences.

It is worth noting that many of the theological perspectives explored above are proposed by individuals who are not traditional members of the theological guild. Both Eisland and Block

share a sociological background in disability studies, with an interest in the religious lives of the disabled (Creamer 2006, 88). Their interdisciplinary status arguably reinforces the lack of attention given to disability from within theology itself. Whilst their 'theological credibility' may be challenged as a consequence of this; I propose that rather in occupying these 'insider'/ 'outside' positions, such perspectives are in fact well placed to generate theological thinking out with the constraints of dominant theoretical frameworks (Goto 2018, 32).

Swinton however, whilst acknowledging the socio-political dimensions of disability, is uneasy about the way in which theology might become too comfortable in merely responding to social issues. In contrast to Betcher, he considers that,

> … very often the conversation between social analysis and theology tends to move only one way: from the experience of disability toward changes in theology… theology simply responds to the insights of sociology. There is no clear theological voice which can effectively challenge the sociological analysis. The premises are set before the conversation begins (2012, 445).

This research, in articulating a social problem requiring a theological response, could be subjected to this critique. I also come from an interdisciplinary background, and while I respect Swinton's conviction that theology should develop its own voice, I suggest that his perspective assumes a theological a-historicity which neglects the multi-valency of our situated lives. Neither our lives, nor indeed our theological thinking, develop in a social historical vacuum. Rather, as I have articulated in chapter four, our social histories profoundly affect our social presents. Furthermore, this critique neglects that the 'social analysis' of disabilities developed throughout such theological positions does not merely stem from a sociological interest; but from the real, lived experiences of individuals whose lives have been touched by the very issues they seek to challenge.

However, despite my reservations, I do share another of Swinton's concerns in respect to exactly who counts as disabled in such theologies of disability (2012, 175). While I acknowledge the utility of liberation theologies of disability in articulating the interplay between socio-political discourses and disabled lives I have sought to identify in chapters one and two; I do so with an awareness that such theologies are themselves often shaped by the same dominant assumptions they seek to challenge by relying too heavily on essentialist constructions of disability rooted in the body. The theologies of accessibility articulated above propose a model of inclusion which, while promoting an acceptance of bodily

difference, arguably assume a universality in respect to intellectual capacity which neglects cognitive developmental conditions, such as autism (Swinton 2012, 177).

Given that autism is characterised by difficulties in engaging in the social world neurotypical people take for granted, as Shakespeare and Watson problematise in chapter one, I propose that it is perhaps naïve to consider that we may be able to make the social world accessible for people with autism in the same way that we can make buildings accessible. In moving - beyond paradigms of accessibility, perspectives such as Betcher's propose that genuine inclusion may only be attained by changing the way in which people are educated and socialised to value each other through a radical and universal transformation in attitudes. However, Brian Brock counters the assumption that macro social solutions can ever address the challenges that disability raises, asserting that 'all the ramps and lifts in the world are a poor substitute for open hearts' (2019, 2). He proposes that a truly inclusive theological response requires both personal and communal transformation. In what follows, I will explore how a communitarian model, as proposed by Brock, may look to address these tensions.

7.3) Communitarianism and Solidarity.

Communitarian theologies respond to Brock's challenge for attitudinal change by positioning the Church as being at the heart of a community which is responsive to and responsible for a compassionate bearing with one another's burdens. Influenced by the work of Karl Barth in responding to times of social crises and fragmentation, communitarian models advocate a return to scripture as means of providing coherence and constancy (Graham et al, 2018; 88). Informed by canonical narrative theologies which position the bible as a means of providing the scripts which guide our actions, such an approach both re-constructs and re-affirms a coherent Christian identity which is not only rooted in faith but lived and enacted in acts of praxis shaped by uniquely Christian values (Hauerwas 1990, 55).

Bringing together elements of liberation theologies which propose a commitment to challenging social injustice and marginalisation, and principles of Catholic social teaching which engage in the practice of mutual solidarity and compassionate obligation to one another; communitarian disability theologies highlight the revelatory potential of disabled lives in unsettling and challenging our perceptions of what a community of genuine acceptance should look like (Brock 2019, 137; Swinton 2012, 184). A communitarian model of disability must therefore foster the level of inclusion and acceptance which would

significantly challenge the stigma, judgement, and exclusion that I have shown colours the lives of mothers of children on the spectrum.

The work of influential theological ethicist Stanley Hauerwas is foundational to the communitarian model's response to issues of disability. In contrast to the liberation theologies outlined above, Hauerwas was particularly concerned to explore how the experience of individuals with cognitive and intellectual disabilities might shine a spotlight onto our communal moral character - revealing how we value persons with difference (2005, 54). John Swinton, who develops the communitarian approach of Hauerwas, is also particularly concerned with how theology responds to intellectual conditions such as Down's Syndrome (2003), Autism (2009, 2012) and dementia (2012). He has been particularly vocal in critiquing theologies of accessibility as concealing the dynamics of power at play in excluding individuals with cognitive difference, which I have problematised in the preceding section.

Critiquing a secularised and ahistorical distinction between faith and ethics, Hauerwas, much like Betcher, considered that theology has traditionally drawn on principals of modernity which equated disability with suffering. Life-long developmental conditions (such as we could describe autism) thus present as particularly problematic, as they do not fit with the expectation that suffering is temporal. It is quite one thing, Hauerwas asserts, to be present and sympathetic with someone who is suffering for a few days or a few weeks; it is quite another to 'be compassionate year in and year out' (2001, 550). Naming the potential to misconstrue 'pity' as 'compassion', Swinton asserts that merely identifying as Christian does not inherently imbue individuals with the ability to offer genuine solidarity in the face of such perceived suffering (2003, 11). Rather, he affirms the need for a Christian identity which is actively engaged in the faithful practice of Christian community (2012, 187). Swinton proposes that a genuinely hospitable Christian community begins with the recognition that God provides us a blue-print for relationships formed out of equality, acceptance, and love (2003, 69). In such a way, he is seeking a much deeper understanding of inclusion incarnated in committed communal life:

> It is therefore essential that rather than striving simply to do things for the
> intellectually disabled, we begin to learn what it might mean to genuinely be with
> them… through God's accepting, incarnated love…intellectually disabled people can

begin to discover that they have value, that they are loved, and that they in themselves are essentially loveable (1997, 19).

In advocating unconditional acceptance over notions of accessibility, communitarian models of disability assert the revelatory potential of engaging in a caring relationship with another person without sympathy or expectation of reward (Nouwen 1997, 43). However, by their association with the taken for granted 'everydayness' of the domestic sphere, the potential of caring relationships as revealing genuine models of community are often overlooked. In contrast to theologies of disability which are often taken from the position of the disabled adult, Hauerwas considered that parents of children with disabilities reveal a distinctly valuable and formative example of the kind of compassionate hospitality a Christian community is called to bestow. He proposes that the uncritical acceptance demonstrated by this parental model can offer a blueprint for the kind of patient, loving presence he believes to be critical in bearing with sufferings which are ongoing, and from which no purpose or meaning can be drawn. De-legitimising the notion that any children, much less children with additional support needs, are the sole responsibility of the parents; this position reminds the Church of the real material implications and obligations of the promise offered in baptism (Hauerwas 2005, 58).

Certainly, we mothers have all, at one time or another, considered how much lovelier life could be if others could demonstrate the same uncritical acceptance that we have developed for our children. And in situating the parental experience of disability as distinctly generative of theological thinking, Hauerwas's model of communitarianism has significant implications for this research. In the first instance, it recognises the argument put forward in chapter five that the knowledge of mothers is a potential collaborative resource for professionals in both expediting diagnosis and in developing successful support strategies for children. Second, this position highlights that while parents are the primary source of care, they should not be the *only* source of care. I have proposed that attitudes which present parents, and in particularly mothers, as solely responsible for the development and behaviour of children place an undue burden of responsibility function to inhibit our ability to ask for support.

However, although Hauerwas was arguably revolutionary in recognising the potential value of parental knowledge in respect to how we consider childhood disabilities; he uses the gender-neutral term 'parents' to describe what I have argued is a particularly gendered experience. In concluding chapter three, I have identified that caring for the needs of others,

particularly in respect to children and even more so when a child has additional support needs, is frequently 'a mother's burden.' I have argued that the work of caring labour is most often disproportionately situated on women, who shoulder a weighty responsibility in ensuring that their children's complex needs are met. Furthermore, the occlusion of women through the use of an apparently gender-neutral term leads us to a wider critique of Hauerwas's thinking.

Developing a feminist liberation critique of Hauerwas's theology of communitarianism, Gloria Albrecht suggests that his particular model of the family is premised upon traditional archetypes in which 'doing the hard work of sticking out a marriage without reflecting much on whether one is fulfilled,' has particularly problematic implications for women (1995, 56). She contends that communitarian theologies often neglect the inherent structural inequalities and hierarchies within the Christian community and assume a universality of experience and character which, as Althaus-Reid (2000, 18) and Goto (2018, 221) have identified, is often the experience of the white, Christian male. Building on such critiques, Nicholas Healey argues that such issues of epistemic privilege raises significant concerns as to the issue of authority in representing the voices of others within theology, proposing that Hauerwas's confessional rhetoric utilises a sermon like approach which disguises its deeply exclusionary aspects.

Hauerwas situates himself as an outsider to the issue of disability, and so his interest in the subject, out with the context his background in medical ethics, is unclear. Echoing criticisms Swinton has levelled at liberation theologies (2012, 175), Healey suggests Hauerwas appears to be merely arbitrarily appropriating a social issue to further his particular agenda of demonstrating the uniqueness of the Church as a moral community (2014, 5). Healey also shares Albrecht's concerns in respect to what he considers Hauerwas's universalisation of 'the Church'. Denominations in differing social locations and in differing points in history vary so considerably that there is arguably no such thing as a universally accepted 'Church' or indeed the Christian formed in this ecclesial context. Healey contends that,

> …Formation is not simply a product of enacting a given set of practices. Persons are also formed by their reflections, discussions, and decisions about which practices to enact and how, as well as by their inevitable confusion over such matters. Our characters are constructed as the products of ongoing negotiations, whether explicitly or entirely un-reflected or somewhere in between (2014, 95).

In this sense, communitarian models which position the paradigm of a 'hospitable community' as one which is distinctly and uniquely Christian arguably present an uncritically constructed notion of both 'community' and the Christian person. It could be argued that there is there is nothing particularly or distinctly 'Christian' in the 'Christian character' Hauerwas describes; in fact, many non-Christian people live similar lives with very similar values. For someone who themselves is outside this conception of 'Church', but who holds themselves accountable to many of the values Hauerwas purports to be exclusively Christian, I find this issue particularly problematic.

I am, nevertheless, moved by (albeit arguably utopian) visions of a community which responds to the suffering of others by simply seeing and bearing with them. For parents, and particularly mothers, who often feel isolated and stigmatised by other's attitudes towards autism, and exhausted by its daily realities, the old adage that 'it takes a village to raise a child' holds particular significance. Whilst that village may not, in reality, resemble Hauerwas's vision of Church, it offers an important reminder that we ought not to be alone in our particular struggles. In the course of this research, I was asked what such a 'community of solidarity and inclusion' might look like for parents with autism. This, admittedly, gave me considerable pause for thought. My answer was perhaps frustratingly pessimistic.

Whilst it would be tempting to imagine a community in which our responsibilities and burdens were shared and supported equally, without judgement or expectation; in reality, this still would not be sufficient to resolve the challenges we face or to make life easier for our children. It is often unfeasible for others to provide the kind of practical support that mothers of children on the spectrum could genuinely benefit from. Compassion is a great thing. On days when we feel particularly burdened, the knowledge that another recognises your struggle can be profoundly comforting. Such comfort, however, is arguably often fleeting when there is little respite from the struggle itself. In chapter five, Both Abigail and Scarlet described challenges in obtaining acceptance and support for their children's conditions from within their own families, highlighting that even when ties are perceived to be fundamental and unconditional, they cannot always be counted upon to be so. In this sense, I question how members of a community of solidarity might ameliorate the irresolvable, conflicting, and deeply complex struggles of a lived experience that they themselves do not, and cannot, fully share.

7.4) Autism Theologies: Thinking differently, loving difference

In situating this research, I have proposed that the ambiguity and lack of understanding in relation to autism has led it to be an issue which is largely occluded theologically, and which has also left mothers theologically silent. Although still woefully few, theologies which attend to the specificity of autism as a lived experience which is generative for theological thinking are beginning to emerge. These perspectives can largely be seen to draw from the preceding theological models. Viewing autism from perspectives of accessibility (as in the liberation model) they are nevertheless more deeply informed by communitarian theologies. As I have shown these emphasise themes of inclusion and hospitality to dispel the assumption that autism must be socially isolating by highlighting the potential contribution individuals with autism can make to the church community. The models I will explore below focus upon three particular 'communitarian' themes: inclusion, acceptance, and love.

Theologians such as John Gillibrand (2009), Tom Reynolds (2008) and Brian Brock (2019) have drawn on their own lived experiences to articulate the theological tension provoked by having a child with autism, challenging the Christian community to see their children through their eyes. Speaking of the stigmatisation he has experienced in parenting a son with both Down's Syndrome and autism, Brian Brock admits that 'at the deepest level, and behind these more mundane hopes, I can hope to enjoy Adam. I hope that others, too will… say with unfeigned sincerity: 'I'm glad you're here.' (2019, 193). Proposing a response which attempts to bridge the experiential gap between the neurotypical and the neuro-diverse without attempting to normalise or paternalise autistic difference, Brock considers that greater understanding and empathy, rather than an attempt to 'think autistically,' make our communities a less hostile and judgemental place for families with autism (2019, 193).

Echoing the views explored in the preceding section, this approach emphasises that an attention to how someone orientates their lives around the needs of another can provide a deep and challenging theological reminder of our responsibility to welcome one another with compassionate hospitality (Reynolds 2008, 42). Developing this position, Tom Reynolds considers that theologies which offer true inclusion must acknowledge that rather than weakness, the vulnerability revealed by conditions such as autism highlights our mutual dependence, challenging us to find new ways of forming strong and loving connections with one another (2008, 118). Interestingly, the contributions to theologies of autism explored above have come from fathers who themselves have children on the autism spectrum. This

supports my assertion, and affirms Hauerwas's position, that the lived experience of parents can afford significant potential in generating theological insights into disability generally, and autism specifically.

Approaching this from a rare 'insider perspective' as a person with autism in the Church, Grant Macaskill supports Reynold's theological model of vulnerability, appealing to a Pauline paradigm of human frailty which affirms the value of weakness and responds to it with love (2019, 186). Drawing together the threads of acceptance and hospitality identified above, he considers that true acceptance of difference might require neurotypical individuals to sometimes adapt to the person with autism's way of being in and seeing the world, proposing a theology of 'accommodative love' (2019, 118). A commitment to remembering and anticipating the minutia of specific needs and wants a child with autism may have, whether that be, as I described, the right socks, or as Naomi shared, the correct yoghurt, demonstrates, I would argue, a praxis of loving attention which strongly resonates with Macaskill's model of 'accommodative love.' Arguably, it is this kind of adaptive love which enables mothers and care givers to continue in the daily and often seemingly insurmountable challenges they face.

Reinforcing Macaskill's position that loving acceptance requires a sincere and genuine willingness to consider and adapt to another's ways of thinking, Swinton utilises Christine Guth's Article 'Horses live to run…' to highlight that 'accommodative love' often requires a self-critical shift in perceptions. Articulating Christine's experience of coming to the revelation that for her autistic and apparently 'unloving' husband, love was displayed in the seemingly inconsequential realities of daily routines, he observes that Christine was forced to confront her assumptions of what love actually is. He asserts that how we love one another can inform how we come to think of the love of God,

> To love God is to live a life that is routine and ordered. To love one another is to make sure that each night at exactly the same time you will sit down and have a conversation about the day; a wilful conversation that reflects a wilful form of love (it's good that you exist; I'm glad that you are here) that is ordered and predictable and within which no offence is caused. Love is a form of action and a mode of routine (2014, 268).

Problematising Christianity's reliance upon Western cultural constructs of 'romantic love' as incompatible with images of individuals with autism as un-empathetic, undemonstrative and

unfeeling; Swinton draws on Christine's narrative to challenge us to 'think autistically' by self-critically examining our own normative constructions of abstract concepts such as 'love' (2014, 269).

However, whilst I support Swinton's critique of commonly held assumptions in respect to autistic individual's capacities for emotion, I find his own schemas of love to be similarly uncritically constructed. I would argue that Swinton not only generalises neurotypical love as being overly romantic and sentimentalised but also overgeneralises autistic love as being merely practical and un-intuitive. Swinton's model of theological response to disability generally and autism specifically seems to over rely on the simplistic promise that 'God is love.' Irrespective of whether the subject is Down's syndrome or autism, Swinton very often begins with insightful and nuanced criticisms of contemporary challenges to disability yet ends with very uncritical and essentialist proclamations of Christian love. I find that his conclusions also echo the rhetorical tone of Hauerwas's work which Healey finds deeply troubling, in that it asserts a liturgical authority which theological academic research typically does not, nor should have (2016, 64).

Although arguably making strides in bringing autism into theological conversation, I propose that current theologies which draw on autistic experience rely too heavily on pre-existing theologies of disability, thus replicating the same issues and limitations of these models. The theologies of autism examined here are similarly problematically constructed in ways which accentuate unhelpful constructions of difference. In the following section, I will look to theologies of limits as proposing a paradigm of personhood which perhaps more closely attends to the reality of the experience I am seeking to reflect upon.

7.5) Towards A theology of Limits; Vulnerability and Human Suffering.

In previous chapters, I have charted how definitions of autism have been expanded in recent years towards a more inclusive and diverse 'spectrum' model of difference, which seek to move away from limited and medicalised paradigms of difference. Whilst the communitarian and liberation perspectives explored are similarly critical of medical paradigms of disability, I have suggested that they do, albeit tacitly, also rely on constructions of difference as a starting point from which to respond. In contrast, emerging theologies which propose a 'spectrum model' of human experience are arguably more responsive to the issues of accessibility and inclusion. This theological turn positions that human beings, all human beings, are situated on a spectrum of 'limits' to their lived experience; with some limits, such

as the limits presented by impairment, more profound than others. Swinton observes that while 'liberationist theologies focus on empowerment through political participation; this group of theologies focus on revelation through the recognition of shared weakness' (2012, 448).

Critiquing liberation models as too narrowly concerned with definitions of disability which both rely on difference, theologies of limits affirm the position that disability is no one thing. Reinforcing the tenuousness of disability as a category of difference, Deborah Creamer argues that the likelihood is that we all, at some point in our lives, will experience limitations on our physical health (2008, 96). Rather than a deficit, this perspective situates limits as a natural, neutral, and intrinsic part of our human nature. In contrast to constructions of disability as bodily difference, a theology of limits 'emphasizes a characteristic of humanity-one has limits…rather than being an array of unfortunate alternatives to omnipotence, (limits) are an unsurprising characteristic of human nature (2008, 94). This, Creamer suggests, offers us an understanding of human limits which allows us a more positive way of being, proposing that 'our limits need not (and ought not) seen as negative…rather, they are an important part of being human' (2008, 64).

Developing Creamer's position, Shelly Rambo proposes a theological recognition of embodiment in respect to human limits in attending to what she describes as 'wounded bodies.' Whilst the use of this term suggests a similarly physically orientated stance to the those already critiqued, Rambo instead utilises this term hermeneutically as a descriptive category for lived, embodied experience; encompassing psychological and emotional trauma and suffering as well as embodied experiences of illness and impairment. By reframing 'wounds' in such a way that does not neatly fit within traditional paradigms of physicality or 'healing,' she acknowledges the potential of 'multiple traumas'; observing that struggles are often compounded by many different, sometimes competing, social forces and experiences (2010, 145). She proposes that theodicies which imply restoration or resolution from trauma neglect the cyclical, ongoing, and enduring nature of struggles which are 'lived with' and 'without end' (2010, 15). Rambo's work can be seen to offer potential release from the oppressive normative structures of tradition explored above which neglect the 'ongoingness' and 'everydayness' of suffering as simply part of our normal human lives.

Acceptance of human limits as advocated by Creamer and Rambo thus challenges the enduring and damaging theological schemas which consider suffering as some form of divine

punishment. We are all arguably guilty of attempting to find theodical justifications for our experiences. I found myself profoundly moved when Abigail reflected on one particularly difficult moment, in which her son questioned why God made him autistic. This reminded me of a tearful conversation in which I asked my mother a similar question. 'Is he being punished because of me? Am I being punished? Why us?' My mother, who knew such things, replied, 'My darling, God knows what we can handle. And he knew that you are the only person in the world who could handle him.' Abigail responded to her son with similarly tender pragmatism, 'Because son, God has put you with a family that he knows can support you. Somebody in this world has got to have autism, sweetheart, it might as well be someone who can be supported and loved through it.' These insightful women unwittingly affirmed Rambo and Creamer's position that while there is no answer to the question of suffering, we can address this within a perspective that takes cognisance of human, and also divine, potentialities and limits. In acknowledging the limits of both our personhood and of the divine, such a perspective opens up the potential for more fluid and diverse modes of theological reflection:

> Rather than thinking of limits solely in a negative sense (what we, or what God, cannot do), this perspective offers alternatives for thinking about boundaries and possibilities. In an age of war, terrorism, economic injustice, and environmental risk, a recognition and theological affirmation of limits seems more responsible than apathy or omnipotent control and offers a perspective that can lead to hopeful possibilities of perseverance, strength, creativity, and honest engagement with the self and the other (Creamer 2008, 113).

Theologies which acknowledge our human limits, and the often theologically irreconcilable nature of struggle and suffering as part of our human experience, arguably offer a more holistic and realistic model of inclusion than the paradigms of disability explored previously. Furthermore, they are particularly useful in generating new theological thinking which helpfully re-frames our relationship to God in a way which 'not only offers corrective guidelines to established theologies but also itself raises new theological possibilities' (Creamer 2008, 78). I am thus drawn towards a theology which offers a recognition that autism 'is what it is' and not some divine form of punishment or moral challenge to learn through difficulty. In the preceding chapter, I have articulated that such pragmatic acceptance is crucial to a mother's ability to cope with and respond to the challenges of their lived experience. Instead of looking to faith to provide explanations or solutions such an

approach suggests that perhaps God rather gifts us with the theological wisdom we need to deal with the suffering and unresolvedness that comes from being human.

7.6) Summary

In this chapter, I have considered the utility of disability theologies in responding to the challenges mothers face in navigating their children's autism. I have demonstrated the usefulness of liberation theologies of disability in highlighting the stigmatising impact of discourses of normalcy on the lives of those who do not fit within these parameters. I have considered the work of Shelley Rambo, Deborah Creamer and, with some reservations, Stanley Hauerwas as useful in articulating lived experiences of struggle which do not neatly fit within the confines of physical impairment. In contrast to other theological models of disability, theologies of limits arguably resonate more strongly with autism as an invisible condition, situated on a spectrum of difference.

I have highlighted the utility of theological contributions which attend to issues of inclusion by advocating loving acceptance, recognising the particular potential of theologies which acknowledge the significance of familial care giving as a profoundly generative means of theological reflection. However, I suggest that these models continue to exclude mothers from the theological conversation. I contend that mothers show remarkable and distinctly resilient forms of loving beyond the communitarian models examined in this chapter, which can arguably be considered revelatory and liberatory in praxis. In the following chapter, I will situate the theological challenge revealed within this research as being a distinct form of maternal experience rooted in everyday struggle, and consider this within current theologies which attend to the maternal and the everyday as generative sources of epistemic value.

Chapter 8) Mothers 'in the struggle'

What has emerged from this research is a distinct and complex lived experience which presents an equally complex and distinct theological challenge. In sharing our stories, it was revealed that mothers are facing unusual and particular struggles in their experience of mothering children on the autism spectrum, shaped by complex and often conflicting social and political discourses on disability. The sources of the maternal struggle I have illuminated throughout this thesis are inter-relational, woven on both the personal and the societal level. Individuals with autism and their families are undoubtedly disadvantaged socially, economically and suffer from intense stigma and marginalisation. Viewed against the backdrop of material inequality and social policies which fail to respond to our pressing need for services, it would have been tempting to situate this thesis within a liberationist theological reflection. Liberation theologies, as I have explored, offer a particular resistance to oppression.

My participants, and I suppose, myself, in writing this thesis, actively participate in acts of resistive and liberatory praxis every day. These women are advocates, researchers, campaigners, educators. They are arguably making more strides in liberatory praxis in the everyday realities of negotiating their children's curriculum and access to activities, clubs and churches within their community than my academic exercise in presenting their stories could ever hope to achieve. At the same time, these efforts are approached with a heavy measure of pragmatism. We are winning small battles for own children, sharing battle tactics and knowledge so that other children may benefit. However, the macro-structures which shape and contribute to our struggles are so complex and over-arching at a societal level that it would be naïve and idealistic to believe that we are likely to see considerable, meaningful change within the fleetingly short span of our children's childhoods. Thus, our experiences cannot not simply be reduced to that of socio-political marginalisation. These social forces undoubtedly shaped our experience of struggle; yet we were also profoundly affected by our daily realities of mothering, in the unrelenting 'little stuff' which we know will re-start, cyclically and ceaselessly, day after day.

While the theologies of disability explored in the preceding chapter could be seen to attend to some of these issues; I found that such theologies did not attend to everyday lived experience, nor to the intersectionality of the competing social discourses which affected our everyday lives. Mothers, I have argued, are most typically the primary care givers of children

generally, and atypical children particularly. Thus, I consider the absence of attention to maternal experience within disability theology to be peculiar at best and at worst, a missed theological opportunity. I propose that the distinct experience of mothers of children on the spectrum is one which is even more significantly occluded from research, yet one which has the potential to provoke a particularly new and insightful form of theological thinking. The question then arises, what is distinct about the particular experience of maternal struggle which I have revealed, and how do we respond to it theologically? This has proven to be more challenging than the question I initially expected to answer.

While considering this issue my son asked me, with learned thoughtfulness, 'What bit are you working on now, Mama?' 'Struggle,' I sighed, contemplatively. 'How are you getting on?' he asked. I laughed. 'I'm struggling.' He paused for a moment. This pause invariably means one of two things from an eleven-year old boy- he is considering whether or not this is interesting enough to him to pursue the conversation, or he is choosing an appropriate social response to bring me some measure of comfort in my admission. Eventually he also sighed. 'Well. You see the irony here.' Who says autists do not understand abstract concepts?

In the course of our lives, I would anticipate that we have all, at one point or another, considered ourselves 'Pues, ahi, en la lucha' , or 'in the struggle' when asked how we are doing (Isasi-Díaz 2004a, 229). The mothers in this thesis have all, at one point or another, been told 'I don't know how you do it,' upon our answer. This is problematic in a number of ways. It is a closed question- or rather, it is a statement, rather than a question. It leaves little opportunity to respond. It asserts, I know nothing of your struggle, but also shuts down the invitation to share it with me. It is, I assume, intended to convey a recognition of our struggle but also our resilience. However, this presents a simplistic kind of sympathy, which is, oftentimes, experienced more as pity than empathy. And so, in response to those who exclaim; I don't know how you do it! this thesis has sought to find a way to tell you.

As mothers of children on the autism spectrum, in the course of sharing our lived experiences with one another, we all laughed and cried with one another when considering this question; we could all agree that we were, quite simply, struggling. It also became alarmingly clear that while at a surface level literature alluded to autism as presenting 'unique challenges' to daily living, these challenges were often listed arbitrarily, with very little critical examination of how such challenges are really lived and experienced for mothers. In what follows, I will explore this lived experience within the context of feminist theologies which acknowledge

the significance of motherhood as a profound source of epistemic value, before considering the contribution of theologies which attend to the complexity of struggles which are rooted in the seemingly mundane practice of everyday living. In shifting away from theologies of disability, towards theologies which attend to women's lived experience, I will examine whether such theologies may be better placed to offer a more nuanced response to the particularity of the lived experiences which have emerged within this thesis as a distinct form of maternal struggle.

Maternal Thinking: A neglected source of knowledge

Feminist theory, in the fields of psychology, sociology, and theology have contributed extensively in highlighting that mothers experience struggle in way that is distinctive to women, and often as a consequence of their simply being women (Miller-McLemore; 1994, Butler; 1999, Althaus-Reid; 2000, Rich; 1976). Dominant discourses which romanticise the experience of motherhood as something biological, natural and altruistic have caused the conflicts of mothering to be silenced, hidden, and neglected from any real critical inquiry. Perhaps more significantly, mothers struggle against an insidiously dominant discourse which suggests that women who experience struggle in their motherhood are somehow 'anti-woman', unnatural, and uncredible. We are unreliable witnesses to our own testimony (Bons-Storm 1996, 18).

In the preceding pages, I have articulated an experience of mothers which is similarly and dangerously silenced. We were all too often as mothers conflicted by the traditional narratives of what motherhood is assumed to be, in contrast to the reality of motherhood as we truly live it. I have caught glimpses of myself and others on the pages of Adrienne Rich (1976), Riet Bons Storm (1996) and Bonnie Miller-McLemore (1994) as they bravely revealed the unthinkable, much less nameable- that mothers are not always brimming with love and patience and utterly fulfilled by their children; but rather are often conflicted, exhausted, and drained from the ceaseless demands and expectations of motherhood. I have admitted my own complicity in this silence by being reluctant to share how overwhelmed and exhausted I have often felt in my role as a mother. Adrienne Rich, writing candidly on the physical and emotional toll of motherhood asks us,

> What woman, in the solitary confinement of a life at home enclosed with young
> children, or in the struggle to mother them while providing for them single-handedly,

or in the conflict of weighing her own personhood against the dogma that says she is a mother, first, last, and always—what woman has not dreamed of going over the edge, of simply letting go, relinquishing what is termed her sanity so that she can be taken care of for once, or can simply find a way to take care of herself? (1977, 279)

This evocative account can be seen to resonate strongly with the issues raised in chapter six; for mothers of children with autism, caring demands are exhaustive, unrelenting, and leave little time for considerations of mother's own well-being. Echoing the incongruity Nicholas et al note between motherhood and a 'job with delineated hours' (2016, 926), Clare Wolfteich rejects the popular assumption that maternal conflicts lie in the 'balance' between work and motherhood. Drawing on Patricia Hill Collins' term 'motherwork', she asserts that only when we acknowledge 'mothering *as* work and to mothering *in relationship to* other spheres of women's labour' will we begin to see that women's roles are interconnected and often indivisible (2017, 6). Whilst Wolfteich contends that Rich 'speaks over women who may interpret mothering in terms of sacrality, vocation, or empowerment', she notes that 'mothering can be a site of oppression and/or freedom, suffering and/or fulfilment,' and that these conflicts are currently occluded theologically (2017, 141; 145).

Where such conflicts are attended to, Bonnie Miller-McLemore suggests that they often draw from unhelpful theologies of 'agape' or 'altruistic love,' which harmfully reinforce unrealistic representations and expectations of maternal experience (1994, 102). Such theologies of motherhood portray women as adopting their child-rearing responsibilities with a self-sacrificing commitment and seemingly limitless love for their children; however, in reality, this is by no means a natural state and by no means a constant state of being. In chapter seven, I shared my unease at academic attempts to 'theologise' love, particularly when such attempts may provoke universalised and unhelpful stereotypes of loving. Mothers, like anyone else, lose patience. We become tired, at times we may even feel overwhelmed and resentful of the demands of our children. Presenting mothers as endless and virtuously giving, Bons-Storm asserts, creates a dangerous expectation on mother's abilities to continue to give beyond their means,

> Most women are rightly convinced that many persons around them are in need of kindness and loving care. So they give it. Only there is no limit to the giving. To stop or to limit the caring and giving would mean to stop playing a role that is seen as their destiny as women (1990, 61).

In the preceding chapters, I have highlighted that in respect to autism, such damaging and unhelpful stereotypes of mothers as virtuously giving have simultaneously functioned to inhibit research into autism itself by laying blame with unaffectionate mothers, and also significantly impacted mother's ability to voice the struggles and challenges of their experiences in fear of being considered 'not loving enough.' Miller McLemore proposes that such theologies also support the perception that self-sacrificing love is what is necessarily *distinct* about mothers and their abilities (1994, 104). In the preceding reflection, I have described an encounter with a support agency which could arguably be seen to be shaped by this very misconception. The belief that mothers can, not least should, be able to manage whatever challenges their children present stoically and without complaint can in very real terms be seen to continue to shape provision of support at an institutional level for mothers of children with autism.

I have articulated that the women I spoke with felt very strongly that their thoughts and value as mothers were respectively ignored, neglected, or discounted by the professionals tasked with supporting them. Despite mothers' intimate knowledge of and creative engagement with our children's needs arguably being the best source of 'raw data' practitioners could utilise during diagnostic and intervention processes and would arguably function to expedite and simplify processes which are currently arduous, complex and protracted; sadly Kanner's legacy lives on, and there often remains a distinct disconnect between the contribution of the parent, and the perceived authority of professionals in assessing diagnosis and providing support (Claiborne-Park 2000, 179). These insights also have the potential to reshape social visions.

Mothers, by virtue of their conflicting demands, have had to develop ways of thinking and acting which are anticipatory and creative, immediately balancing the needs of the now with the consequences for the future. In 'Maternal Thinking: Towards a politics of peace,' Sarah Ruddick contends that in fact what is distinct about mothers is that they possess a unique and generative way of thinking that has the potential to offer very real profound insight on socio-political issues (Ruddick 1994, 20). The variously creative and pre-emptive tactics which mothers of children with autism can be seen to employ our efforts to maintain our children's well-being arguably demonstrate precisely the kind of anticipatory and adaptive thinking that Ruddick exemplifies. These tactics, whilst every day in practice and nature, are often also tacitly employed in provoking 'resistance' to standardised models of learning and support

provision which do not accommodate our children's various, and varying, needs. Heather Walton reminds us that,

> While a romance still exists as to the nature of maternal care it will be impossible to address the dilemmas women face…To recognise that these uneasy, painful relations are ones in which powerful emotional force is located is to begin to understand that they are possible sites from which to engage in the project of political transformation (2001, 9).

Motherhood is not a role which one can easily abdicate. I would suggest that even when women do, they are nonetheless irrevocably changed by having been a mother. I have sought to demonstrate that mothers, much like is assumed of those on the spectrum, *think differently*. As Nicholas et al highlighted in chapter four, the needs of our children pervasively and unrelentingly shape our thinking. However, in contrast to personal tragedy models of disability, I propose that whilst the distinct forms of maternal practice outlined above can arguably be described as forms of 'struggle' in a woman's daily life and thoughts; mothers can also be shown to draw significant strength from and uniquely respond to these struggles in a way which is distinctly generative and meaning making. As Miller-McLemore asserts, 'we are most alive when passionately engaged in life's struggle, not when reflectively detached… The academy does not usually understand this creative generative tension. A mother might' (1994, 142).

The Everyday: a site of struggle and resistance.

Being 'passionately engaged in life's struggle' is very often most strongly enacted in the 'everydayness' of life as we live it. The experiences of myself and the other women who have shared their stories have highlighted that our struggles are most often fought day to day. Whilst we are acutely aware of the 'bigger picture' in respect to school placements, continuing access to resources, and the impending reality of 'aging' out of support provision[28]; these larger issues are often forced to be peripheral to the intricacy and immediacy of the daily planning required to be responsive to our children's needs. I have demonstrated that for mothers of children on the spectrum, even seemingly inconsequential everyday acts such as dressing, or remembering to buy the right yoghurt, can have profound significance and meaning for our children, and by extension, ourselves. I have described the

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[28] Children's support services are typically withdrawn once an individual reaches the age of 18.

myriad of ways in which autism symptomology plays out in the taken for granted spheres of 'normal' daily living; from eating and sleeping to speaking and hearing. It is invisible, yet tangibly pervasive in the ways in which it manifests in everyday life, and distinctly problematic when considered in respect to theologies of inclusion and adaptation.

In 'Mujerista Theology', Ada María Isasi-Díaz reflects on a seemingly inconsequential moment at a bus stop with a young mother. Díaz observed that the woman's son was smartly dressed and appeared clean, healthy and well cared for. In contrast, the mother was visibly exhausted, dishevelled, holding a take-away coffee and a doughnut that was likely her breakfast. Whilst many would have merely glanced at the duo and moved on, Díaz was struck by the many conflicting decisions that woman likely had to make that morning (2011, 52). Was she drinking take away coffee because her income did not allow for the luxury of buying enough groceries for her to eat breakfast at home? Had they only enough water to wash her son and his clothes? Is she exhausted from the competing demands of working to support him, and being present enough to meet his needs?

Isasi-Díaz's observation echoes the difficult and unseen challenges shared by Naomi and I. Our mornings were dictated by a myriad of seemingly tiny decisions and battles which had to be waged to simply get our children to school. The 'dailiness' of our lives were significant sources of struggle that were peculiar to our particular context. In this sense, we were keenly aware of the reality that Isasi-Díaz goes on to admit; that she, much like the other mothers at the school gate, occupied a position of privilege in which mornings were easy, and tough decisions simply didn't have to be made (2011, 55). Isasi-Díaz affirms that while we can often be seen to struggle from the effects of forces from above, the reality of such struggles cannot be detached from the seemingly unremarkable practices of everyday life. The 'big stuff', she contends, affects the 'little stuff', but it is the 'little stuff' which can often feel the biggest struggle.

Yet the everyday is not simply a site of struggle, it is also a site of resistance. The liberatory potential of the everyday has been developed by feminist theologians who critique traditional theologies neglection of 'the personal sphere' for its potential to shape and transform social, political, and theological praxis (Isasi Díaz, 2004, 67; Walton 2014, 9; Miller-McLemore, 1994, 142). Describing such everyday acts as 'tactics', De Certeau furthers that even when we are engaged in practices which are seemingly routine and unconscious, we are often actively engaged in small but profoundly significant acts of resistance against dominant

socio-political discourses (1988, xvii). De Certeau proposes that whilst seemingly unremarkable or habitual practices such as walking or the creation of a meal have been discarded as trivial by analytic enquiry, they can in fact be shown to be poetic forms of making which demonstrate creativity and agency in the 'everyday struggles and pleasures' of our daily living (1988, xx). Attention to the everyday, particularly the everyday lived maternal experience of a condition such as autism which so significantly and profoundly affects daily living demands a recognition that life is messy. It is complex. It is shaped by social, political, and theological discourses which are interwoven into knots impossible to detangle. Theologies which attend to the liberatory potential of the 'everydayness' of struggle offer an important insight into the complexity of such lived experiences.

Developing this from a post-colonial feminist perspective, Ada Isasi-Díaz affirms the liberatory potential of lived experiences of everyday struggle as vital theological source (2004; 2011). Critiquing dominant theological paradigms which position struggle as a form of suffering, Isasi-Díaz develops a theological response which re-envisions struggle as an active, resistive way of living which she describes as 'en la lucha' (being in the struggle) (2004a, 229). In this sense, 'en la lucha' rather 'represents a statement about survival, a comment on economic and social circumstances, a comment on coping and perseverance, and contains seeds of a commitment to be engaged, to be in struggle' (Schussler-Fiorenza 1996, 339). Central to Isasi-Díaz's theology of struggle is the concept of 'Lo cotidiano'. While she utilises this in various contexts to convey different meanings, 'Lo cotidiano' broadly describes a process of active, ongoing participation in the choices, tactics, and conversations (Latina) women engage in an everyday politics of resistance. It refers to the 'stuff' of Hispanic women's daily lives; their shared but not common choices, practices, and understandings; complex, transitory, and formed in the struggles of everyday life (Isasi-Díaz, 2004, 67).

As I have raised in chapter four, parallels can be drawn from Isasi-Díaz's notion of 'shared but not common' experience and the lived experience of the mothers in this thesis (2004a, 142) Whilst the struggles which emerged can be seen to be shared, they are experienced and resisted in different ways. This holds particular resonance for the lives of mothers who are waging daily battles to obtain social support, fair healthcare outcomes, and inclusive education for their autistic children; and yet also battling the inconsistency and relentlessness of a daily life shaped by sensory overloads and disrupted sleep patterns. In chapters five and six, I have noted that whilst the unusual challenges of our children's daily routines and habits

can be a significance source of struggle, mothers of children on the spectrum often develop creative ways of engaging with this this struggle which resist the potential for overwhelment.

It must be noted, however that Isasi-Díaz's theology of lo cotidiano was developed in response to the particularities of the struggles of Hispanic women. Kwok Pui Lan questions whether by affirming this specificity, Isasi-Díaz's insights can really be translated to other contexts (2011, 35). Thus, I am cautious of the potential dangers of co-opting or colonising the experiences of others to suit a methodological ends (Goto 2018, 28) Kwok raises an important observation. Although Isasi-Díaz, as a Cuban-American woman, situates herself within her own particular research context, her reflection above highlights that even within a perceived 'community' the experiences of those within that community may be more unequal than equal. In my methodology chapter, I have problematised the issue of authority in being able to speak to experiences which are like our own, yet also not our own. In responding to Isasi-Díaz Kwok asks, how can we, as academics, authentically speak to the experiences of others, particularly when the voices of those others resist our theological scripts? (2011, 35).

As researcher, much like Isasi-Díaz, I am within the community of women I am seeking to research. While I came to this research with an understanding of many of the issues which might emerge, my knowledge of these issues could not assume exactly *what* they might reveal for my research. My participants were similar to me in many ways, speaking of struggles I knew all too well. However, their experiences were distinct from my own in many ways too. One such way was that they all had more than one child. This does not, in of itself, appear very significant. Nor did it to me. However, in considering my own experience, and questioning what might be different about the voices I am seeking to represent, it became particularly meaningful.

In reflecting on their shared stories, it was evident that certain aspects of their motherhood experience differed considerably between their children. The differences were often subtle; however, it was clear that mothering a child with autism involved considerably more time demands, thought, physical effort, and financial consequences. What has been revelatory to me is that I myself had until recently (and admittedly naively) considered the daily struggles I experienced as rooted in the experience of mothering generally, rather than mothering with autism, specifically. In reflecting on these subtle, yet significant differences, I suggest that while mothering with autism embodies many aspects of maternal struggle I have explored in this chapter, these challenges are *magnified* by their relationship to autism. This positions the

experience of mothering a child on the autism spectrum as a distinctly amplified and intense form of maternal struggle, and one which is not attended to within current theologies of motherhood.

Summary

In this chapter I have critiqued the reluctance of theology to fully engage with mothers as an important and generative source of theological reflection, articulating an experience of motherhood which defies incorporation into the dominant ideological paradigms of 'traditional motherhood.' I have considered how theologies which attend to issues of struggle in everyday contexts can speak to the experience of mothers whose lives are shaped by struggles which are disregarded as seemingly mundane and unremarkable, yet which significantly inform their choices, practices, and experiences of living. What is particular about the lived experiences which have emerged in this research is that they are doubly constrained by both dominant discourses of disability and dominant discourses of motherhood, and yet do not fit neatly within either. In the same way that I have considered theologies of disability neglected the experience of mothers, so too have theologies of motherhood and struggle not fully attended to the added complexity of motherhood in relation to disability.

Our lived experiences are thus revealed to be theologically problematic, as they cannot be adequately reconciled within any one theological discourse. A theological response which attends to the particularity and distinctness of such experiences must be similarly particular and distinct; resisting the temptation to neatly round the edges of what is revealed to fit within the boundaries of what has already been written. In the following concluding chapter, I will draw together theological elements which hint at this particular experience, from these proposing a theological response which attends to the complexity and ongoingness of lived experiences which are simultaneously ambiguous and mundane, resisted yet unresolved.

Chapter 9) Pragmatic Unresolvement: Towards a new theology of struggle

> Practical theology wants to keep our relationship with the world so that we are never quite 'done' with things; rather, always undoing and redoing them, so that we can keep the 'doing' happening- passionate-, keen, expectant—never satisfied, never quite finished (Veling 2005, 7).

This research has sought to develop an understanding of autism as a deeply ambiguous, misunderstood condition, resistant to disciplinary categorisation. I have demonstrated that autism occupies a position of incongruence in that it can be seen to be strongly shaped by dominant discourses of disability, and yet is 'invisible' and 'dis-embodied' in ways which disability theory largely neglects. Autism is thus 'unresolved' in many ways. Its cause is unclear; individual's symptoms can be seen to change, improve, or regress in unpredictable ways. Thus, what we know and understand about autism is continually evolving. What has emerged from the sharing of our stories is that mothering a child on the spectrum is an experience which is similarly complex, distinct, and currently theologically occluded. Our children's needs are varied and conflicting, often hidden within the seemingly unremarkable events of daily life. Facing these challenges in silence, we have had little opportunity to speak to our experiences.

While I entered this thesis with an awareness that what I may find might 'render my world stranger' (Bennett et al 2018, 143), I perhaps naively anticipated that our accounts would, nonetheless, echo much of what has been written and find their theological home. However, as Goto and Kwok have reminded us, lived experiences, even when assumed to be common, are subjectively intersectional, and therefore inherently resistant to generalisation (2016, 29; 2011,). In the preceding chapter, I have asked how practical theology may respond to such hidden voices which 'unsettle our theological assumptions'. Goto suggests that our very compulsion to answer to this question, to generalise or categorise experiences to fit an expected outcome, is at the root of a fundamental problem in the way practical theology constructs knowledge (2016, 222).

In attempting to reconcile our findings within traditional 'conceptual frameworks', Goto proposes that we inhibit our own ability to generate new knowledge, instead preserving what is already assumed to be known. What is 'already known' in practical theology, Tom Beaudoin suggests, is shaped by an unconscious and unquestioned white, male 'christianicity' which forms the theological blueprint for our practices, knowledge and

interpretations (2016, 18). In his de-construction of the 'practices' of practical theology, Beaudoin reveals formulaic processes at work which he suggests unconsciously shape what we consider to be 'theological;'

> …an intervention is normally framed in a theologically naturalized or essentialised fashion, such as claims about God-material showing itself in, through, or in relation to practice, along these familiar lines; God cares about X, Jesus is concerned with Y, the Spirit is known through Z (2016, 16).

This formula suggests a coherence and orderliness in which practice and theory are unproblematically reconciled. The reality however, as we know, is much more complex.

Approaching these tensions from a feminist, post-colonial perspective, Marcella Althaus-Reid has been particularly vocal in her critique that practical theology has been constructed within occlusive discursive regimes which determine exactly whose experiences count as theologically significant (2000, 18). As a female practical theologian who is 'outside' of a faith tradition, I have all too often felt the seductive pressure to situate my writing in relation to what has gone before, to speak in a 'Christian' voice that is not necessarily my own in order to legitimise what I am saying. My participants themselves all had distinctly different attitudes to faith and relationships with the divine. Some, indeed, had none. If I had attempted to reconcile their voices within normative epistemological boundaries, would this have precluded them from even entering the discussion?

Heather Walton considers that these issues raise fundamental questions as to 'whether practical theologians possess the capability to engage with voices that resist incorporation into conventional frames of academic credibility and coherence' (2018, 10). As someone whose voice resists such conventional frames, the question 'but am I really a theologian?' has plagued me throughout this research. Frustrated by the gaps and silences I encountered when attempting to locate our experience theologically, the gnawing doubt crept in 'If theology does not speak to this experience, is it even really theological?'

Drawing on Beaudoin's work in *Conundrums in Practical Theology* (2016)*,* Walton suggests that it is indeed right that we should question what is 'theological' about our work. However, she proposes that perhaps the gnawing anxiety this question provokes stems not from our own academic insecurities, but rather from a deeply hidden awareness that how we measure what is 'theological' is itself what is arguably problematic (2018, 226). Walton suggests that perhaps the answer is, 'We have never been theologians' (2018, 224). This provocative

declaration is not intended as a sweeping rejection of the work of theology, but rather an invitation to challenge our deeply held beliefs over what our task as theologians really is.

Increasingly, practical theology is being challenged to adopt more diverse, interdisciplinary models of theological reflection. In a pluralistic globalised society, Walton proposes that instead of lingering within the nostalgic comfort of tradition, we ought to re-consider how practical theology can creatively respond to the ambivalence and ambiguity of our post-secular world (2018, 226). Developing this from a feminist phenomenological perspective, Elaine Graham has offered nuanced and sophisticated contributions on the challenges of post-secularism and post-humanism within practical theology; urging us to find creative and engaging ways of moving between the 'rocks and hard places' of what we think we know, and what is really in front of us (2013, 60). Challenging us to become more comfortable with blurred boundaries and theological ambiguities, she reminds us that 'difference serves as disclosive, in that a deeper and larger truth is revealed as resting in diversity and pluriformity' (2002, 200).

Beaudoin affirms that practical theology must therefore 'hold open pre-Christian, Christian, post-Christian, and non-Christian meanings all at once, and let those meanings be non-exclusive to each other' (2016, 28). Considering what this may mean for the discipline, he asks 'is practical theology left with empty hands? No-or rather, Yes: practical theology is left with hands that become theological by how they give away what was never the property of Christianity to begin with' (2016, 28). This is not to suggest that practical theology ought to 'throw the baby Jesus out with the bath water.' Tradition is important. Rather, what the work of Beaudoin, Walton and Graham highlight is that practical theologians should now take the opportunity to critically examine our own epistemological preconceptions, defamiliarizing what we presume to be theology and pushing us towards new and diverse ways of knowing.

In the preceding chapters, I have explored many different theological responses in considering how I may come to locate and draw meaning from this particular maternal experience. These theologies are all distinct, however I would argue that they largely share a common thread in that what we are offered are theological reconciliations, whether their aims are at the personal level of accepting love (Swinton, 2012; Mackaskill, 2019; Reynolds, 2008) or at the social level of affecting change (Eisland, 1994; Block, 2002; Isasi-Díaz, 2014). In the theologies explored, what can arguably be demonstrated is a thread of 'overcoming.' Yet, as I have sought to highlight, our stories defied the archetypal narrative

pattern of 'beginning, conflict, and resolution' (Atkinson 1998, 3; Walton, 2018, 2). The concept of 'overcoming' thus offers little value to an experience of motherhood which is rooted in the ongoing daily realities of struggle, challenge, grief and joy from which there is no overcoming. I argue that in fact the suggestion of overcoming is potentially harmful, as it implies an end point to struggle which for some never comes.

In considering my participants struggle, I too fell into the trap of attempting to locate the 'how' in their survival. How did they cope, how did they make sense of the struggle, how did they find meaning in their experiences? I myself have been asked this question many times. I have often been left wordless in response, at other times frustrated by its naiveté. The simple answer to this was, we just did. My subjects and I are all distinct. Some of us acknowledge relationships with the divine, others do not. Yes, we spoke about our experiences having made us better people, and they have doubtless provided a different perspective on life. Yet the ways in which we considered this transformation or the meanings we attached to it were all very different. While some possessed a belief in the revelatory power of their experience, others were merely trying to get through the day. This was our life, there was little choice. As our shared accounts have highlighted, there is often little opportunity for respite.

While I have sought to demonstrate that whilst this particular maternal experience has been shown to be strongly shaped by socio political policies from above, the daily challenges of everyday living are also so all-encompassing that we must carefully 'choose our battles' in deciding exactly which struggle takes precedence. In being faced with such a choice, one or more battles are necessarily and inevitably lost. Our stories have reflected an active, ongoing resistance against institutional barriers to our children's well-being; yet also admitted a weariness in acknowledging that our potential to ever fully overcome these is limited. Thus, our 'tactics of resistance' are enacted with an acceptance that they are unlikely to solve all of our challenges, rather, they may ameliorate them just enough to fortify us for the next battle to be waged.

Drawing from Bonnie Miller-McLemore (1994, 142) and Sarah Ruddick (1994, 20), I have situated this pragmatic adaptability as a distinctly active, anticipatory, and resilient form of 'maternal thinking' which has significant generative potential for engaging with alternative stories of motherhood. Challenging the relegation of motherhood and its praxis to the 'domestic sphere', I have proposed that the everyday tactics of attentive mothering I have described are instead creative sites of resistance against the absence of institutional support.

In attending to the conflict of struggles from both 'above' and 'below', I have considered the work of Isasi-Díaz (2002; 2014) and De Certeau (1989; 2002) as particularly constructive in illuminating the tension between the political and the personal on our daily lives. Walton, drawing from De Certeau, proposes that attention to the everyday reveals the unnameable and unknowable in our encounter with the other, in a way that opens us up to the disruptive possibility of transformation (Walton 2014, 184). In reminding us that the 'everyday' is not a site of passive acceptance or mundane banality, but rather that some of our deepest theological challenges can be found within the mundane, messy, complexity of everyday moments; these theologies acknowledge the liberatory potential of the everyday as a site of struggle and resistance.

I have expressed my deeply held reluctance, however, to disingenuously represent our experiences within a context of 'liberation.' Liberation implies a release from the *sources* of struggle, which, in this particular lived experience, is not only unrealistic, but is in many ways impossible. Autism is a life-long developmental condition. Many of the struggles we as mothers face have been shown to be directly related to autism symptomologies: which, as I have highlighted, may improve, but will never disappear. In a similar way, while the organisational and attitudinal sources of struggle we experienced may be resisted; they are so overarching that we often simply do not have the time, resources, or energy to overcome them.

Describing her work on trauma as 'suffering which does not go away,' Shelly Rambo invites us to find 'resonance in the unknowing', resisting the urge to find theological justifications for experiences which are uncomfortable, unsettling, and unspeakable (2010, 15). Echoing Rambo's reflection of the ongoing and everydayness of living with multiple traumas, recent work by Nicola Slee has highlighted the potential to become over-burdened by everyday 'multiple overwhelmings' which are complex, overlapping and multi-faceted, yet also an inescapable part of life (2017, 21). Drawing from Deborah Creamer's theology of limits as a natural, unremarkable part of living, Slee considers a theological re-framing of overwhelment and struggle as normative, rather than counter-intuitive, to our daily lives (2017; 26). Acknowledgement of our 'limits' not only speaks to the practical acceptance of what we cannot change but also defies the dominant theological imperative to seek resolutions. It does not assume that all struggles can be easily be made sense of, nor should they be, but rather invites us to endure; creatively, actively, pragmatically, in the midst of and in spite of our struggle.

Attending to the particularity of the experience developed throughout this thesis as an ongoing and distinctly difficult form of maternal struggle, I propose an interdisciplinary theological response which recognises that experiences are not a-historical, singular or unrelated, but rooted in the overlapping and complex forces of daily life which do not easily make sense within any singular framework. I propose that what is currently absent, and what is needed, is a theology which attends to life as it is and does not attempt to silence experiences it cannot neatly explain within the accepted discourses available to it. In response, I offer a new theological thinking, drawing from the theological approaches which have almost touched, but not quite reached, the lived experience I have revealed in this thesis. I invite you to consider a theological response which acknowledges that life is often unsettled, unresolved, and that not all challenges can be quite so neatly tucked away.

Responding to the ambiguity and restlessness of lived experiences whose edges are blurred and permeable, I propose a theology of 'pragmatic unresolvement.' In drawing together the threads of active, every day maternal praxis revealed in this thesis, this theological response is *pragmatic* in proposing an acceptance of the cyclical, conflicting, and irresolvable forms of struggle which are out with our ability to conquer. Attentive to the irresolution and ambiguity of lived experience, this theological response is also *unresolved*, in that it recognises the ongoing, cyclical, and compounded nature of struggles which do not have a definitive end point, nor the potential for overcoming. Theologies which attend to the unsettled, the unknowable and the ambiguous may offer significant revelatory potential in challenging our deeply held assumptions about both our tasks as theologians, and our relationship to the divine. They may give space to reflect on experiences which are not temporal, immediately visible, or easily understood.

Presenting us with the theological challenge to see and bear with the ongoingness and unsettledness of daily living, a theology of pragmatic unresolvement seeks to blur the boundaries between immanence and transcendence in a way which is fluid, adaptive and 'never quite done' (Veling 2005, 7). In an age of ever increasing uncertainty, of economic instability, political tensions, and global health inequalities; it is ever more important that we move beyond dichotomous theological scripts of the Christian/ non-Christian, of divine omnipotence or secular abandonment, and 'consider this more risky, immanent and vulnerable image of a God who permits Godself to be caught up within the overwhelming' (Slee 2017, 31). Reminding us that our tasks as theologians is to risk transformation, Walton

revels in the complexity, ambiguity, chaos and wonder of life as it is, not as we expect to find it,

> I know I am most alive in the messy, compelling, tragi-passions of everyday life. I do not seek deliverance from them but rather revelations within them. In fact the thing I probably most fear is the resolution of contraries in a peaceable whole. The stark irresolutions we encounter (they make both beauty and tragedy) are what make us human, and for me these are also the key to understanding God in the light of incarnation (2014, 86).

Conclusion

In beginning this thesis, I considered that its theological contribution would be to highlight a lived experience which was occluded, obscured, and difficult to name. I anticipated, however, that the stories presented would find their theological home within the words and pages of others who had chosen to share their lives. Instead, what has emerged is a theological response to the gaps and silences in those narratives, to the tensions and conflicts between what is considered known in practical theology and lived experiences which defy to be known.

In proposing a theology of pragmatic unresolvement, I do not presume to have offered a new, cohesive and complete methodological approach. Rather, in drawing from theologies of limits, I acknowledge that this theology too is limited. In undertaking research which looks to the particularity of mothers, I have admittedly excluded the voices of fathers, and indeed individuals with autism themselves. As I have touched upon in chapter four, this thesis also reflects a predominantly white lived experience, and thus does not investigate the ways in which racial inequalities may significantly impact this experience. This theological reflection has not been intended to be an exhaustive analysis of these many different perspectives; rather it is but one perspective of a complex issue.

In highlighting the experience of mothers, I hope to have afforded insight into the experience of autism itself, opening a conversation into how we may reflect more authentically on autism. This is merely the beginning of a conversation. Its emergence was unanticipated but instinctive, responsive to the theological silences it encountered. Thus, it is the beginning of something which is not yet done. It is a call to invite others to consider wading into the

murky waters of a theological engagement with life as unknowable, unsettled, and thoroughly untameable.

Epilogue

Unprecedented

Uncertain

Socially Distant

These are the watchwords which are defining our 'new normal', as it has come to be called. There is nothing normal about it, which, in a strange way for us, is almost comforting. We are used to making 'new normals.'

In the final weeks of my writing, our world was rendered stranger than even we were used to. We had heard rumblings, murmurs, a foreshadowing of what was to come. Yet when it came, it felt sudden, abrupt, like jumping into cold water you expected to be warm. On the day of the announcement, Micah had a mere twelve weeks left of Primary School. We had submitted a placing request to our high school of choice, and he was anxiously trying to stem back the flow of time until he would have to say goodbye to the faces, rooms, and routines he once knew. As it would turn out, goodbyes were to come a lot sooner than expected. We were in 'lockdown'. In response to the catastrophic damage COVID 19 was wreaking across the globe, we were plunged into a state of suspended animation, urged to 'stay home, to save lives.'

On that last school day, I waited at the same spot I had every day for seven years, but it was different now. He was different now. No longer did I stand in dread, anxious of the day he had had. Our days have slowly, gradually, become, for all intents and purposes, something close to 'normal'. That last day was not to be one of those days. That last day, he came out of the main door. Flanked by his teachers, they formed a guard of honor, clapping as his class tearfully left school for what was likely to be the last time. At one time, his participation in this would have been unthinkable. That day I watched as he walked out shoulder to shoulder with his peers, fighting back tears, but a part of it all. We didn't know if they would be able to return. We knew simply that we had to mark this moment for them, to pre-empt a conclusion that was yet to be drawn.

It has since been 10 weeks since that day. There have now been over 400, 000 deaths worldwide. Our 'new normal' is composed of oxymorons; 'self-isolation', 'socially distant',

'working from home.' All of our carefully calibrated equilibriums have been thrown into disarray. Our routines, disordered. Our social supports, severed.

With all the unknown, and in the absence of the comforting and reliable structure school provided, many of the issues we had thought were things of the past have re-surfaced. The 'tics' which we had believed to have disappeared years ago, are now a regular occurrence. Micah's anxieties are manifesting in the 'little things' he may exert control over; once again, shoes are his nemesis. My days are spent anxiously trying to pre-empt these challenges, trying (often futilely) to create some sense of order to his little world. In between these attempts, I am working from home, writing, teaching…washing, cooking, comforting…mothering. On some days, I have been able to balance these commitments; on others, I have been left hollow, exhausted from the effort.

And yet, there is a curious sense of calm in our imposed isolation. I have been able to re-learn who Micah is, to see him through my own eyes, and not the stares of others. We have very recently learned that, despite our fears, he will in fact be able to attend the school we had hoped for. I am acutely aware, however, that many of the carefully choreographed mechanisms which have sustained his ability to manage will not follow him there. Right now, we don't know what High school will look like when it comes. Will he continue to learn from home? Will I be able to return to work? We don't know what the world will look like. I don't know how he will cope with all the change, the uncertainty, the unknown. All I can hope for is that others will learn to enjoy Micah, and say, with 'unfeigned sincerity, I am glad you are here.'

Post-Script: Micah's own words.

Having autism doesn't necessarily mean that you are extremely hard to take care of or will always have trouble managing things. But I feel as though being diagnosed with autism is challenging, it's a strange thought being different than other people. I also have Tourettes Syndrome, which can be challenging because I have had multiple ticks. ADHD is also a challenge. I take pills to limit my extra energy. It is sometimes difficult to take a pill every morning and night. Sometimes I forget to take it, but most of the time I remember.

I think I have grown so much from when I was younger. I went from being an aggressive kid with anger issues to one of the most relaxed people I know. I think that when I was younger it was probably very challenging for my mum, and it still probably is. But I think we have bonded so much throughout my life it's extraordinary. I hope she thinks so too.

Appendix 1: Participants and Interview Process

Interview Process

In beginning this research, I approached a local non-profit autism organisation and the staff team at my son's primary school to facilitate a call for participants to contribute to this research. They kindly agreed to notify their respective communities about this research and invite mothers willing to share their experiences of parenting a child on the autism spectrum to participate.

From the responses received, I selected three participants. These participants were selected on the basis that they did not possess any potential vulnerabilities (as defined by the University's guidelines on vulnerable groups), that their child had a completed diagnostic assessment of autism, and that they had demonstrated awareness of and access to support if required.

The interviews were conducted between June 25th 2019 and September 25th 2019. My son's primary school offered the use of a confidential meeting room to ensure participant and researcher safety, and anonymity. Initially, I had anticipated to require between one and three interviews with each participant in order to establish a position of trust and to obtain sufficient depth of data.

Each taking around two hours, my participants spoke candidly and openly about their diagnostic journey, their feelings during and after diagnosis, and the challenges they faced as a consequence of their child (or children's) condition. The depth of detail in each interview was abundant enough that no follow up interviews were required, although this was left open as a possibility should my participants want to revise, add, or redact anything shared in the initial meeting.

Participants

The first participant, Naomi, is a mother at my son's school whose son's diagnosis mirrored my own (Aspergers, ADHD & Tourettes). Naomi is married and had two other neurotypical children to accommodate in addition to her son. This was revealed to add a particularly distinct facet to her experience, in which she faced additional challenges as a result of the competing needs of her family. Naomi reflected that her identity had been somewhat taken over by her son's diagnosis, in that she was unable to maintain her career, hobbies, and social life.

Scarlet is a local mother of a son and a daughter. Her older daughter has a diagnosis of ASD, while her son does not. Scarlet is divorced and lives alone with her two children. She described having a supportive partner, although they do not live together. Scarlet also described many challenges of lone parenting which resonated with my own experiences, particularly the enhanced stigmatisation we felt as a consequence of being single mothers. As a mother of two, Scarlet echoed Naomi's conflict around balancing the needs of one child against the other. Scarlet felt very strongly that children with an autism diagnosis and their families were not adequately supported within the local authority, reflecting that many of the professionals she encountered displayed outdated or prejudiced attitudes towards autism which delayed her daughters diagnosis, and access to support.

Abigail is a married mother of two children: a daughter and a son, both on the spectrum. She was able to compare the diagnostic process for each, noting that it was significantly longer, and more challenging, for her daughter than for her son. She felt similarly strongly that her family had been let down by inconsistent diagnostic processes and education policies which were slow to respond to additional support needs. Whilst her daughter is able to maintain a mainstream school placement (due to extensive strategies put in place by Abigail herself); Abigail's son could not, with Abigail successfully advocating for an additional support needs placement for him.

Themes

Whilst each participant had distinctly different social histories and contexts, central themes emerged from their interviews which informed the results of this thesis. These included:

- Difficulty in obtaining a diagnosis
- Stigmatising and occlusive attitudes of others (particularly within professional contexts)
- Conflicting emotions of relief, anxiety, fear and loss in relation to their child's diagnosis
- 'Battling', 'Fighting' and 'Advocating' for understanding and support for their children.

Whilst each participant brought their own unique context to the interview, it became clear that each of us were navigating the challenges of our distinct maternal roles against much wider social and structural inequalities. This indicates that while the experience of mothering

a child on the autism spectrum can be demonstrated to be more challenging than typical mothering, some of these challenges could be ameliorated by more inclusive and supportive social policies.

Appendix 2: Sample Interview Questions

- How old is your child?

- At what age did your child receive a diagnosis?

- How long did the diagnostic process take?

- Do you feel the support available to you throughout the assessment process (if any) impacted your response to the diagnosis?

- How do you feel the diagnosis has impacted your family?

- How do you feel the diagnosis has impacted the relationship with your child?

- Could you share some of your experiences or challenges of parenting, before or after diagnosis, which you feel may be relevant to the project?

Appendix 3: Consent Form

 University of Glasgow

<div align="right">College of Arts
Theology and Religious Studies</div>

CONSENT TO THE USE OF DATA

I understand that Eilidh Campbell is collecting data in the form of unstructured/ semi-structured interview, life writing, journal writing, or creative methods requested by participants for use in an academic research project at the University of Glasgow.

This project will be researching the emotional impact of parenting a child on the Autism Spectrum and looking to establish parallels between some of the emotions experienced following a diagnosis of autism, and what are considered to be 'grief emotions' commonly experienced following a bereavement.

This project will be using contemporary literature in the fields of theology, gender, grief and disability studies, along with excerpts of personal life stories from participants in their chosen method of communicating. For example, life writing, journal entries, or interviews. This research will be used to form the basis of the researcher's thesis for submission in Doctorate of Practical Theology.

I give my consent to the use of data for this purpose on the understanding that:

1. I have discussed the project with the researcher and am aware that it deals with sensitive and potentially difficult issues. I have considered the potential risks associated with this and am willing to participate. I understand that I can withdraw from the project if I find participation uncomfortable or distressing.
2. I have the choice to leave any question unanswered.
3. Interviews: Interviews will be transcribed, and the recordings deleted.
4. All data and materials will be anonymised, meaning my name and all identifying information will be removed or redacted.
5. Project materials in both physical and electronic form will be treated as confidential and kept in secure storage (locked physical storage; appropriately encrypted, password-protected devices and University user accounts) at all times.
6. I may withdraw from the project at any point up until the anonymisation of materials is completed (October 1st 2019). If I choose to do so, all materials I have provided will be destroyed immediately.

7. I understand that once the materials are rendered anonymous, then in accordance with current legislation (General Data Protection Regulation) I will no longer have rights relating to the use of the data unless I have legitimate grounds for concern that I remain directly identifiable from it.
8. Project materials will be destroyed on completion of the thesis.
9. The thesis resulting from this research will be available in the public domain via the University Library website.
10. The anonymised material may be cited and discussed in future publications derived from the thesis, both print and online.

Name of Participant: _____ Date: _____

Signature: _____

- **Researcher's name and email contact:** Eilidh Campbell
  e.campbell.3@research.gla.ac.uk
- **Supervisor's name and email contact:** Heather Walton heather.walton@gla.ac.uk
- **Department address**: No 4. The Square, University of Glasgow, G12 8QQ

Appendix 4: Participant Information Sheet

The aim of this research is to gain a deeper understanding into the experiences and challenges faced by parents of children on the Autism Spectrum, in order for parents experiencing struggle to be better supported theologically and pastorally following a diagnosis. In particular, I will be looking to identify parallels between the emotions experienced following a diagnosis of autism and the emotions most commonly associated with the grieving process.

I will be looking for personal accounts of experiences prior to, during, or following diagnosis; reflections on the emotions experienced during this process, or any thoughts on your experience of parenting with autism generally that you wish to share. As a mother of a child with Autism, I will also be a participant as well as researcher to this process.

This project is intended for submission in April 2020.

Q&A

What is the research for?

You will be participating in a research project for the purposes of a thesis submission for the completion of the researcher's PhD at the University of Glasgow.

Who is the researcher?

The research is being undertaken by Eilidh Campbell, doctoral student in Practical Theology at the University of Glasgow who is also a mother to 10 year-old boy with Autism. The researcher has a full and current PVG, and has a background in social care.

How long will the research take?

The participant based involvement for this project will be during the final year of the research process, May 2019- April 2020, however your active participation in the project will consist of no longer than the initial 6 months of this duration. The completion of your participation will be October 1st 2019. The frequency or duration of your involvement is optional, as your participation is voluntary. Your participation is anticipated to consist of 1-3 meetings, either by telephone or face to face in a meeting room facilitated by the local authority (Goldenhill Primary School).

How will I be contacted?

The methods of communication will be participant led, which means I will be requesting information in whatever format you feel most comfortable with. I intend to conduct between 1-3 semi structured interviews, either by telephone or face to face in a meeting room facilitated by Goldenhill Primary School. However, should you prefer, you may choose to submit a creative contribution. This may take the form of life writing (i.e writing about a particular moment or experience from memory, and reflecting on that experience), unstructured interview (an open discussion in which you are free to tell me what you wish either in person or over telephone), journal entries should you wish to use a journal throughout the process, or any other creative methods which feel comfortable to you.

How will my information be used?

Your responses will be used as independent case examples, highlighting aspects of experiences or emotions associated with parenting a child on the autism spectrum which will be explored in the thesis.

Your responses will be presented as accurately to your own words as possible, and in the case of any edits, will be provided to you for your approval or amendment. You may review, amend, or withdraw any response given throughout the research process until the date provided for final completion of anonymised data (October 1st 2019). Your withdrawal may be given verbally, or in writing at which point any and all information provided by you will be destroyed.

Will this be confidential?

The research process is confidential. Any personal information collected will be minimal, and only what is necessary and fit for purpose in accordance with GDPR regulations. Your data will be anonymised for presentation in the thesis, to ensure your confidentiality. Any information relating to you or provided by you will be stored securely and confidentially on a secure University storage drive and any unnecessary data will be destroyed. The research data collected will be destroyed following submission of the thesis.

What do I do if I have questions, concerns or complaints during the process?

As researcher I will be available throughout the process to answer any questions or concerns, however if you feel more comfortable raising any issues with an independent party, a University of Glasgow Doctoral supervisor will be available as point of contact.

Contact details for researcher: Eilidh Campbell   email: e.campbell.3@research.gla.ac.uk

Contact details for supervisor: Heather Walton   email: heather.walton@gla.ac.uk

Where can I find support during the research process?

As researcher I aim to support you throughout the research process. However, prior to undertaking your involvement, we will rehearse the potentiality of any triggers or emotional distress, and discuss the resources and support currently accessed by you as your point of contact should you experience any stress or emotional disruption relating to discussing your child's diagnosis. Further to your existing support networks, there are several external support agencies available to parents of children on the Autism Spectrum (See below).

National Autistic Society Helpline: 0808 8004104

NAS Parent to Parent Helpline: 0808 8004106

Vale of Leven Autism and Aspergers Forum: 01389 750384

West Dunbartonshire Social Work, Children and Families: 0141 562 8800.

CAMHS (Children and Adolescent Mental Health Services): 01389 817324

Adult Mental Health Service: 0141 941 4400.

[**www.autismlinks.co.uk**](http://www.autismlinks.co.uk)

Appendix 5: Risk Assessment

1.1 Physical Risk

Identified Risks	Likelihood High/ Medium/ Low	Potential Impact Who might be harmed and how	Risk Management	Mitigating Factors
Low risks identified due to face to face interviewing process.	Low	Physical risk to researcher Vulnerability of participant depending on location of meeting.	The option of telephone interviews will be offered where appropriate. Meetings will take place in a private meeting room facilitated by the local primary school to my participants. This will function both to preserve privacy and anonymity, and as a safe space within a public building to ensure neither participant or researcher will be alone or vulnerable.	The building itself has it's own security, with secure door entry, security cameras and fire safety procedures in place.

1.2 Psychological Risk

Identified Risks	Likelihood High/ Medium/ Low	Potential Impact Who might be harmed and how	Risk Management	Mitigating Factors
Discussion of a sensitive topic may produce strong emotions/ distress in participants.	Medium	Participants may find it difficult or upsetting to share their stories, particularly if this is the first time.	There will be a clear and open dialogue with participants before consenting to the research project on the potential emotional impact. During the initial conversation, researcher and participant will rehearse the potentiality of emotional	As the research is also personal to myself as researcher, there is also the risk of emotional distress in my own undertaking of the project. This will be managed through supervision and the external support resources of the participants.

			distress and confirm the pre-existing resources and support accessed by the participant which they may reach out to in such an event. The intended participants all have existing support networks ranging from the local CHALMS team, social work, school counsellor and local autism groups.	
Vulnerability of participants	Medium	Although the participants will be adults not perceived to be of a 'vulnerable' group, however, they are caring for a vulnerable group and the sensitive nature of the topic may evoke emotional responses.	The researcher has a current full PVG for both adults and children, and a background in social care working with vulnerable adults with complex support needs. Through this role, protection of vulnerable adults course has been completed. Regular informal check ins will be had with participants to ensure their well-being. Participants will be reminded that this research may bring up emotional subjects and that they may partially or fully withdraw from the process at any point should they experience distress or be affected by external life stressors which may be compounded by the research process. Participants will be encouraged to make use of their preexisting supports,	Changes in circumstances will be monitored, as dramatic life events may potentially increase a participants vulnerability

			however information will be provided as to external support agencies available to participants should they be experiencing emotional distress.	
Potential Disruption to family life	Low	Participants may find sharing challenging experiences may bring up tension in the family unit.	Regular check ins will be undertaken with the participants involved to ensure their emotional needs are being met and that their circumstances have not changed (impacting their potential vulnerability). Participants will be encouraged to access their existing support agencies should difficulties arise, and will be provided with information as to alternative support agencies should they prefer.	
Being known to the researcher	Low	Participants may feel anxiety about being known to the researcher in terms of confidentiality or potential judgement.	The participants will be voluntary and already known to the researcher, so a relationship of trust has been established. They will only be requested to provide information which they feel comfortable sharing, and may withdraw this permission at any time.	

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