The Experiences of Stress, Support, and Self-Care in Mothers of Children with ASD –
An Exploratory Study

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Declaration

I declare that this thesis is entirely my own work, other than the counsel of my supervisors, is an accurate reflection of work, and has not been submitted as part of another degree at the University of Limerick or any other academic institution.

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Joanna Connolly                Date
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Abstract

**Introduction:** The existing literature confirms time and again that parents of children with Autism Spectrum Disorder (ASD) experience higher levels of stress than other parents. The current study aimed to explore the subjective lived experience of mothers of children with Autism Spectrum Disorder and gain insight into their perspectives on sources of stress as well as strategies and supports they engage in or would like the opportunity to explore.

**Methods:** A qualitative design was undertaken and semi-structured interviews were conducted with participants. Twelve mothers of children with a diagnosis of ASD were interviewed. Interviews were audio recorded and transcribed verbatim by the researcher for analysis.

**Results:** Data analysed using Interpretative Phenomenological Analysis (IPA) led to the development of five super-ordinate themes: Experiences of ASD; Interacting with Services; Experiencing ASD in the Family; Recognising Mental Health; and Aspiring for Change.

**Discussion:** This study provided an opportunity for mothers to speak openly and subjectively about their experiences of the stressors associated with raising a child with ASD. The study findings are discussed in relation to the existing literature. Implications for policy, education, clinical practice, and future research are discussed with particular emphasis on family-centred practice in service delivery.
“I’m almost in a state of constant stress, so much so that I don’t really know what calm feels like anymore.”

Chapter 1: Introduction

1.1 Overview

The aim of this study was to explore the experiences of stress in mothers of children with a diagnosis of Autism Spectrum Disorder (ASD). Within the literature, there are a great deal of studies exploring the existence of stress in parents of children with ASD. However, there is a lack of focus on the individual lived experiences of stress in this population, despite the growing acknowledgement of the importance of having these voices heard. The current study sought to address this gap in the literature and provide a clearer understanding of individual accounts of stress, self-care, and support with mothers of children with ASD in Ireland. Thus, the study’s overarching research question was ‘What are the experiences of stress, support, and self-care in mothers of children with ASD?’

Twelve individuals, based along the East Coast and Midlands of Ireland, were recruited for this study. All participants were mothers of children with a clinical diagnosis of ASD. This study utilised a qualitative approach, specifically Interpretative Phenomenological Analysis (IPA), to explore aspects of mental health, coping, and resilience related to raising a child with ASD. The qualitative approach used here was inductive, preserving and emphasising the unique nature of each individual’s experience.

This study finds that stress is a universal and constant companion for mothers of children with ASD, permeating aspects of life such as family relationships, perspective on society, concerns for the future, and considerations around mental health. Supports are available but lacking, with mothers seeking to change existing support structures or seeking alternatives to the standard offered by the state. Self-care appears to be tenuous at best, with mothers acknowledging shortcomings in their ability to mind oneself in the context of prioritising the wellbeing of those around them.

The contribution of this study is to advance the limited qualitative data on maternal experiences and needs related to stress and coping when raising a child with ASD. This study provides a greater insight into the challenges and unmet needs faced by this population, and allows for further understanding as to how services could be better equipped to meet the needs of individuals and their families who are supported by those services.
1.2 Thesis Structure
Chapter Two will examine current knowledge available in the literature in the field of parenting stress and self-care in the context of having a child or children with ASD. Chapter Three will outline the methodology used including the research design, data collection, and data analysis. Chapter Four will depict the main research findings with a combination of first-hand quotes and accompanying interpretation. Chapter Five will explore the main research findings in the context of the current literature examined in Chapter Two, as well as provide a conclusion and personal reflections on the research project as a whole.

1.2.1 Chapter 2: Literature Review
This chapter reviews the relevant literature in relation parenting a child with ASD. Literature on stress, parenting stress, and resilience is explored with particular focus on the impact of ASD on parenting stress and ability to recruit resilience as a coping strategy. Related literature on family-centred practice is presented, with a focus on how this relates to service provision and development of current policy in Ireland. The chapter concludes with an exploration of gaps in the current literature and an introduction to the main aims of the current study.

1.2.2 Chapter 3: Methodology
This chapter discusses the rationale behind the theoretical framework and research design. The processes of participant recruitment, data collection, and data analysis are outlined with each step involved clearly outlined. Ethical considerations as well as issues of reliability and validity are also addressed here.

1.2.3 Chapter 4: Results
This chapter outlines the findings from 12 transcribed and analysed interviews with participants. Findings are depicted as 5 main superordinate themes with their own inherent subordinate themes. Direct quotes from participants are used to illustrate each theme along with accompanying interpretative comments.

1.2.4 Chapter 5: Discussion
The findings in Chapter Four are explored here in the context of the available body of knowledge examined in Chapter Two. In addition, the research will be critically appraised with reference to strengths, limitations, implications for clinical practice, future research, and education, and policy development. The chapter concludes with an overall summary of the research and a reflective piece which examines the researcher’s experiences with the research process.
Chapter Two: Literature Review

2.1 Literature Search Strategy
In order to identify relevant existing literature, a comprehensive search strategy was utilised with the following databases: PsychInfo, PsychArticles, PubMed, Google Scholar, Cochrane Database, JSTOR, and ProQuest Dissertations and Theses databases via the Glucksman Library in University of Limerick as well as the TARA database via the Berkeley/Lecky/Ussher (BLU) Libraries in Trinity College Dublin. Unpublished theses and dissertations were accessed through professional contacts. A wide range of potentially relevant key search terms were searched for within these databases in order to identify relevant articles, drawn from the overarching research question: ‘What are the experiences of stress, support, and self-care in mothers of children with ASD?’ Search terms were used alone or in conjunction with each other, and included the following: ASD, stress, parenting, caregiver, parental stress, self-care, family-centred care, HSE, intellectual disability services, Ireland, diagnosis, assessment of need, parent-clinician relationship, parent-professional relationship, parental experiences, Interpretative Phenomenological Analysis. Titles and abstracts of papers found through search results were reviewed and the most relevant articles were saved for reading and critiquing. Additionally, the reference sections of these most relevant articles were examined and further relevant publications were identified for review.

The structure of the literature review was initially envisaged as an inverted triangle, with general information around the broader topics of “ASD” and “Stress” presented at first to provide a framework to the area, and more specific information around this study’s own research question presented towards the end of the chapter as the focus of the literature review became more explicit. Given the contemporaneous transitional period of Disability Services in Ireland, the inclusion of details on current policies was deemed to be crucial in placing the importance of the current research in context of the lived experiences of Irish families receiving support from such services.

The content of the literature review was originally focused on stress and parenting a child with ASD. However, as the literature review progressed, the concept of “resilience” became more prominent in the literature found using the above search strategy. It quickly became apparent that “resilience” deserved its own dedicated section in the chapter, a decision that was easily reinforced following data collection and analysis (See Chapters 4 and 5). Thus, the non-linear nature of conducting a research study – i.e. revisiting the literature before, during, and after
data collection and analysis – influenced primarily the content of the literature review, and also the structure of the review, in that the order of content was rearranged over time so that a coherent narrative would be presented.

2.2 Autism Spectrum Disorder

ASD is a neurodevelopmental disorder characterised by deficits in reciprocal social interaction and communication, and engagement in restrictive and repetitive patterns of behaviour (American Psychiatric Association, 2013). Individuals with ASD vary widely in their presentation; for example, some individuals with ASD will have superior IQs, while up to 50% of individuals with ASD in Ireland will have an intellectual disability (Department of Health, 2018). Males are up to 4 times more likely to be identified with ASD than females, a consistent observation found in the vast majority of epidemiological studies (Department of Health, 2018), although the topic of girls/women with ASD being under-diagnosed or receiving later diagnoses is an issue currently receiving some attention in the research (Dean, Harwood, & Kasari, 2017). Along with the core components of deficits in social communication and restrictive and repetitive behaviours, children with ASD also have a high rate of internalising and externalising disorders and as such are more likely to meet criteria for additional mental health disorders (Salazar et al., 2015). Internalising disorders may include emotional or anxiety disorders, while externalising disorders include Oppositional Defiance Disorder (ODD) or Attention-Deficit Hyperactivity Disorder (ADHD) (Schrott et al., 2018). A population-based study in the United States found that ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses was found to be 83%. The co-occurrence of one or more psychiatric diagnoses was found to be 10% (Levy et al., 2010). These studies point to the complexity of ASD, given the heterogeneity of presentations in ASD itself, and also the likely co-morbid conditions that may manifest in a great deal of individuals with ASD.

2.2.1 Prevalence of ASD

Given the lack of a specific nationwide autism registry in Ireland, it is difficult to pinpoint a prevalence rate for ASD. The Department of Education have used a prevalence rate of 1.5% based on the number of children with a diagnosis of ASD who are accessing special education services (in Department of Health, 2018). In addition, a recent epidemiological study in Ireland reported a similar rate of ASD prevalence (Boilson, Staines, Ramirez, Posada, & Sweeney, 2016). This is in line with international rates cited in the literature (Fombonne, 2018). An increase in prevalence rates of ASD has been noted nationally (Department of Health, 2018).
and internationally (Centers for Disease Control and Prevention [CDC], n.d.). While the exact cause for this increase in prevalence remains unclear, a number of theories have been posited to explain this phenomenon. Advancements in screening and diagnostic techniques may be contributing to increases in the ability to categorise individuals as having ASD. Broadening of the diagnostic criteria for ASD with the publication of the DSM-5 could have contributed to some increase in prevalence rates. Additionally, improvements in the general layperson’s awareness of the signs and symptoms of ASD may lead to increases in parents or teachers raising concerns, allowing for greater recognition of the disorder by health care providers which may otherwise have gone undetected in years past.

Research into the causes, contributions, and manifestations of ASD are ongoing. One emerging neurodevelopmental theory suggests an interesting hypothesis which may influence the development of ASD in the growing brain, known as the dysconnectivity theory in autism (Thomas, Davis, Karmiloff-Smith, Knowland, & Charman, 2016). One recent study demonstrated how traditional categorical models usually used for describing illness or disease may not be best suited for a dimensional disorder such as ASD, and explored the utility of a hybrid model which integrates both categorical and dimensional approaches (Kim et al., 2018). The emergence and utility of sophisticated analytical procedures alongside theoretical conceptualisations may continue to aid development of knowledge surrounding the nature and expression of ASD, which may in turn lead to further developments in clinical management and family-centred practice interventions. Overall, it is generally accepted that the causes of ASD are complex and multifactorial, with a combination of neurodevelopment and the environment being contributing factors alongside the strong role played by heredity all combining in the development of ASD.

2.3 Stress

A formal definition of stress is as follows: “stress refers to a broad class of problems differentiated from other problem areas because it deals with any demands which tax the system, whatever it is, a physiological system, a social system or a psychological system and the response of that system” (Lazarus, 1971). This definition of stress focuses on the concept of psychological stress and was developed in the field of cognitive psychology. Since this stress theory was first proposed, it has undergone a number of revisions (Lazarus & Launier, 1978; Lazarus & Folkman, 1984; Lazarus, 1991). In the latest version (Lazarus, 1991) emphasis is placed on the relational nature of stress. Stress is not defined as a specific type of external or environmental stimulus, nor is stress defined as a specific pattern of reactions to such stimuli,
be those reactions physiological, behavioural, or psychological. Rather, stress is viewed as a relationship between individuals or systems and their environment. “Psychological stress refers to a relationship with the environment that the person appraises as significant for his or her well being and in which the demands tax or exceed available coping resources” (Lazarus and Folkman 1986, p. 63). This definition emphasises two processes as central mediators within the person–environment transaction or relationship: cognitive appraisal and coping (Krohne, 2002).

This theory proposes that stress results from an interaction between an individual person (or a family unit) with the environment. When the individual perceives that the environmental stressors have overwhelmed or outstripped their available resources, the individual engages in coping mechanisms in order to restore an equilibrium in functioning. If the coping mechanisms recruited by the individual are either maladaptive or insufficient to adequately meet the posited challenges, the resulting outcome is stress.

Individuals have available to them a number of potential “buffers” or resources that may mediate the experience of stress. These buffers may allow the individual to perceive that they have a greater number of resources available to them which can counter the environmental stressors they are experiencing. Buffers can take the form of social support (Bowen et al, 2014), cognitive processing styles (Creswell & Lindsay, 2014; Conner & White, 2014), or feeling connected with others in terms of similarity of emotional experiences (Townsend et al, 2014). An increase in buffers would in theory increase an individual’s perceived ability to manage stress and potentially ameliorate the experience and impact of stress on the individual’s physiological, emotional, or psychological wellbeing.

There exists decades of research surrounding the impact of stress on wellbeing. The potential ramifications of stress are numerous and varying in degree of severity, but can include physical and/or psychological symptoms such as restlessness, fatigue, depression, gastrointestinal symptoms, and an increased risk of heart disease or ulcers (Lovallo, 2015). A review of stress and health states that exposure to stress has more of an impact on psychological and psychiatric health than previously believed, with ongoing chronic stressors having a more negative impact on mental wellbeing than experiencing a negative event or trauma (Thoits, 2010). Thus it could be argued that the ongoing stressors of parenting a child with ASD may have such a profound impact on parental mental health that it would be negligent for disability services to not explicitly address this issue. Folkman and Lazarus emphasised the importance of recognising
that stress, and indeed stressors, are individual and unique, and will not necessarily have the same impact on each individual. As such, stress is subjective and perhaps not best measured by objective quantitative measures, as the majority of research into stress tends to do. This will be discussed further in Section 2.5.

2.3.1 Parenting Stress
Parenting stress is a specific type of stress defined as the aversive psychological reaction to the demands of being a parent. Parenting stress usually occurs when a parent’s perceptions of the demands of parenting are not adequately matched to the perceived resources available to the parent that are required to deal with those demands (Liles et al., 2012). It may be acceptable to presume that all parents may experience some degree of parenting stress; indeed, experiencing a certain amount of parenting stress is considered normal (Nelson, Kushlev, & Lyubomirsky, 2014). Moderate levels of stress can be adaptive and allow for the successful conquering of challenging circumstances or events. However, elevated levels of parenting stress are seen in parents of atypically developing children, with a good deal of research focusing on the impact of stress on mothers in particular (Benson, 2014; Conner & White, 2014). These higher levels of parenting stress may have significant impact on the psychological well-being of the mother as well as a wider impact on the family unit as a whole (Craig et al., 2016).

2.4 ASD and Parenting Stress
ASD in particular has been shown to be associated with higher levels of parenting stress, as behaviour difficulties in children with ASD correlate with increased parental stress (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). Behavioural and emotional difficulties are common in individuals with ASD, and also serve as strong predictors of parental stress levels (Craig et al., 2016; Giovagnoli et al., 2015). As described earlier, ASD has a high rate of co-occurrence with other developmental, psychiatric, neurological and medical conditions. These co-morbid conditions often feature internalising and externalising behaviours. Children with ASD may exhibit such behaviours to a degree where they reach diagnostic criteria for other disorders or disabilities, or their behaviours may be below the diagnostic thresholds. Nevertheless, the presence of behaviours that challenge and the parents’ perception of their ability to cope with these behaviours is an important factor in parental stress levels, arguably more so that the presence of the core features of ASD (Vasilopoulou & Nisbet, 2016). Children with emotional and behavioural problems common to ASD impact on overall levels of parental distress, such as stress, tension, anxiety and depression (Firth & Dryer, 2013). The severity of the child’s ASD – in other words, mild, moderate, or severe in diagnostic terms – does not
appear to impact the parental experience of stress, but some studies have suggested that the severity of the social or behavioural difficulties expressed by the child may positively correlate with levels of parental distress (Hill-Chapman, Herzog, & Maduro, 2013). In other words, the label or diagnosis given to the child may be less important than the degree to which the parents are challenged by the behaviours expressed by the child.

Additionally, lower cognitive function in children with ASD may place additional demands on parents and thus increase levels of parental stress (Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña, 2016), although these findings are not universally supported (Craig et al., 2016). The impact of intellectual disability has been found to be distinct from the impact of ASD and higher intellectual functioning of the child with an ASD diagnosis does not appear to moderate the stress experienced in the family. (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Thus, any family with a child on the autism spectrum is at risk of increased stress levels.

2.5 Methodological Trends in Current Research

A good deal of the extant literature on parental stress and ASD focuses on self-report measures of stress. For example, a recent study investigated the impact of a parent-based behavioural training intervention on parental stress, and found significant improvements in well-being of parents of children with ASD (Schrott et al., 2018). Training parents to effectively cope with behavioural difficulties in children with ASD can be useful and has economic benefits in reducing need for team-based intervention. This particular study utilised standardised self-report measures. A large amount of research on stress in families with children who have a disability also tend to narrow their focus on one or two factors associated with distress, such as depression, anxiety, or marital discord as primary indicators of stress (see Hayes and Watson 2013), despite difficulties in concretely establishing links between stress and distress. It would be remiss of researchers and clinicians alike not to acknowledge the fact that distress can arise for a number of reasons that may not be directly linked to having a child with a disability or disorder, for example pre-existing physical or mental health conditions, financial constraints, or a myriad of other possible environmental stressors. A level of awareness into our own limited abstraction of stress is necessary, alongside an awareness of the potential disservice we do to research and clinical practice by continuing with a reductionist conceptualisation of stress through measuring the concept based only on one or two quantitative indicators.
Some studies have moved towards a more objective approach utilizing physiological measures of stress, most commonly salivary cortisol (Padden & James, 2017) as well other biomarkers such as cardiovascular activity (Foody, James, & Leader, 2014). Cautious interpretation of physiological measures and self-report measures of stress is warranted given the complex interaction between subjective and objective measures of individual experiences (Padden & James, 2017). Authors of a systematic review into physiological measures of stress in parenting and ASD note that a narrow range of physiological measures of stress have been employed in the research, most commonly salivary cortisol, and that a range of other physiological measures could be included to provide a broader understanding of stress in this population (Padden, Concialdi-McGlynn, & Lydon, 2018). While such research would be interesting and would certainly add a good deal of understanding surrounding the very real impact of stress on our bodies, it appears uncommon for the subjective experiences of stress and the lived experiences of parental stress with a child who has ASD to be included in such studies. The individual experience appears lost amidst the graphs and tables and numerical data, and the real-life consequences of heightened physiological stress on a cohort which self-reports greater experiences of psychological stress remain to be elaborated upon.

An interesting feature of the existing literature on parenting stress and ASD is the focus on utilising a quantitative-based, medical-model approach to extracting useful data. Studies tend to use specific measures of stress, comparing one disability with another disability or with typical development. Researchers have been recommended to pinpoint different variables by controlling for behavioural phenotypes and thus pinpointing with greater precision the impacts of core deficits associated with ASD (Hayes & Watson, 2013; Totsika et al., 2011). The value of quantitative data is not in question here; it is clear that volumes of valuable data provide great insight and potential to influence policy and funding for improved services. Nevertheless, a continued focus on the existence of family stress and day-to-day difficulties does little more than confirm that yes, these families are experiencing high levels of stress. Practical benefits arising from further quantitative studies in the area are difficult to envisage for parents of children with ASD who are currently living with high levels of stress. Adopting a qualitative approach to data collection may fit more neatly with the ethos of family centred practice (which will be discussed in detail in Section 2.7). This in turn resonates strongly – in theory – with a needs-based approach, which focuses more on what the family and their child need from a service as opposed to categorising the intervention that will be provided based on a diagnosis.
Every family’s situation is unique with varying nature of stressors and levels of support structures that may fluctuate over time.

Many recommendations in the literature speak in broad and sometimes vague terms when exploring how parental support can be provided. For example, “[parents] should be provided with interventions and resources to empower them…to reduce stress and enhance quality of life” (Craig et al., 2016). Arguably it is not the responsibility of researchers to conceptualise of specific, practical and realistic interventions from services. However, this highlights the existing disconnect between research and practice and serves only to contribute to the delay in putting research recommendations into practice. It may be that the nature of quantitative research allows the researcher to see the data from a more removed perspective, whereas qualitative research provides a more intimate and immediate experience for the researcher which may spur on greater desire for change.

2.5.1 Comparative Studies – ASD and Typical Development
Studies which compare an overall measure of stress in families who have a child with ASD with families of children with typical development (TD) are common in the literature. When compared to parents of typically developing children, parents of children with ASD are more likely to have diagnoses of depression (Cohrs & Leslie, 2017) and report higher levels of distress, anxiety and depression (Padden & James, 2017) as well as a lower quality of life (Vasilopoulou & Nisbet, 2016). Mothers of children with ASD specifically are at increased risk for clinically significant psychological distress (Jokiranta et al., 2013). Parental stress and parental mental health difficulties are strongly interlinked, with each having a tendency to increase vulnerability to the other (Deater-Deckard & Scarr, 1996). For example, high levels of parenting challenges may precipitate the onset of mental health difficulties, while a predisposition to mental health difficulties may negatively impact ability to cope with parenting challenges. Both processes may occur in tandem and aggravate the other (Yorke et al., 2018). The interactions of parental stress and parental mental health need to be acknowledged and addressed in order to adequately meet the needs of parents accessing services for their child with ASD.

2.5.2 Comparative Studies – ASD and Other Disabilities
Also common in the literature are studies which make comparisons in overall stress in families of a child with ASD and families of a child with other disabilities such as Down’s Syndrome, Fragile X Syndrome, Intellectual Disability, Fetal Alcohol Spectrum Disorder (FASD),
cerebral palsy, or externalising behaviours (Craig et al., 2016; Hayes & Watson, 2013; Wong, Mailick, Greenberg, Hong, & Coe, 2014). Interestingly, while parents of children with other forms of Neurodevelopmental Disorders (NDD) understandably experience higher levels of stress compared to parents of typically developing children, parents of children with ASD experience higher levels of parenting stress when compared to parents of children with other types of NDD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hayes & Watson, 2013). The findings of these studies are broadly in agreement that parents of children with ASD experience higher levels of stress than parents of children with typical development or parents of children with other disorders or disabilities. Accordingly, a meta-analysis by Hayes and Watson (2013) demonstrated large effect sizes when comparing levels of stress in parents of children with ASD to these two different groups: parents of children with typical development, and parents of children with a diagnosis of other disabilities. It is abundantly clear from the literature that parents of children with ASD experience higher levels of stress than other parents. It follows from this that the experiences of stress in parents of children with ASD are significant enough to warrant access to supports from disability services.

2.6 Resilience

The experience of stress is dependent on the individual perception of the overall situation, including the perception of available resources. Resources can include coping strategies used to manage stress. In recent decades, research into the impact of stress has broadened to include the concept of resilience, which may be considered as a factor which influences coping ability. Much like stress has been conceptualised as a dynamic and subjective process (Folkman & Lazarus, 1985), so too has resilience been thought of as a set of stages with experiences unique to each individual. Resilience is a process which originates with the abilities and resources available to the individual, which enable the individual to respond in an adaptive manner to their particular stressor or stressors, and may lead to more adaptive outcomes (Schetter & Dolbier, 2011). Past research on resilience has focused on the human response to extreme and traumatic circumstances, such as natural disasters, chronic and fatal illnesses, and developmental outcomes to adverse childhood experiences (in Schetter and Dolbier, 2011). However, research in this area is moving towards a broader conceptualisation of resilience in the face of long-term, chronic stressors.

Resilience has been referred to in various terms by different researchers. Resilience can be thought of as positive outcomes despite adverse experiences. Others refer to resilience as a type
of response to a single stressor or multiple stressors. Alternatively, some refer to resilience as a type of protective factor which allows for positive adaptation to stressful events or environments. A relatively recent theoretical formulation was proposed which neatly encompasses all the above-mentioned conceptualisations of resilience (Zautra, Arewasikporn, & Davis, 2010). The authors define resilience as incorporating three separate yet intrinsically linked components. First, recovery refers to a return to baseline functioning following exposure to a major stressor similar to re-engaging with homeostasis. Second, sustainability refers to the capacity to continue on during stressful situations or in stressful environments and maintain functioning without disruption. Finally, growth refers to enhanced adaptation above and beyond pre-existing levels of functioning. This framework refers to all the processes involved in resilience and is similar to the concept of stress as an over-arching process as opposed to a finite and defined event or singular moment in time. A framework which encapsulates the dynamic experiences of resilience maps well onto the dynamic experiences of parenting a child with ASD.

As it stands there are no clear and universally agreed-upon definition of resilience. Generally speaking, resilience can be defined as “the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress” (American Psychological Association 2014). A paper arising from the plenary panel discussion at the 2013 meeting of the International Society for Traumatic Stress Studies explored dominant themes in contemporary resilience research and identified multiple perspectives in the definitions and processes inherent to resilience (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). As the contributors to the content of this paper provide multidisciplinary perspectives, the discussion here will be limited to those perspectives which are most resonant with the experiences of participants in the current study.

One proposed definition of resilience is “a process to harness resources to sustain wellbeing” (Panter-Brick & Leckman, 2013). Resilience is seen not as an attribute or a capacity, but as an evolving system which can be drawn upon. The idea of harnessing resources allows for the contemplation of the most relevant available resources for the population at hand, which varies for parents of children with ASD depending on what services are available to them, what level of formal and informal supports they can access, and their individual family circumstances including the severity of symptomatology expressed by the child with ASD. The concept of “sustained well-being” allows for a broader interpretation of resilience as not just the absence
of illness; again, a concept which may resonate with parental experiences of getting by despite a lack of self-care and prioritising the needs of their child and wider family above their own.

Another proposed definition of resilience is “the capacity of a dynamic system to adapt successfully to disturbances that threaten the viability, the function, or the development of that system” (Southwick et al., 2014). In this definition, the dynamic system could refer to an individual (i.e. the parents of the child with ASD), the immediate family unit including siblings and partners, the extended family, the school, and the services which support the child and their family. This definition allows for individual interpretation of what the system incorporates, and conceptualises the system as an entity that responds adaptively to challenges and setbacks. This again may resonate well with the experiences of parents of children with ASD, who have unique and changeable systems which respond in their own ways to meet the challenges they face while raising their family and managing other facets of day-to-day life.

2.6.1 Resilience and Parenting in ASD

There are a number of stages associated with supporting a child with ASD. Each of these stages have their own unique stressors and place their own demands on the resilience of a parent or family unit. There is the pre-diagnosis stage, where parents may notice some communication difficulties or challenging behavioural issues. Gaining access to services for assessment and subsequent diagnosis is its own particular challenge in Ireland, which will be discussed further in Section 2.8 in the context of the Disability Act and the Assessment of Need process. Following diagnosis, parents report experiencing a variety of emotions, including despair, denial, self-doubt, blame, and inadequacy related to doing enough to help their child (Lutz, Patterson, & Klein, 2012; Nealy, O'Hare, Powers, & Swick, 2012). Once a diagnosis has been made, new and varying stressors occur in a myriad of ways, including but not limited to: coordinating with services and schools; making changes to work and career life; adjusting their hopes for the future, both for themselves and for their child/children; adjusting to other people’s perceptions of an “invisible disability”; and learning to cope with challenging behaviours such as disruptive sleep, eating difficulties, social skills deficits, and behavioural outbursts. These stressors can feasibly occur at any stage throughout the child’s development, for brief or protracted periods of time, and could reoccur as the child grows and encounters new and unique challenges in their environment. Strategies to help parents cope with stress and build up resilience are required so that families can reach optimal functioning whereby all needs are met, including those in the relationship between parents, the relationship with other children, and the relationship between the child with ASD and the wider family (Estes et al., 2013).
Resilience can be developed and enhanced through personal self-care practices alongside environmental support structures (Alexander, Rollins, Walker, Wong, & Pennings, 2015; Cho & Jung, 2014). Although a good deal of research into self-care and resilience focuses on health care professionals (Skovholt & Trotter-Mathison, 2014), the findings could feasibly be generalised to parents of children with ASD who take on a permanent or at least long-term caregiver role, which is somewhat analogous to the roles played by health care professionals. A systematic review on stress and resilience for parents of children with intellectual and developmental disabilities found a variety of resilience factors for parents, including support for coping style, optimism and social supports (Peer & Hillman, 2014). The degree to which such factors are recognised and supported in services remains an intriguing variable in its own right.

As the majority of literature on parenting and ASD relates to parental stress (Bonis, 2016), it is clear that parents require professional support and guidance in managing their stressors and building resilience, in addition to the support required for gaining knowledge around ASD and managing their child’s care. Despite the severity of the child’s symptoms, it has been found that parents can manage to mitigate their own stress with appropriate levels of support from services (Derguy, Michel, M'bailara, Roux, & Bouvard, 2015).

It is clear from even a cursory glance at the literature that the processes involved in coping with stress and recruiting resilience are intricate, subjective, and difficult to predict or mediate. It is also clear from multiple sources, including academic literature, articles from the national media, interactions with families who have a child with ASD, and observations from working in Intellectual Disability Services, that the various processes involved in raising a child with ASD can come with a huge amount of stress and require a great deal of resilience. What remains unclear is the extent to which services accommodate and provide support for this, as opposed to simply recognising stress as a factor for families without stepping in to help mitigate the impact of stress or provide resources to bolster resilience. The following sections detail a useful framework through which services can be delivered, followed by an exploration of some recent studies conducted in an Irish context, which may shed some light into how much services can and do support families as a whole.

2.7 Family Centred Practice

In order to address stress and the mechanisms through which stress is managed in families (e.g. resilience), services that support individuals and their families require a framework through
which these issues can be acknowledged. Family-centred practice is a widely-used term throughout paediatric health settings, so much so that the phrasing appears multiple times in policy documents, training materials, induction booklets, and publicly-disseminated information packs. Despite the familiarity of the term and the many and varied descriptions of the model, a concrete definition of family-centred practice has proven to be difficult to pinpoint. Family-centred practice itself has been defined as follows:

“Family-centred practice includes three key elements: (1) an emphasis on strengths, not deficits; (2) promoting family choice and control over desired resources; and (3) the development of a collaborative relationship between parents and professionals.”

(Espe-Sherwindt, 2008)

Professionals working with the family-centred model need to “replace the role of decision-maker, agenda-setter, advice-prescriber and expert with the more challenging role of partner, listener, facilitator and consultant” (Espe-Sherwindt, 2008). Family-centred practice represents a move away from the familiar medical model, where the professional knows best, towards a model of inclusion, flexibility, responsiveness and openness. Transition between two very different models can be a long and arduous process, as is reflected in the current literature.

Another attempt at a comprehensive definition of family-centred practice states that:

“family centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients.”

(Shields, 2015)

The definitions provided above represent only a small sample of available definitions or descriptors available in the literature; a comprehensive overview of all possible interpretations of the model is beyond the scope of the current review. However, it is fair to say that all definitions of family-centred practice share the core concepts of the model, regardless of the words used to depict the model.

Although family-centred practice has been ostensibly implemented across the globe, reviews of the available research over several decades speak to pervasive barriers to the implementation
of the model. A lack of knowledge and skills on the part of the service provider is a reoccurring theme (Pickering & Busse, 2010; Power & Franck, 2008), as well as role stress and a lack of appropriate resources and general organisational failings which prevent a thorough adaptation of the model into practice (Chadwick et al., 2013). This has also been demonstrated with both qualitative and quantitative data in the Irish context (Coyne, 2015), which is perhaps unsurprising given the seemingly chronic and unrelenting financial and other resource-based stresses faced by the HSE. Although family-centred practice is widely accepted as a promising model for the delivery of services, it would appear as though the model is not yet fully embraced by services (Guralnick, 2017).

Although many professionals and the services they work in often claim to embody family-centred practices, there is an abundance of evidence to suggest that the model is not truly incorporated into day-to-day practice. This existing discrepancy between the principles of family-centred practices that services claim to embody and the actual regular practices certainly cannot be explained by the lag that commonly occurs when translating theory or research findings into practice, given the length of time family-centred model has been in existence. It is regularly cited that it takes an average of 17 years for research evidence to make its way into clinical practice (Green, Ottoson, Garcia, & Hiatt, 2009); the model of family-centred practice has been in existence since at least the 1980s (Glasper, 2015) and had certainly been in development for decades prior again (Hospital & Platt, 1959). A number of research studies have identified several potential explanations for the discrepancy in service ethos and service delivery. Research findings show that potential barriers range from the knowledge and attitudes of professional service providers, the lack of dissemination of research findings to the appropriate audience, and a lack of training, resources, and time on the part of professionals that would empower them to work constructively and adaptively with families (Bruder, 2010; Fleming, Sawyer, & Campbell, 2011; Ocloo & Matthews, 2016).

One study investigated the impact of clear written materials on parents, service providers, and health science students, and found that as the material was perceived to be important, the subsequent growth in knowledge and awareness could lead to greater potential for facilitation change in practice (Law et al., 2005). This is a somewhat promising result, although a cynical reviewer might well wonder why exactly clear written materials aren’t already in common use for families and service providers alike. If obvious solutions to long-existing barriers are only recently being introduced and investigated, the implementation of family-centred practice will continue to be a lengthy and onerous process.
2.7.1 An Example From The Irish System

A common method of intervention in children’s disability services in Ireland involves inviting parents to attend programmes such as the Early Bird Program, an 8 week post-diagnostic programme offered to parents of children who have been given a diagnosis of ASD. The parents can learn strategies on how to help their child with difficulties they encounter, and adjust their style of interactions to better support their child. However, given the limited resources inherent to many health services, and the subsequent long waiting lists for assessment and diagnosis, often families are left with little to no input from services in the months or years preceding and following the programme, despite a myriad of needs they might have. Research suggests that the ASD “journey” begins not with a diagnosis, but when concerns around the disorder being a possibility are first raised (Connolly & Gersch, 2013). In reality, then, while it might be true that while the programme itself may be aligned with family-centred practice as an intervention which emphasizes capacity building and resource and support mobilization by families, it could be argued that the lack of timely individual follow-up may lead to situations which align more closely with other family-oriented models. Other models include professionally-centred supports, family allied supports, and family-focused supports, all of which vary in their viewpoints of the interactions between the family unit and the professionals involved (Dunst, 2002). For example, some services which may have the capacity to only offer such programs while families are placed on waiting lists for more individualised interventions may not truly be embodying the concepts of family-centredness. They could be seen to be adhering more to the professionally centred model, in that families views and opinions are given little or no credence, as families that request more support and intervention would not necessarily feel that they are being heard. Alternatively, services which engage in such practices could be seen as falling under the family allied model, in that families are viewed as agents of professionals for carrying out professionally prescribed recommendations and courses of action. Offering a limited type of intervention as a first step in engaging with services, and having in existence waiting lists and lack of staffing which do not always adequately meet the needs of the child and the family, cannot be said to align with family-centred practice. Families are not supported in making informed choices and acting on their choices if services are so limited that the families have a lack of choices available to them. Limited interventions do not allow professionals to act as agents of families who strengthen existing skills and promote acquisition of new skills. As it is the family who ultimately determines the effectiveness of Early Intervention services, it is vital that each family receives the type of support that allows them to tend to their child’s individual needs (Hile, Milagros Santos, & Hughes, 2016).
Parent education programs which are designed to manage the behaviours of the child with ASD are repeatedly found to be effective, yet the parents still report high levels of stress following implementation of these programs (Bonis, 2016). This may indicate that the management of difficult behaviours is not sufficient in mitigating the stressors associated with having a child with ASD. Financial concerns, worry about the future, changes in self-perception regarding one’s role as parent, friend, or member of the workforce are all potential stressors which are not routinely addressed in parent education programs, or indeed in the extant research literature. Perhaps a more holistic focus on stressors commonly faced by families with children who have an ASD diagnosis may provide additional benefits to parents and help ameliorate their experiences with stress.

2.8 Current Policies in Ireland

2.8.1 Background: The Disability Act 2005
The Disability Act 2005 places a statutory obligation on service providers to support access and services for people with disabilities. Part 2 of The Disability Act is the section of legislation which introduced the Assessment of Need process, whereby children born after June 1st 2002 or a young person aged over 16 are entitled to an Assessment of Need (AoN) if it is felt that they have a disability. By law, the assessment must be commenced out within 3 months of receiving an application, and must be completed 3 months following commencement. If the AoN is not completed within this time, the service must state the reasons why and set out a timeframe for completion. In the years following the implementation of the Disability Act, waiting lists in disability services have continued to rise and services do not always have the ability to complete AoNs within the six-month timeframe of receiving the application.

2.8.2 Progressing Disability Services 2010
The Progressing Disability Services for Children and Young People (commonly shortened to PDS) is a national programme established by the HSE in 2010. The programme was established on the recommendations of a report published in 2009, the Report of the Reference Group on Multi-disciplinary Service for Children aged 5 to 18 years (Department of Health, 2009). The aim of the PDS programme is to allow the delivery of equal family-centred services for children and young adults with disabilities across Ireland by restructuring the organisation of children’s disability services. The HSE National Service Plan for 2019 states that the HSE will improve access to therapy services for children by implementing PDS, “while recognising the challenge in relation to complying with the Disability Act 2005” (HSE, 2019). The implication here is that the HSE recognises its obligation to provide services, but is somewhat hampered in doing
so due to a lack of adequate resources. Indeed, The Irish Times reports that the HSE is facing legal action by frustrated parents who have not been able to access the assessments and associated disability services they are entitled to in a timely manner via the AoN procedure (Carolan, 2017).

2.8.3 PDS: Current Progress
The PDS program is now in its ninth year and progress remains ongoing, with some parts of the country adapting to new structural reorganisation faster than other areas. A reconfiguration map, available to view on the HSE website, displays the discrepancy in services across geographical location quite clearly. 7 regions have fully reconfigured into Children’s Disability Network Teams (CDNTs), and these regions are largely confined to the south-west and mid-west although Meath and Kildare/West Wicklow are also included. 9 regions primarily in the midlands and north-west are reconfigured into CDNTs for Early Intervention only, with school age services continue to be provided by the HSE and Voluntary Organisation Teams. The remaining 16 regions are not yet configured, primarily along the south and east coast including the greater Dublin area, with children’s disability services continuing to be provided by the HSE and Voluntary Organisation Teams. This map provides some clarity on the current configuration of disability services across the country, and highlights the “postcode lottery” effect, the fact that the level and type of service received is often dependent on where one lives, which is often referred to in frustration by individuals and their families supported by disability services. One recent example of such a discrepancy in service provision based on location was highlighted in 2018 by RTE coverage of a family living in Portlaoise (O’Sullivan, 2018). Their youngest child was showing signs of ASD but had received nothing in the way of services despite an AoN application sent to services more than 6 months previously. The family’s eldest child, in comparison, had received excellent early intervention services in Co. Wicklow when he first engaged with disability services. The article ends with the parents discussing the possibility of moving the family to a different catchment area in order to secure better services for their children.

2.8.4 Review of Contemporary Services
In May 2017, Minister for Health Mr Simon Harris requested a review by the HSE into the operational effectiveness of existing health service responses in addressing the needs of those with ASD (HSE 2018). This review involved receiving input from a number of key stakeholders, including service users and their advocates as well as various service providers. The review resulted in nine overarching themes emerging from consultation with these key
stakeholders, most of which described the types and nature of barriers to adequate service in Ireland today. These themes were: 1. Access and Clear Service Pathways; 2. Collaboration: Interdisciplinary and Interagency; 3. Standardisation and Stepped-Care Service Delivery; 4. Communication and Information; 5. Training and Awareness; 6. Evidence-Based Practices and Early Intervention; 7. Forward Planning and Support Through Transitions; 8. Policy Implementation; and 9. Adult Services. Each theme explored difficulties and frustrations in meeting the needs of the individual with ASD, from the perspectives of individuals supported by the services, family members/carers/advocates of individuals supported by the services, and service providers themselves. This review makes for disappointing reading, most especially the direct quotes included from key stakeholders who took part in the review. Some striking quotes are included below:

“No one has provided us with a road map of what we should do and what services would help.”

“There are large gaps in autism spectrum awareness training, knowledge and understanding in frontline services, in health care, in schools, in colleges, employment services, social services, and in local government.”

“Nother review into services for individuals on the autism spectrum. This will be the fourth review I have been involved with in 17 years – it will probably make access to supports and services more difficult than they are at present, because this is what happened after the other reviews.”

These quotes highlight the basic failings of service provision throughout the journey of assessment, diagnosis, and ongoing intervention, as well as depicting a sense of despair and lack of hopefulness regarding any positive future change.

The review provides a list of ten recommendations to improve the HSE’s service provision. While these recommendations do appear to address the concerns raised by vested parties throughout the review process, practical steps towards implementing these recommendations are yet to be taken. At the publication of this report and a companion report, entitled “Estimating Prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies”, Minister for Health Simon Harris stated that a programme board would be established with a view to implement the changes recommended alongside a national Public Awareness Campaign related to ASD. These initiatives are set out in the HSE National Service Plan for 2019; however, at the time of writing, it remains unclear
as to when exactly the programme board and awareness campaigns will be implemented. As a result, a timeline for addressing the concerns raised in the review report remains unknown. The lived experiences of daily stressors and systemic frustrations will remain unchanged for individuals with ASD and their families/carers while waiting for the health service to act upon the findings of its own review.

2.9 Current Challenges for Irish Families
A recent study on the perspectives of Irish parents and their experiences with accessing services for their child with ASD does not paint a flattering picture of Irish service provision (Twomey & Shevlin, 2017). Parents spoke of feeling disempowered and demoralised through using the services, they stated that they did not feel like active participants in the intervention process, and they reported a need to highlight their child’s deficits rather than work from a strengths-based approach in order to access services and engage in conversations with professionals. Although this was a small scale research study, incredibly rich data was gathered which should have professionals and service developers taking stock of how families experience interactions with services. Results from this and other studies (Connolly & Gersch, 2016; Finneghan, Trimble, & Egan, 2014; C. Ryan & Quinlan, 2018) may suggest that clinical staff can forget how isolating and confusing the processes of diagnoses and intervention can be, and recognise that an integral part of delivering services includes changing the more traditional dichotomous approach and instead fostering a sense of partnership.

In October 2018, The Irish Times reported on an Irish study (Roddy & O’Neill, 2018) which estimated that the additional costs for a family with a child with ASD is greater than €28,000 annually, due to the additional costs of using private services to supplement those provided by the public system, lost income and informal care. In comparison, the authors state that the annual expenditure by the state per child on ASD-related expenditure was slightly above €14,000. Results from a regressions analysis indicated that autism severity is linked to greater expenditure by the family, but not by the state. In other words, the state does not invest more resources in a child with a more severe presentation and the associated more complex needs than a child with a milder presentation. This is despite the fact that the current diagnostic criteria for ASD distinguish between severity of symptomatology based on the intensity of needed supports (Mehling & Tassé, 2016). These resources are instead sourced by the family and provided for by rearranging work commitments, career pathways, help from informal supports such as friends and family, and seeking private therapies. Therefore it would appear
as though a much greater burden is placed on the family regarding meeting the needs of the child with ASD, a burden which is not necessarily supported by or held evenly with the state.

2.10 Gap in Existing Literature

It is well established that parents of children with ASD experience greater levels of stress than parents of neurotypical children, as well as parents of children with other disabilities. A vast number of papers on the subject recommend that interventions should not focus solely on the child, or on helping parents to develop skills to support their child, but should also focus on helping parents to address and deal with their own experiences of stress and resilience in this often life-long journey of caregiving (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). What remains unknown is the types and levels of supports parents experience when their child receives an ASD diagnosis in the Irish healthcare system. It is not known to what degree ASD services offer support to parents of service users, whether parents proactively seek out their own support networks, and how parents perceive the impact of caring for a child or children with ASD on their own wellbeing.

Some qualitative research does exist and adds a much-needed perspective on the individual experiences of the difficulties experiences by mothers and families in raising a child with ASD (Safe et al., 2012; Gorlan et al., 2106; DePape & Lindsay, 2014). However, the vast majority of existing research on this topic is quantitative in nature, while qualitative publications are difficult to locate despite some calls for an increase in qualitative research (Bölte, 2014). A recent special issue of The Journal of Autism and Developmental Disorders focused its publication on parents as primary caregivers (Nordahl-Hansen, Hart, & Øien, 2018). While the articles included in this particular issue are fascinating and bring to the foreground a number of contemporaneous concerns for parents of children with ASD, all of the research is quantitative in nature. Interestingly, although the introduction cited above included a section on Future Issues, no mention was made of the need for qualitative data. It seems as though a bias towards quantitative, measurable, and objective datasets still prevails despite some recognition of the importance of individual experience. The current research aims to bridge that gap in knowledge by exploring in-depth the individual lived experiences of stress and support in parents of children with ASD living in Ireland during a time when services are in a state of protracted change via semi-structured interviews yielding qualitative data.
2.11 Current Study

From a review of the literature it appears as though limited supports are offered to parents who are caring for a child or children with a diagnosis of ASD. These limitations may arise due to a number of factors, including limited resources available to services in their efforts to support parents, lack of knowledge of the importance of parental well-being in the implementation of home-based interventions for children with disabilities, and a disconnect of some degree between the tenets of family-centred practice and the implementation thereof throughout the country. Based on the existing body of literature and experience in working with parents of children with ASD, it appears there exists a greater need for services to acknowledge the recommendations in the literature regarding supporting parents through the treatment of their child, and put these recommendations in place through clinical practice. The interconnections between family stress, family resources – including resilience and available service supports – and outcomes for the family must be integrated into the framework of service provision. The researcher posits that if the needs of this specific population with recognised levels of increased stress are not addressed and met by the health services in a timely manner, the long-term impacts of increased stress may place an additional burden on a number of factors: the mental health of the parent; the support services surrounding the parent of the child with ASD and the wider family; and the ability of the child with ASD to develop and thrive to the best of their capacity.

Given the magnitude of quantitative data in the area of stress and well-being in parents of children with ASD, which sets out time and again that this population of parents are quantifiably more stressed than other parents, it would be decidedly unhelpful to pursue another quantitative research project and gather a dataset of numbers and statistics to confirm information that we already know to be true. The individual, subjective, lived experiences of a population vulnerable to stress and stress management can give rise to much richer data and allow a unique insight into the daily struggles and accomplishments of parents who are negotiating access to services, managing expectations for their child or children, acknowledging concerns for the future, and, for some, balancing a busy home life with demands of work and career. Individual perspectives on singular experiences can be captured only through in-depth engagement provided by qualitative methods. Previous quantitative research has shown time and again that these parents have greater levels of stress; however what these studies don’t necessarily show is the individual experience of heightened levels of stress and supports, and the individual interpretation of those stressors and supports. It is here,
with the nuances of specificity and universality in lived experience, that a new and different level of understanding can come about. Focusing on the individual lived experience can allow for unique insights into the challenges, successes, and competencies of this population, and hopefully in turn inform education, clinical practice, research, and policy so that services can be more in tune with the strengths and needs of families who have a child with ASD.

The existing literature has recognised that higher levels of parental stress are associated with raising a child with ASD. It appears as though the research into experiences of stress in parents of children with ASD consistently recommends that strategies be implemented by services which address parental stress and coping mechanisms. Services are recommended to implement such strategies in order to ensure that home-based or clinic-based interventions put in place to support the child can be adhered to and yield effective results. The needs of the caregiver must be taken into consideration when a child requires additional parental involvement, as well as when developing and delivering interventions which impact the home life.

The primary research question of the current study is:

What are the experiences of stress, support, and self-care in mothers of children with ASD?

The aim of the current research project is focus on the individual experience of stress in parents of children with ASD using a qualitative approach. The study will examine the nature of the main stressors and any secondary stressors that are significantly impacting on the parents' lives. The research will also examine supports, framed as self-directed methods of coping skills / self-care, and to explore whether any external supports are routinely offered to parents to help them manage their stress or if parents feel that they are expected to proactively seek out such supports without explicit input from their child’s health service. Additionally, the study aims to explore whether parents experience services as taking on the recommendations of the research by recognising and addressing the needs of the parents when planning and delivering an intervention for the child with ASD.
3. Methodology

3.1 Chapter Introduction
This chapter provides a description of the methodologies used in the current research in chronological order. A step-by-step account of the procedures undertaken to facilitate data collection is provided, beginning with the granting of ethical approval and changes made following a small pilot study. The type of research design used in the study, including a rationale for the type of analysis chosen, is described here. This chapter then describes the recruitment procedure, including inclusion and exclusion criteria, an account of how the participant sampling was conducted, and some demographic information about each individual and the overall sample size. There is then a section which outlines the materials used to collect the data, namely the interview schedule. Data collection is then described. A section on data preparations followed by a section on data analysis outlines the steps taken to transform the raw data into the existing research findings. Finally, issues of consideration in qualitative research are explored at the end of the chapter.

3.2 Ethical Approval
An application for ethical approval was made in November 2016 to the ethics committee based in University Hospital Limerick. This committee covers clinical research conducted in the HSE Mid-West region. Full ethical approval was granted by this ethics committee by the end of December 2016, covering both a small pilot study and a larger research study that was to form the basis of the current research study.

3.2.1 Informed Consent
Informed consent was sought and obtained from each participant prior to the collection of data. This process was managed by providing participants with detailed Information Sheets and Consent Forms to read before the scheduled interviews took place (see Appendices B and C). Each participant was provided with space before and after each interview to ask questions about the interview process and research study in general. All participants were informed of their right to withdraw at any time and were provided with reassurance that participation, lack of participation, or withdrawing from the research would have no impact whatsoever on the services they, their child, or their family were receiving.

3.2.2 Confidentiality
The issue of participant confidentiality was considered in some detail. All potential participants were assured that participation in the study would have no impact on their engagement with
services or other research projects. Only the principal researcher would have knowledge of who had opted to take part in the research, and no other person involved with the research would have access to that information.

### 3.2.3 Potential Risk

There was considered to be a very slight risk of psychological discomfort involved in participating in the research study. It is possible that participants engaging in an interview about personal experiences with self-care, support, and stress may become upset or distressed during the course of the study. In this event, it was envisaged that the lead investigator would explore with the participant if they would like to stop the interview. If the answer was no, the interview would continue. If the answer was yes, the interview would be stopped and the participant would be debriefed. The lead investigator would ensure that the participant had contact details of their GP or mental health provider if the participant felt they needed to link in with someone about their mood following the interview. In the case of the two participants who engaged in face-to-face interviews, the lead investigator also ensured that these participants were safe and happy to leave the research site.

Additionally, the lead investigator also followed up with all participants after collecting the data to manage any risk. Approximately one week after the interviews were conducted, the lead investigator contacted the participants and checked in on their well-being. If the interview process had had a negative impact on the participant, the lead investigator would encourage the participant to link in with their GP or mental health team.

### 3.3 Changes Implemented Following the Pilot Study

A Small Scale Research Project (SSRP), which acted as a pilot study for the current research, was completed in April 2017. The SSRP investigated stress and self-care in parents of children with a diagnosis of ADHD. The research was conducted in a CAMHS clinic where the researcher was undertaking clinical placement at the time. The SSRP employed a mixed-methods design as this was a requirement for successful completion of the course assignment.

Two changes were made to the research study following completion of the SSRP. First, it was decided to focus on qualitative data only as opposed to continuing with a mixed methods design. Concentrating on a qualitative approach would allow the researcher more time to engage with the process of data analysis and thoroughly explore the richness of the data and its emergent themes. In addition, it has been well established in the literature that parents of children with ASD live with heightened stress compared to other parents. A qualitative
approach exploring the more nuanced aspects of stress, support and self-care with these parents will provide a more in-depth insight into their experiences, as opposed to yet more quantitative data confirming that these parents are indeed more stressed than others.

In designing this research study, several potential methods of analysis were considered before choosing IPA. Through examination of various available qualitative methods, the researcher was drawn to consider what the research is truly looking to explore. This research is not focused on determining whether or not parents of children with ASD are more stressed or require support for coping skills; this has already been established and disseminated by previous research. The researcher had some interest in how parents talk about their experiences of raising children with ASD, so discursive analysis was considered. Grounded Theory and Narrative analysis were also considered, as the various factors influencing stress, support and self-care were of interest as well as how individual’s stories or narratives related to their sense-making were intriguing to the researcher. However, overall the research was geared towards uncovering personal meaning and sense-making for this particular population of parents. Researchers who use IPA as a research method do so because they are interested in how people make sense of their personal and social world (Smith & Osborn, 2007). IPA allows for a focus on personal meaning and sense-making, an exploration of subjective lived experience. As such, IPA appeared to be the best fit for approaching this particular research topic.

Secondly, additional questions were added to the interview protocol. These questions allow for greater focus on supports received by services attended by the child as well as on the nature and sources of stress for parents. For example, the additional questions “Do members of your child’s MDT ask you about your own stress or health issues?” and “What are your main sources of stress at the moment?” provided space to explore these core issues that are central to the research interests. The development of the interview protocol as a whole will be described in Section 3.6.2 below.

3.4 Recruitment

3.4.1 Inclusion and Exclusion Criteria

To be considered for inclusion in the current research, potential participants had to be over 18 years of age and a parent of a child with a clinical diagnosis of ASD. No specific exclusion criteria were applied.
3.4.2 Participant Sampling

Participants were recruited from two main sources; convenience sampling from a database of potential research participants and via snowball sampling.

Participants were primarily recruited via convenience sampling from an existing database of individuals who had previously participated in other, related areas of research and had provided written consent which explicitly gave permission for researchers to contact them again and invite them to take part in other research projects. The researcher had access to this database via professional contacts with Prof. Louise Gallagher, the field supervisor of the current study. Nine participants of the current sample were recruited in this manner. A small number of participants were recruited via the snowball sampling method; in other words, existing participants recruited further participants through word-of-mouth. Three participants of the current sample were recruited in this way.

3.4.3 Sample Size

In total, 17 potential participants were contacted between August 2017 and December 2017 by the researcher with an invitation to participate in the research. All participants received this invitation via email. 4 potential participants did not respond to either the initial email of invitation or to a second and final email of invitation to participate, and thus were not contacted again. 1 responded to the initial email of invitation but did not respond to follow-up emails in order to arrange dates and times for interview. The remaining 12 participants comprise the existing sample.

As the focus with qualitative research is quality over quantity, as the richness of human experience deserves detailed exploration, Smith and colleagues (2012) recommend using smaller sample sizes. They cite between 4 and 10 interviews as a good size for a doctoral research project. Too many participants in a study can lead to saturation; that is, the researcher may reach a point in data analysis where sampling additional data will bring no more information to their research questions. The researcher opted to recruit the slightly larger number of 12 to protect from any potential loss or corruption of data. As analysis progressed, it became clear that the saturation point was being reached and so recruitment was capped at 12.

3.5 Sample Characteristics

Although this study was open to all parents of children with an ASD diagnosis, only mothers opted to participate. Therefore all participants were female. The sample included a mix of
people who were employed or homemakers. The sample also featured a mix of women in marriages as well as single parents. The majority of participants had more than one child in the family.

<table>
<thead>
<tr>
<th>ID</th>
<th>Pseudonym</th>
<th>Date of Interview</th>
<th>Number of Children</th>
<th>Age of Child with ASD</th>
<th>Co-morbid Diagnosis</th>
<th>Type of School</th>
<th>Mother’s Employment Status</th>
<th>Mother’s Relationship Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>Anna</td>
<td>12/08/17</td>
<td>3</td>
<td>5</td>
<td>Yes</td>
<td>ASD school</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>002</td>
<td>Katie</td>
<td>17/11/17</td>
<td>1</td>
<td>5</td>
<td>No</td>
<td>ASD school</td>
<td>Employed</td>
<td>Separated</td>
</tr>
<tr>
<td>003</td>
<td>Jen</td>
<td>27/11/17</td>
<td>3</td>
<td>10</td>
<td>No</td>
<td>ASD school</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>004</td>
<td>Caroline</td>
<td>20/11/17</td>
<td>3</td>
<td>17</td>
<td>Yes</td>
<td>ASD school</td>
<td>Employed</td>
<td>Separated</td>
</tr>
<tr>
<td>005</td>
<td>Annette</td>
<td>05/02/18</td>
<td>3</td>
<td>24</td>
<td>Yes</td>
<td>Mainstream</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>006</td>
<td>Ciara</td>
<td>21/11/17</td>
<td>2</td>
<td>7</td>
<td>No</td>
<td>Mainstream</td>
<td>Employed</td>
<td>Married</td>
</tr>
<tr>
<td>007</td>
<td>Rachel</td>
<td>11/12/17</td>
<td>2</td>
<td>9</td>
<td>Yes</td>
<td>ASD school</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>008</td>
<td>Amy</td>
<td>11/12/17</td>
<td>2</td>
<td>9</td>
<td>No</td>
<td>ASD school</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>009</td>
<td>Fiona</td>
<td>12/12/17</td>
<td>2</td>
<td>9</td>
<td>Yes</td>
<td>Mainstream</td>
<td>Employed</td>
<td>Married</td>
</tr>
<tr>
<td>010</td>
<td>Orla</td>
<td>23/01/18</td>
<td>3</td>
<td>14</td>
<td>Yes</td>
<td>Mainstream</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>011</td>
<td>Sarah</td>
<td>05/02/18</td>
<td>2</td>
<td>6</td>
<td>No</td>
<td>ASD unit</td>
<td>Homemaker</td>
<td>Married</td>
</tr>
<tr>
<td>012</td>
<td>Lucy</td>
<td>12/02/18</td>
<td>2</td>
<td>4</td>
<td>No</td>
<td>Mainstream</td>
<td>Employed</td>
<td>Married</td>
</tr>
</tbody>
</table>

Table 1: Sample characteristics of study participants

3.6 Materials
The primary instrument used in this research was the interview protocol. The development of the interview protocol will be described below with reference to the semi-structured nature chosen for this research.

3.6.1 Semi-Structured Interviews
A well-designed semi-structured interview allows for some framework to guide the process and ensure all topics are covered, while also giving enough space for flexibility so that participants can talk at length and relevant topics can be expanded upon. Although other methods of qualitative data collection are available, such as focus groups or participant observation, semi-structured interviews were considered to be the most fitting approach for the current research. The flexible nature of the interaction allows the researcher to examine topics of interest in depth as well as observe and follow up with topics of particular relevance to each interviewee.
3.6.2 Interview Protocol

The interview protocol consisted of ten open-ended questions which were worded so as to encourage an open and detailed discussion with the subjective experiences of the participants at the forefront. This was based on existing recommendations from prominent IPA researchers which state that a good interview protocol should gently encourage a participant to discuss the topic at hand with as little prompting as possible from the interviewer (Smith & Eatough, 2007).

Areas of particular interest were identified by the lead investigator prior to developing the interview protocol. These areas were identified through consulting existing literature on the topic, professional experiences of the lead investigator with input from the co-investigators, and a personal interest in the topic of stress, support, and self-care on the part of the lead investigator. These areas of interest included the impact of ASD on family life, the types and levels of support parents experience following diagnosis of ASD, and awareness and management of stress and self-care for parents of children with ASD. The development of the interview protocol were based on these areas of interest and shaped with reference to the guidelines provided by Smith and colleagues (2012) as well as the theoretical framework of the relational nature of stress as defined by Lazarus (1991). Descriptive, narrative, contrast, and evaluative questions were all incorporated into the protocol along with prompts and probes as appropriate. A copy of the interview protocol can be found in Appendix A.

The researcher had received thorough training in conducting interviews prior to engaging in this research study. These skills were acquired over several years of working in a research capacity, first as a Research Assistant and subsequently as a PhD candidate and finally a Post-Doctoral Research Fellow. These skills have also been expanded upon in clinical settings as an Assistant Psychologist and as a Clinical Psychologist in Training.

3.7 Data Collection

All potential participants who had expressed an interest in the research study were contacted via email to arrange a suitable date and time to conduct the interviews. In order to accommodate the busy schedules, geographical locations, and other practical issues unique to each participant, arrangements were made to interview participants either over the phone or in an office available to the researcher, whichever was more convenient to the participant. Two interviews were conducted face-to-face in a quiet office provided by the researcher’s field supervisor, and ten interviews were conducted over the phone from the researcher’s home office.
Participants were provided with a brief overview of the research including a rationale for the study, information regarding how the data would be collected, analysed and stored and who would have access to that data. Participants were informed of their right to withdraw at any time from the research up until the submission of the doctorate thesis in 2019. If participants were to withdraw from the study prior to any data publication, their data would be identified by the lead researcher and securely destroyed. If participants were to request to withdraw from the study following data publication, they were informed that the published data could not be withdrawn from publication but their de-identified data would be located by the researcher and securely destroyed.

Participants were provided with an information sheet to read which outlined a description of the study along with details of their right to withdraw (see Appendix B). Following this, participants were asked to sign a consent form (see Appendix C) which the researcher subsequently co-signed and dated. Participants were asked if they had any questions about the research before the interview began. Permission to record the interviews with digital recorders was then acquired.

3.8 Interview Process

The researcher then switched on two recording devices. Two recording devices were used in order to ensure the data would not be lost should one recording device fail. The researcher conducted the interview while being guided by a semi-structured interview schedule which consisted of ten items. The interview schedule was piloted on one participant in the final sample, which provided the researcher with the opportunity to gain familiarity with the interview schedule and process, as well as critically appraise the overall interview and allow for participant feedback. Following the pilot interview, an additional question “Is there anything we haven’t talked about that you think would be important for us to cover?”, was added. The order of questions was revised so as to provide a more coherent structure to the protocol. However, the content and general focus of the interviews remained consistent.

A conversational tone was adopted by the researcher throughout the interviews. Participants were informed that the study was exploring the experiences of stress, self-care and support in mothers of children with ASD, and that a holistic view of the participants as an individual was of interest. This steps were taken in order to avoid bias and to avoid leading the participants. On occasion, participants were probed on different topics so as to gather richer and more detailed accounts of their experiences. A level of flexibility was maintained throughout each
interview, as participants discussed aspects of their experiences with varying degrees of detail. Participants were encouraged to explore their own experiences as much as they were comfortable. Interview questions were worded in such a way so as to not lead or bias the participants; for e.g., one question around stress was worded thusly: “What are your main sources of stress at the moment?” This question was designed so as to explore the experience of stress in general, as opposed to lead the participant towards discussing stress only in the context of their child with ASD.

Once the interview was concluded, the participant was asked if they had any questions about the process or the wider research study. The researcher checked in on how each participant was feeling immediately after the interview, with a view to acknowledge and validate any residual distress arising from the discussion of emotive topics. Each participant was thanked for participating in the study. The researcher then switched off the recording device. Descriptive information regarding the length of individual interviews is outlined in Table 2.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Interview Location</th>
<th>Interview Duration</th>
<th>Notes on Presentation During Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna</td>
<td>Office</td>
<td>77 minutes 13 seconds</td>
<td>Very talkative during interview; warm and friendly; eager to participate; aware of current policies and legislation around ASD.</td>
</tr>
<tr>
<td>Katie</td>
<td>Phone</td>
<td>49 minutes 1 second</td>
<td>Introspective, carefully considered answers. Aware of shortcomings in current services relative to her family. Easy to establish rapport.</td>
</tr>
<tr>
<td>Jen</td>
<td>Phone</td>
<td>30 minutes 43 seconds</td>
<td>Quiet and uncertain tone. Somewhat open to exploring experiences – became easier as rapport established.</td>
</tr>
<tr>
<td>Caroline</td>
<td>Phone</td>
<td>54 minutes 1 second</td>
<td>Open and chatty; somewhat tense – focused on the needed supports that aren’t available. Easy to establish rapport.</td>
</tr>
<tr>
<td>Annette</td>
<td>Office</td>
<td>79 minutes 30 seconds</td>
<td>Very open and talkative. Visibly and audibly tense. Provided great detail when describing experiences.</td>
</tr>
<tr>
<td>Ciara</td>
<td>Phone</td>
<td>34 minutes 50 seconds</td>
<td>Chatty, warm, and open. Provided rich examples of experiences with ASD. Required very little prompting to explore topics.</td>
</tr>
<tr>
<td>Rachel</td>
<td>Phone</td>
<td>84 minutes 39 seconds</td>
<td>Extremely talkative; focused on many details; difficult to engage in rapport; eager to give her account.</td>
</tr>
<tr>
<td>Amy</td>
<td>Phone</td>
<td>29 minutes 16 seconds</td>
<td>Took some time to establish rapport. Mixture of blunt answers and detailed explorations of experiences.</td>
</tr>
<tr>
<td>Fiona</td>
<td>Phone</td>
<td>39 minutes 49 seconds</td>
<td>Very talkative, easy to establish rapport. Required some probing to consider questions centred on her personal experience as opposed to her child’s needs.</td>
</tr>
<tr>
<td>Orla</td>
<td>Phone</td>
<td>29 minutes 36 seconds</td>
<td>Very opposed to changes in service provision – conversation circled back to this multiple times. Spoke warmly of child; required prompting for detail on other personal topics.</td>
</tr>
<tr>
<td>Sarah</td>
<td>Phone</td>
<td>45 minutes 12 seconds</td>
<td>Open, relaxed style of conversation; explained experiences in good amount of detail; clear on nature of unmet needs.</td>
</tr>
</tbody>
</table>
Table 2: Participant Interview Information

| Lucy | Phone | 39 minutes 10 seconds | Very factual; tense or guarded; required some prompting to provide details but opened up more as rapport established. |

3.9 Data preparation

After the data was collected, a number of steps were taken in order to prepare for analysis. The first step in this process was to depersonalise the data. A random pseudonym was assigned to each participant. Only the primary researcher had access to a password-protected document that denoted which pseudonym was allocated to which participant.

The next step was to create written transcriptions of the audio recordings. The researcher played and replayed the recordings and typed the transcriptions into Microsoft Word 2016 on an Asus Zenbook running Windows 10. Electronic versions of the transcriptions were encrypted with passwords to ensure sole access to the principal researcher. The transcripts were also depersonalised by removing the names of children and other family members, the names of specific locations such as towns or schools, and removing the specific nature of any co-morbid diagnosis the child might have had or the names of any medications the child or parent may have been prescribed.

As recommended by Smith et al. (2012), the transcripts were then divided into three columns, the first (middle column) containing the original transcript, the second (right column) containing a space designated for exploratory comments and the third (left column) containing space to list emergent themes. Exploratory comments were differentiated by type using a specific set of font styles as recommended by Smith and colleagues (2012). An example of the transcript layout with exploratory comments and themes is provided in Appendix D.

3.10 Data Analysis

This section outlines the various stages involved in the interpretation of the data.

3.10.1 Preliminary analysis

In many qualitative approaches, analysis unofficially begins during the data collection stage where the researcher already begins to connect sections of the raw data. In the current study, a process of recording thoughts, ideas, and other various memos was conducted throughout data collection and analysis as a strategy to identify and manage research biases at this stage. However, formal analysis did not begin until the raw data had been fully transcribed and prepared as outlined above.
3.10.2. IPA Analytic Process

The analysis of the data for the current study consisted of a multi-step approach which adhered to the guidelines outlined by Smith et al. (2012). This process is outlined in Figure 1 and the later stages are visually depicted in Appendix 5. This process was rigorously adhered to by the researcher, with an extended period of time being devoted to the process of data analysis. Transcripts were read and re-read while listening to the accompanying audio, notes were taken each time the data was engaged with, and periods of reflection were regularly incorporated into the process before the researcher re-engaged with the data once again.

Figure 1: IPA Analytic Process. Adapted from Smith et al (2012).
3.11 Assessing Validity and Quality

As discussed in some detail by Smith and colleagues (2012), Yeardley (2000) proposes four broad principles for assessing the quality of qualitative research. These four principles are: (1) Sensitivity to context; (2) Commitment and rigour; (3) Transparency and coherence; and (4) Impact and importance. A critical appraisal of the current research using the above principles is described below.

3.11.1 Sensitivity to Context

The researcher demonstrated sensitivity to context throughout the research project by immersing herself in the relevant available literature, choosing IPA as a method appropriate for close examination of idiographic experiences, designing an interview protocol which allowed for acknowledgement of socio-cultural influences, and repeated and consistent engagement with the data throughout the analysis process.

3.11.2 Commitment and Rigour

The researcher demonstrated awareness of commitment and rigour at several points throughout the research process. Consultation with a co-investigator on the appropriateness of the interview protocol, ensuring the comfort of participants and remaining attentive to their words throughout the interviews, critical discussion in supervision of the researcher’s systematic analysis of the data, attendance at numerous research workshops, and the presentation of project development and findings on several occasions prior to thesis submission all demonstrate clear examples of adherence to these principals.

3.11.3 Transparency and Coherence

These principals are primarily demonstrated by a clear and thorough description of the process involved in data collection and analysis. In addition, engagement in research supervision allowed for review and audits of transcripts, notes and emergent themes, and the final super-ordinate and sub-ordinate themes, all of which contribute to maintaining transparency and coherence throughout data collection and analysis. Maintaining a reflective journal provided space to note personal opinions, processes and biases, which then contribute to critical reflection on the researcher’s role in the collection and dissemination of data. Finally, each participant will be offered a copy of the final written research in the form of an executive summary in order to demonstrate that their role in the research was acknowledged and valued.
3.11.4 Impact and Importance
The researcher believes that the current research addresses a gap in the current literature and could contribute to the existing knowledge on issues of stress and self-care in parents of children with ASD. It is hoped that the findings of this research could have an impact on the development of further research and consequently the focus of clinical practice and service provision.

3.12 Conclusion
This chapter has provide a detailed description of the methodological design and procedures utilised during this study. The chapter has also explored issues relevant to undertaking qualitative research, such as considerations of trustworthiness and credibility, methodological rationale, and areas of ethical concern.
4. Results

4.1 Introduction

Thorough engagement in the IPA Analytic process led to the emergence of a number of themes from the research findings. There are five superordinate themes and fifteen subordinate themes in total, which are depicted in Table 3 below. The superordinate themes have been organised as moving from broad to specific, with more general topics captured in early themes and more specific and personal topics captured with later themes. This framework was chosen in order to provide a clear representation of the data in a structure familiar to both author and reader, as the broad-to-specific structure is a commonly used pattern in writing and allows for an easy-to-understand flow of ideas. The following chapter will discuss each theme in detail. Illustrative quotes will be incorporated to provide insights into the exact wording and phrasing of participants, with participants being referred to only by pseudonym. Quotes will be italicised and ellipses will be used to denote the removal of extraneous text. Any such extraneous text was removed in order to provide maximum clarity in the meaning of the quoted words. Analytical comments will also be provided to demonstrate to researcher’s interpretation of each theme. Reflective boxes will be included throughout the chapter, which will provide insight into the researcher’s own reflective process throughout data analysis.

4.2 Overview of Research Findings

<table>
<thead>
<tr>
<th>Super-Ordinate Themes</th>
<th>Subordinate Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of ASD</td>
<td>Personal viewpoint on ASD</td>
</tr>
<tr>
<td></td>
<td>ASD and the child in society</td>
</tr>
<tr>
<td></td>
<td>Concerns for future</td>
</tr>
<tr>
<td>Interacting with Services</td>
<td>Insufficient Resources</td>
</tr>
<tr>
<td></td>
<td>Family-centred practice</td>
</tr>
<tr>
<td></td>
<td>Responsibility on Parents</td>
</tr>
<tr>
<td></td>
<td>Informal supports</td>
</tr>
<tr>
<td>Experiencing ASD in the Family</td>
<td>Controlling activities</td>
</tr>
<tr>
<td></td>
<td>Impact on siblings</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
</tr>
<tr>
<td>Recognising Mental Health</td>
<td>Self-care</td>
</tr>
<tr>
<td></td>
<td>Priorities</td>
</tr>
<tr>
<td></td>
<td>Constant stress</td>
</tr>
<tr>
<td>Aspiring for Change</td>
<td>Support at Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Ongoing Support</td>
</tr>
</tbody>
</table>

Table 3: Summary of super-ordinate and subordinate themes.
The first theme, “Experiences of ASD”, encompasses how participants think about and conceptualise ASD in a general sense. Participants explore their own personal viewpoints on ASD, how they feel the manifestation of ASD impacts their child and the child’s integration in society, and their concerns on how ASD may influence their child’s development and future potential.

The second theme, “Interacting with Services”, explores parental experiences with disability services, usually public and sometimes supplemented by the private sector. Participants describe frustrations with insufficient resources, struggles to experience family-centred practices, and their experiences of responsibility in delivering interventions at home. Participants also describe the informal supports they have sought out, and the associated positive and negatives aspects of these supports.

The third theme, “Experiencing ASD in the Family”, examines the impact of ASD on the participants’ immediate families. The need for structure and routine as an imposing and controlling influence is explored. The impact of ASD on the child’s siblings was described in depth by many participants, as well as the impact of ASD on relationships, parenting style and family planning.

The fourth theme, “Recognising Mental Health”, explores the participants’ own mental health in the context of raising a child with ASD alongside typical life stressors. Participants describe their understanding of how they do or do not engage with self-care, why and how they prioritise factors that impact their mental health, and the various sources of constant stress which they are faced with on a daily basis.

The final theme, “Aspiring for Change”, explores participants’ desires around changing the system in which they and their child and family are embroiled. Reflecting on their own experiences with services, participants describe the need for supports at the time a diagnosis is received, as well as continuous on-going support for the child and their family.

The super-ordinate themes described are interlinked, with complex and unique connections to each other. For example, the final theme of Aspiring for Change links to the second theme of Interacting with Services and the fourth theme of Recognising Mental Health, as many participants expressed a desire to have their mental health needs addressed and supported by the services their child attended. The structure of broad-to-specific has been imposed to provide some clarity and ease of understanding when engaging with the personal experiences of participants. However, given the complexity of the topic, interconnections are inevitable.
4.3 Experiences of ASD

4.3.1 Personal viewpoint on ASD

A common experience of coming to terms with having a child with a diagnosis of ASD was a change in perspective of what ASD meant to people. Some participants experienced fear and dread in the run up to, and immediately following, diagnosis.

“Autism would have been one of my worst fears so I would have hoped it wasn’t that... you feel it hits you even if you’re expecting it, but, and you feel a disappointment that that’s the diagnosis.” {Sarah}

“Oh god I suppose in the beginning it was, it was very hard to take you know when she was diagnosed. Also I was pregnant at the time with [younger child] and I do reckon if I hadn’t have been pregnant I would not have had another child, because the fear of having another child with autism would have stopped me” {Jen}

Ciara had a similar thought process regarding the impact of ASD and family planning.

“I didn’t know [son] had autism when I got pregnant with my second child. Em, that might have affected my decision. Well not that I had a decision anyway, he was coming along anyway, but you know it could have affected that, em, if I’d have known what we were in for.”

Ciara highlights an important if uncomfortable point; that having a child with ASD can and does impact mother’s decision-making processes around expanding their families.

The majority of participants described the positive benefits that having a child was ASD has brought to their lives. Having a child with ASD has changed their outlook on life, an experience which participants approach with gratitude.

“Em, I suppose it makes the whole family be a bit more conscious of other people with difficulties. Em, and like you em probably see not lower your expectations but just change your expectation around things, moderate your expectations or or have em be a bit more tolerant or be a bit more em, sort of try, it makes you be a bit more laid back about certain things, you know when you think oh I can’t, I can’t be perfect anyway, so let’s not stress about it” {Fiona}
“Em I think you allow an awful lot of the rubbish and drama that goes on in life in general to fall away because it’s not relevant. Em I think my other 2 children are a lot more mature, em, we’re all less judgemental.” {Caroline}

“I think he enjoys things much more than a child typically would. Like bubbles could be just amazing to him. Colours are amazing. Sometimes I watch the way, the amount of fun he has over something so simple. Em, it’s quite nice.” {Katie}

This change in perspective has not always been an easy transition, with Anna speaking to the resistance she initially had in embracing a new outlook.

“It means you appreciate things more. I mean somebody said that to me at the beginning of the journey and, that, you know, that you’ll appreciate the little things more, eh, you know, and I thought, that’s really trite. Like feck off, you know, that’s, how patronising is that. But it’s true. Like you really really do.”

Orla spoke about her experience of getting to stage of acceptance with her child.

“Em, plus you get to a stage say they get to about 8 or 9 and you just kind of accept that, you know, you try and make the most out of each day with them rather than worry about them, you know. And enjoy them.”

Lucy explored how her experiences of positives were numerous; however, her raw emotions during this stage of discussion were palpable.

“The positives are em you know certainly a huge, you know a huge amount of increased understanding for any disability or for anyone who’s a bit different that you know just trying to do their best to fit in, whether (cries) sorry em, whether child or adult, you know, for both myself and my husband you know that’s certainly something that’s, I am glad I have that now. I’m sorry I had to come by it this way, that I didn’t just have it naturally beforehand.”

Lucy went on to describe how she views the ASD as being an integral part of her child, a sentiment shared by other mothers who see the ASD as a part they would not change or even recognise the child without.

“I wouldn’t change him, em, and having him in our lives is a huge positivity.” {Lucy}
“I couldn’t imagine him now without autism. I’d never know, I don’t know who the child is without autism. I can’t imagine him who he would be. I don’t think there is a personality of [son] without autism. I’ve never known that, I’ve never met that person so to me that person doesn’t exist. The only person that exists is the boy that I have.”
{Katie}

“Like, [husband] has an analogy of the Mi Wadi, like, “Where’s the water, where’s the MiWadi”, like ASD, water, [daughter], just the whole package...” {Anna}

For these participants, their experience of their child is one that is synonymous with their experiences of ASD, and one cannot exist without the other.

Conversely, other participants expressed a level of resentment towards the ASD, describing a desire to take it away and leave their child without the condition.

“But look, if I had a magic wand that said she won’t have it anymore I would absolutely say, take it away. I’m not one of these mothers that says oh I wouldn’t change her. I would. If I could take away her autism, I would.” {Jen}

“You know feck it, if you could pick, like if I could pick I’d have 2 kids like my 5 year old, you know, not, you know like if you boil it down, like I’d have 2 neurotypical kids, thanks very much.” {Fiona}

The direct words of Jen and Fiona really capture how unwelcome and unwished for the ASD has been for them.

Interestingly, one participant Caroline appeared to take solace in the level of severity her child lives with, framing the lack of insight her child can engage with as a protective factor in his satisfaction with life.

“I do think, you know, what are the positives for [son]? I don’t know. The only thing I could say is that [he] is kind of autistic enough that he’ll always have a very sheltered life so I think a lot of people who are more on the Asperger’s end of the spectrum can have it harder because they probably know they don’t fit in. I don’t think [he]’s aware of that so I’m quite thankful for that.”
4.3.2 ASD and the child in society

As well as their own perceptions of ASD, participants explored their views surrounding how their child with ASD functions in society, and how society responds to them. Participants described the anguish involved when members of the community don’t immediately understand or make allowances for the child’s behaviour.

“And they’d try to talk to him and of course he wouldn’t interact and then people go why isn’t he talking you know and it’s like oh please just stab me in the heart a little bit more, you know.” {Rachel}

“But yeah, when you’re put on the spot and have to kind of defend them at times it can be, it can be heart-breaking to have to do that and at the same time explain and it can be horrible the fact that you have to explain yeah there’s a disability… and it’s amazing the looks he can get from people.” {Sarah}

These participants highlight how a lack of knowledge or acceptance of ASD in the community has painful consequences for parents. Ciara described her impression of society’s reaction to her child’s behaviour as a judgement on her own abilities as a parent.

“But it is upsetting because you know people are looking at you. You know people are probably saying to themselves, oh such a bold kid, she can’t manage her child, or you know something along those lines. But it isn’t that at all. Like if they had to realise how much strategies I have to put in place all the time to manage those behaviours and those issues that he’s having, they, they wouldn’t know what parenting was if that, if they had to do that, you know that kind of a way.”
Annette, whose child with ASD is over the age of 18, spoke about the difficulties her son has had with attempting to integrate into society.

“So one of the things, it would be friendship at any cost. It didn’t matter what to him he had to do, he would do it to have a friend... And he would still be, he would still turn himself into, somebody that eh he thinks people want him to be and do things just to have friends and be a cool guy and whatever, instead of being the nerd...he had to sort of hit rock bottom before his behaviour, that sort of spiral down into drug abuse and you know buying drugs for other people and carrying drugs for other people just to make them happy, just to be part of something.”

Katie spoke of similar difficulties with her much younger son, who tries to understand the world around him as, at the same time, the world tries to understand him.

“I suppose I just want him to be happy and I think the world is very difficult for him because everything is harder for him to learn. He’s always in trouble. Like he’s always been told get down, come over, stop, and nobody really recognises that like he shouldn’t as a 5 year old boy, the real stress is on him, you know, it’s not his fault that he’s constantly....it’s not fair on him and I worry about his happiness. Even though he’s quite a happy boy I think deep inside he knows more than he can show. He knows more. And I worry about people’s understanding of autism around him.”

The vastly different stressors associated with mothering children with ASD at different ages is highlighted here, and emphasises that while the stress inherent in that mothering process may well be a shared psychological experience, the individual lived experiences of mothering a child with ASD is not necessarily a unifying or universal experience

4.3.3 Concerns about the future

A prevalent concern for all participants surrounded the unknown challenges that would face them and their child in the future. Some worries were specific and focused on the coming few years.

“The other thing I find very stressful is that she, now she’s in 4th class and she still has to be very carefully managed going in the door to school every morning...I’m beginning to worry if she can’t, if she’s in 4th class and she can’t walk in the school door by herself, how are we going to get her to secondary? I’m beginning to get concerned about that.” {Fiona}
“Oh yeah when he turns 18, I just don’t even want to think about it, that’ll be a whole other problem.” {Amy}

The similarities here between Amy steeling herself to face a looming issue and Fiona avoiding thinking about issues which are further down the road highlight the limited ability any one person has in dealing with stressors when their lives can already be characterised by encompassing more stressors than the general populace.

Other worries were more general and enveloped broader themes and timeframes.

“Thinking about the future I would find quite difficult, you know. Em, will he be able to look after himself, that kind of stuff, you know. Will he be having an independent life?? That kind of stuff I find, I don’t really think about it because I find it too stressful...” {Amy}

“Can he live on his own or in society? I mean he can’t really live on his own but you know, how would he get on in society? Like I’d be literally a third limb for him when he’s out walking or when he’s out you know... I know they do try and job shadow in some places locally here, but, and you do see the odd person with autism working in say the local Spar but how much is that, like is that just for an hour or do they even pay them a wage, you know.” {Orla}

Caroline spoke in detail about her concerns for her ability to provide stability to all her children, especially in the context of being a single mother, and the palpable fear associated with the possibility of things not working out the way she hopes.

“Em, I think, for me it’s the ability to provide for the kids (crying)...To be able to provide for them and pay for college and pay for summers away and J1 visas. I want my other kids to have all of that. And for [son] I just want to have this house, you know. He has a specially adapted bedroom because he was in a wheelchair for a while, and he doesn’t need it anymore but he sleeps well...He’s just so comfortable here.... You know, it’s just me, it’s just me doing all the hospital appointments and I’m tired. So I worry that I’m going to get sick (crying) that would be a worry. And I really don’t want to obviously for me for [son] for the other two. Because they’re so young and they already pick up a lot of slack, you know.”
Similarly, Anna described her anxieties around the future impact of ASD on her other children, as well as touching on how her fears of the future get in the way of enjoying the present.

“I’m in this agonising excruciating period where I don’t know how she’s going to turn out which is horrible because I want to appreciate it her as she is right now, because I think I wasted a lot of time thinking is this autism, is that autism when I should have just enjoyed her. But yeah I do worry about the financial future, her future, because a huge amount of people on the spectrum can’t have jobs or anything like that. And then I worry about [son] and then does my other child have to mind both of them in the future.”

For Caroline and Anna, worries about the future were simultaneously vague and specific, and encompassed a sense of powerlessness, an inability to prepare their children for the future and protect them from difficulties they might encounter.

Reflection Box 2

The emotion in the participants words and voices was most discernible when they spoke of their concerns for their children. The emotional labour that goes into parenting a child with additional needs and an uncertain future is already known to be hugely difficult, but hearing the voices of women currently embroiled in such uncertainty allows this reality to strongly resonate and the difficulties be truly recognised and appreciated.

The differences between participants became most clear as this theme emerged. Participants had children of different ages, with different comorbidities, in different school settings; the mothers themselves different in employment status and relationship status. While the goal was to recruit a fairly homogenous sample, as is the norm with IPA research, the heterogeneity of the participants perhaps reflects the heterogeneity of the experience of ASD itself.

4.4 Interacting with Services

4.4.1 Insufficient resources

Participants spoke at length about their experiences with services supporting their child. The common experience appeared to be disappointing and unfulfilling, with long waiting times, a lack of response to requests for help, and an overall sense of frustration and hopelessness. Participants spoke of services appearing to be non-existent for them and the frustrations this brings.

“You’re kind of waiting say a year, year and a half to get your child assessed and then you’re waiting another year and a half to two years for your child to access services. So you’ve absolutely nothing during that time.” [Sarah]
“You’re looking for services that are non-existent, you hear about Early Intervention which just doesn’t exist either and you know you want to do the best, to give your child the best possible chance to live in society, but it doesn’t, it’s inadequate to what they need, you know.” {Orla}

Amy spoke of her disbelief at the lack of needs-based services, despite waiting for assessment and intervention for quite some time.

“You see initially where [son] was diagnosed we thought it was just a speech problem…I put him on the waiting list for Speech and Language. But then, this was like 5 years ago, he came to the top of it and they rang me, he’s at the top of the speech and language list, I can give you an appointment, and I said oh things have changed, he’s actually been diagnosed with autism, she goes oh I’m really sorry, you’ll have to go on to another list. I just hung up (laughs). You are having a laugh, after 12 months of me waiting. That kind of stuff we have to put up with.”

Participants described letting go of hope that services would meet their needs, and deciding instead to try and cope by themselves instead of being vulnerable to service providers.

“And we try not to think about it, we just try to get on with it ourselves and put our own strategies in place and get our own private or whatever, but it really does require a multi-disciplinary team. And you can’t procure that.” {Ciara}

“But I, I find that nothing really changes, even if you tell somebody like that, things don’t change. That was my experience. Twice or three times I have said, I’m on my knees and I can’t keep going, I can’t do this, but nothing changed so I, I’m not going to do it anymore…” {Caroline}

What these parents are communicating is a strong sense of disconnect from the services, where the framework through which they should be receiving the most guidance and support is at best lacking and at worst non-existent.

4.4.2 Family-centred practice

Participants discussed their experiences of accessing, or attempting to access, family-centred practice with the services they engage with. Lucy described the lack of concern shown regarding her own well-being and ability to manage.
“Like there’s maybe been some sort of like, that must be really hard on you as well, or you know some maybe comments like that but without really kind of em delving into it I guess.”

Orla spoke about her frustrations with the somewhat cavalier attitude of the services as the mother being the expert, without sufficient support from the services themselves.

“And they tell you you’re the expert, and yes I am an expert but you know, there’s only so much you can do...In one way maybe their intention is good but it, it, one thing doesn’t fit all, do you know what I mean, it has to be specific to what the child needs, you know, or the family.”

Similarly, Anna described her enthusiasm to lead interventions with her child but was taken aback at the lack of ongoing guidance available.

“Like, you know, I’m prepared to do the work, em, it’s just you know being able to, I remember in the first meeting, I said that. I said look I’m prepared to do the work...but I want you to support me in my learning. And, you know, can I lift the phone? And basically they were like, eh, no (laughs). Em so, you know, which I understand, I do understand that, I know the resources aren’t, you know, are limited, but.”

For Caroline, her desire to ensure the wellbeing of her entire family has not been met by the services she attends with her child.

“Healthcare providers I know are there for your child so it’s not always their job to give you, point you in the right direction, but a more holistic approach would help because it’s not just, our whole family is you know profoundly affected by autism. My children probably need more help than they get in terms of mental health.”

Caroline has succinctly encapsulated the need for services to carry the ethos of family-centred practice, without having had direct experience of such services herself.

4.4.3 Responsibility on parents

Throughout all interviews, participants explored feeling alone in navigating systems and providing interventions for their child with ASD. Lucy described a sense of feeling uneasy and unprepared with attempting to understand the various systems involved in supporting her child.

“You know again I feel like I’m, we’re navigating that very much by ourselves em, the Early Intervention Team has been a bit of help, but, no they have been but I guess I still
just feel like I’m, it’d be nice if there was more direct linkage there between the Early Intervention Team and the schools you know... that I shouldn’t have be trying to kind of coordinate all that and figure out what would be the best thing to happen.”

Amy was more explicit about her experience of services as separate to the family system, with an “us vs them” perspective and a sense that interventions in theory and in practice are very far apart from one another.

“It’s very family-based you know and they expect parents to do everything...they’ll do loads of parent information night, you know, and you go down and take all the notes and come home and you apply it at home. Which in theory is lovely but (sighs) I’m not an educator, you know, I’m a mother and I can only do what a mother can do, d’you know.”

Despite praise for the information that is provided by services, Katie expressed frustration with the lack of support in implementing and maintaining interventions at home.

“Like these courses are excellent but you do the work. You know it’s not like these people are actually working with your child, it’s kind of it teaches you strategies, they talk to you about these strategies, and then it’s up to you to maintain it at home. And that’s what the really really really difficult part of it is, is trying to do all of this.”

**Reflection Box 3**

It was striking how participants recognised the positive attributes of the services, mentioning the quality of courses and the help they have received. It would be easy and understandable for parents to lambast services entirely given the strain they are under and the shortcoming that do exist in ID services.

### 4.4.4 Informal Supports

In every interview, participants spoke about the informal supports that they have turned to, either online or in their local communities. Some participants welcome the extra support as a huge bonus in their lives which provide shared understanding and would not have been available to them if their child had not been diagnosed with ASD.

“Like I’ve made some fantastic friends as a result of [child]. You know, people that I’ve met that would be life-long friends, that I’d go out with regularly, you know, for coffee mornings and stuff, so it’s great, because they understand, you know. They’re kind of on the same page and stuff like that, so”. {Amy}
“It’s a good bunch, we have a good bunch there. And I said I never wanted to meet any of them. I said I never wanted to meet ye, but now that I have met ye…I mean I wish my child didn’t have autism. You know what I mean? If [son] didn’t have autism I would never have met these people.” {Jen}

“They all go, well my kid did X or, and they’re not funny but you can laugh about it, and it’s just so, to have that kind of level of support and parents going, they don’t pity you, you know, we all just share our experiences and we get a little bit of strength from that, you know, so that we don’t feel alone, it’s great, you’re not isolated.” {Rachel}

The message being communicated here is that the shared experiences and understanding with other mothers in similar situations is priceless and not to be underestimated.

Conversely, some participants had negative experiences with informal support groups and found such groups to be more harmful than helpful.

“I have very mixed feelings about it. I find there’s an, I’ve nearly left it an awful lot of times, there’s an awful lot of em, there’s an awful lot of negativity on it, you know, and I don’t, and I don’t mean there’s people obviously people upset about stuff that happens with their kids but an awful lot about like you know no-one else understands and you know just a lot of kind of, a lot of negativity. And I don’t find that very useful, you know, about no-one else understands, well yeah I know but I didn’t understand 2 years before I had [son] and you can’t just magic, wave a magic wand and you know expect, you’re kind of thinking the worst of people, they don’t understand because they don’t know. They’re not trying to be, people aren’t trying to be em, what’s the word, you know they’re not, they’re not trying to be malicious in their misunderstanding, you know.” {Lucy}

“To be honest with you, I find the stress of some parents to much so I try and stay away from it…You need sometimes people who aren’t involved, do you know what I mean, that, because you’re picking up their stress as well as worrying about your own, you know…you’re going to get people feeding off people that are just, you know, highly stressed, so they’ll never see the light at the end of the tunnel or just make the most of each day.” {Orla}
Participant descriptions of not being met, either through services not meeting their needs or other mothers of children with ASD being at different stages in their own processes, really serves to highlight the loneliness inherent in navigating services and parenting a child with additional needs.

4.5 Experiencing ASD in the Family

4.5.1 Controlling activities

ASD as an imposing influence on family life was a common experience for all participants. Mothers spoke about having to carefully plan ahead the day’s activities to accommodate the ASD.

“Being on your own or something with the two of them by yourself is just an absolute no-no, on a busy road or something. Do you know what I mean, like if we go to a playground it’s always one that’s like where you can park right beside and the playground’s right there, you know, and that you don’t have to navigate, yeah, navigate roads.” {Lucy}

“We just have to be quite selective about where we go. Like I couldn’t go in to a coffee shop with him for a cup of coffee, because they don’t sell chips. Do you know that kind of way? Something so small like that could set him off.” {Amy}

The need to be attuned to every detail and possible triggers in what some or most others would consider routine daily activities is communicated very clearly through the above examples.

Participants also described the ASD as constraining and curtailing family experiences.

“Em, it means that we have to keep very strictly to routines and em it can be very difficult to try new things. Em, to try a new restaurant or a new activity or new em you know a new place to go, it can be quite difficult.” {Fiona}

“You can’t just decide at the drop of the hat, oh come on let’s go to the zoo. Because you don’t know what way is she going to react.” {Jen}
Katie described the ASD as almost overwhelmingly controlling, limiting her activities and extinguishing her socialising.

“My social life is completely isolated because I can only go where he wants to go. He has aggressive behaviours. He leads my life, he controls my life. So I’m very limited on where I can go. I go to where he wants to go.”

There is a sense of loss communicated here with the few quotes above, with a lack of spontaneity and new activities due to an inability on the child’s part to engage in such behaviour, and an unwillingness on the mother’s part to subject their child to something so potentially upsetting, highlighting perhaps a loss of the mother as an individual with their own needs and desires as these are eclipsed by the needs of the child with ASD.

4.5.2 Impact on Siblings

Mothers with multiple children spoke extensively of the impact ASD has on their other children, exploring their own role of parent to multiple children while remaining primary caretaker to the child with ASD. Sarah explained that her neurotypical child has taken the brunt of behavioural outbursts.

“I wish they’d kind of do something for siblings on it as well because it is a hard thing to explain...If something’s getting to him or if he’s very tired and just gets angry he has difficulty controlling his emotions so he’ll just hit out at his brother...it’s hard to deal with and for his brother to understand. I’ve kind of gone through a book with him on that and you know it kind of works for a while but he has got a little older now so he’s learning to fight back, but...so it can be (sighs)...”

Sarah has clearly gone to some lengths to ease her other child’s experiences of his brother with ASD, but her sighs and pauses as she speaks reveal the toll this added stress has been taking on her own well-being.

Some participants described how their other children have adapted to their sibling with ASD by changing their role in the family. Ciara described how her other son now acts as the older sibling in guiding his brother with ASD.

“His younger brother is now taking the role nearly like a big brother, where he’s going “[brother], you’re not allowed do that” or if he runs away or does something like that, he’s nearly giving out to him. Like he’s an older sibling rather than a younger sibling, Because he understands, yes, yeah.”
Caroline explained how she feels her neurotypical children have grown up a little faster as a result of their sibling with ASD, an experience she regrets on their behalf.

“I think there’s an awful lot of responsibility I wish they didn’t have. My son can be quite aggressive so they’ve been on the receiving end of that and they’ve seen me on the receiving end of that quite a lot and that, I know, is awful for them, you know, and they’d rush in to try and help and that kind of thing, and it takes an awful toll...They’re trying to just mind me a little bit, which is, it’s a positive but it’s kind of a negative too because (voice breaks) you don’t want them to have that level of responsibility... You’d love for them not to have the awareness that that kind of stuff goes on.”

Annette describes how her son with ASD can negatively impact the wellbeing of her other children and the family as a whole by attempting to regulate himself.

“So he, to fall asleep he would need em maybe a television on, music on, his iPad on, just you know tons of covers over him, even just to get asleep. But we’re all kept awake. Like that’s the biggest problem my daughter has is you know em, not being, the disturbances to her. Especially even now, she’s working on her thesis and she’s doing her final exams, she just did her Christmas ones and she’s fretting over the finals, you know, but there’s no consideration to that.”

Jen described the reactions of her other children to their sibling’s behaviour as an additional stressor in the family.

“I probably find what’s stressful in my life is if [daughter] acts up, how the other kids react. Like, don’t get me wrong, she really isn’t that much trouble, ok. But if we were in the car somewhere and she starts this screaming business, or maybe just keeps repeating a word, like “Go to Tesco”, and we’re going, and she just keeps saying it, sometimes I find [son], he’s 10, he can go “Oh for god’s sake! We are going”. Then I’m telling him not to shout at her. That’s, you know, that’s pretty stressful....”

Reflection Box 5

The extent to which parents have to be mindful of every member of their family is highlighted brilliantly by these mother’s explorations of their concerns for all their children, emphasising that they are both caregiver to the child with ASD as well as parent to their other children. The empathy these mothers clearly hold for their individual children truly seems to be never-ending, an impressing and humbling experience to be witness to.
4.5.3 Controlling Relationships

Participants explored the impact of having a child with ASD on relationships within the family. Lucy spoke about the stress that a child with ASD can have on a marriage, bringing emphasis to the multiple roles she must juggle.

“I’d like to think myself and my husband have a very strong relationship, but it does, it can be tough at times, you know, it can be tough, just it can be tough. Because obviously it’s very upsetting seeing [son] upset over something and then, it’s very hard not to take that out on each other as well.”

Sarah spoke of her attempts to maintain solidarity within the marriage and the family unit, while acknowledging the practical barriers that exist.

“We feel that our challenges with him are also his challenges with life, does that make sense, so it’s like a shared challenge for everyone, we’re in it kind of with him, but it’s easier to kind of work through that way...I suppose the main issue is I can never get out with my husband together. You know so anytime one of us takes a break, it’s the other one that stays minding the children.”

Other participants explained how relationships with members of the extended family have been strained, as individuals in the family have not made efforts to bond with the child who has ASD.

“Well I’ve two nieces now and they kind of just don’t react to her at all. You know. They probably wouldn’t even say hello to her to be honest.” {Jen}

“The rest of my family don’t really get it, none of them, like I’ve brothers and sisters and stuff but they don’t, they’ve never minded [son], like ever ever ever, em so I used to get very cut up and hurt about that but I don’t anymore because it actually just hurts me more than, just trying to accept it is the way it is...” {Caroline}

The ramifications of ASD and its associated difficulties seem to be far-reaching, rippling out beyond the child and the primary caregiver and having its presence felt throughout relationships with other individuals. This also provides insight into the multiple roles played by participants in the current study; not only the role of mother, but also that of primary caregiver, partner, sibling, aunt, and peacekeeper.
4.6 Recognising Mental Health

4.6.1 Self-care

Participants explored their own levels of self-care, with the general consensus being that self-care has not been a priority despite general recognition of its importance. Participants spoke of a perceived inability to engage in adaptive forms of self-care due to tiredness.

“Like I’m so exhausted and so exhausted you know it’s almost too tiring to go and do something else that will release your stress, like go for the run or go for the walk or whatever, so just have a glass of wine you know or have a beer and then so I’m quite conscious of that and so I think you know that, that my own relationship with the stress I have and how to relieve that isn’t very good so I am, so I think that’s not a healthy way to get rid of your stress like so em...the self-care really is like obviously it’s a problem.” {Fiona}

“I know that I’m not, if you wanted to ask me about me, how I feel about myself at the moment, I know that I’m not looking after myself properly. I know that I’m working hard, I’m not eating properly, I’m putting on weight, and I know that’s all down to stress... Em, nothing (laughs), I’m not looking after myself at all at the moment...Em, I also probably drink too much alcohol. Em, I smoke. Em, and all of that like I just don’t think, I never find the right time to address it. And I’m overweight.” {Ciara}

For these mothers, their insight into their stress and management thereof was refreshingly blunt and insightful, with clear recognition that existing coping strategies may not be optimal but they may be all that is achievable.

Annette spoke about the very real and tangible impact stress has on her physical well-being, with a sense of resignation that she could not mitigate the current stressors in her life.

“Em I know stress has played a huge part in health conditions that I have. I regularly, every 6 months for years now I have a brain scan because I have lesions on the brain and eh I get migraine, I suffer severe migraine, and it’s all connected, and stress is a huge part of that. And I can’t take that stress out. I go to a neurologist every 6 months, and we talk about different ways of trying to reduce stress headaches and stuff, and I can’t take that element of stress out of my life because it’s there. So it as an impact that way, you know.”
4.6.2 Priorities

In discussing self-care, a good deal of participants explored how they did not prioritise their own wellbeing for themselves, but rather for the benefit of their child with ASD. Participants explored fears that if they did not mind themselves, there may be no-one available to provide sufficient care for their child.

“I mean I suppose again it’s a bit of a generalisation but I suppose yeah your main thought about yourself is just trying to be the best parent you can for them, trying to push the independence, trying to nurture them in every way you can and love them in any way you can. You know and getting the balance right between not having them too sheltered as well and getting all that autism acceptance out there, into the workplace as well for older, for when he’s older, you know.” {Sarah}

“Em, he’s a worry because you know you want to stay well to look after him as long as possible because he has an intellectual disability so he’ll always need somebody involved with him, he’s not somebody high on the spectrum, you know….Just to stay well, to mind him, really, that’s my priority because I do have a long-term illness so you know.” {Orla}

The point coming across here is that these mothers desire to keep well primarily for the benefit of another, a selfless act which embodies the role of a full-time caregiver.

4.6.3 Constant stress

Participants were very open in exploring their experiences of stress. They unashamedly and unabashedly described their high levels of on-going stress, expressing concern that their stress levels were unsustainable and yet inevitable, with no relief in sight.

“Em, I suppose this level of worry and stress isn’t really very sustainable. Em, that it, em, like it’s going on a long time now, and that’s not, it’s not really going to go away…I’m probably never going to actually feel relaxed.” {Fiona}

Some participants spoke about coping in the day-to-day, taking things as they come and being completely unfamiliar with the sensation of relaxation.

“Every minute and every hour I’m keeping myself going, but I don’t really think, I can’t imagine that it’s sustainable…I don’t know how to say it but I’m just getting by and I’m not saying that mildly. I have to take every hour as it comes and you know I can’t…yeah,
I’d be very worried about myself. Emotionally, physically, em... I can’t imagine that this amount of stress in one person’s life could be, could keep going.” {Katie}

“I think I’m almost in a state of constant stress (laughs). So much so, that em, I don’t really know what calm feels like anymore. I remember, like, I was reading the newspaper one day, a couple of Sundays ago, and I had this like strange, unfamiliar feeling wash over me, and I thought, oh gosh, that must be relaxation. And it’s crazy.” {Anna}

Other participants openly discussed their experiences of passive suicidal thoughts as well as a need for psychiatric intervention.

“Honestly I was probably borderline suicidal at that point. I was certainly having suicidal ideation you know, I can remember there was a time when there was a news story on, something had happened in the States where some mom had bundled her kids into the car and drove them off a bridge. And the news pundits were all, how could a mother blah blah blah, and I remember at the time... going I can kind of see that (laughs) which is a terrible place to be. Really a horrible place to be.” {Rachel}

“I am taking anti-depressants. And I did go off them for a while, and I nearly lost my mind. And I ended up in the doctor’s crying, saying that if she was dead, everything would be so much better. And then the guilt for saying that. Now this was probably 4 years ago. And the doctor said to me if I had a euro for everyone that looks after someone with special needs that say them things, I’d be rich. You’re not the only person, which did help. But I reckon now I’m just going to take these forever, because I’m not going off them again.” {Jen}

The chronic and pervasive nature of the stress experienced by the participants is described in such an honest and unfiltered manner that the stark truth of their reality is crystal clear impossible to ignore or dismiss.
4.7 Aspiring for change
4.7.1 Support at Diagnosis
While all participants explored negative or mixed experiences with services, participants were eager to express how small changes in service provision could be of benefit. Mothers described their experiences of receiving the diagnosis and the lack of concurrent support, with two participants describing rather bleak encounters:

“The only support we were offered was an introduction to a waiting list.” {Ciara}

“But essentially the autism just, they give you the diagnosis and then that’s it, forget it like. It just falls flat on its face and it’s feck all like, there’s nothing for you…” {Fiona}

Caroline recalled in detail her experience of receiving her son’s diagnosis, and the clinical manner with which she was dealt.

“The actual day he got his diagnosis I look back on it and I can, I can still smell the air in the room. It’s such a profound moment, that even when you’re expecting it you’re blindsided. And I remember, because he was 4 and he was playing at my feet, and the woman who had diagnosed him through like this public service, em, public system, you know, handed me a leaflet and said like there’s respite available when he’s 10 because you’ll need a holiday on your own…It was a very callous way, and that was really the effort of support that I was offered, that when he was 10 he’d be able to go for respite.”

Sarah generated ideas on potential beneficial supports, while drawing on her own negative experiences of receiving a diagnosis of ASD for their child from services.

“At the time of diagnosis you are not given a single thing of support. You’re given not as much as a pamphlet of information on autism, you just receive absolutely zero kind...
The bluntness with which participants speak of this pivotal moment in their life and their child’s life effectively communicates the bluntness with which they experienced the delivery of the diagnosis and also the provisions of support from services.

**Reflection Box 7**

It struck me that some participants recall the moment of diagnosis with such clarity reminiscent of traumatic memories. Lack of resources notwithstanding, it feels imperative that individuals supported by the service and their families are treated with more empathy and respect than recalled by these participants. Additionally, it is disheartening to hear parents talk about their desires for more integrated family-centred practice in this regard, when this has been lauded by the research for decades and the majority of ID services purport to provide services under such a framework.

### 4.7.2 Ongoing supports

As well as support at time of diagnosis, participants were cognisant of the need for consistent ongoing support from services as they face changing needs and challenges with their child. Orla described the barriers involved in accessing ongoing support for her child because of the current divide between Intellectual Disability Services and Mental Health Services:

> “And you have that because the problem with ASD too is you have the autism but you have mental health problems, so the child and adolescent mental health don’t want to work with the ASD children, and then they say well part of their diagnosis involves mental health, and they just keep ping-ponging the poor children in between...so that’s not helping anyone.”

Fiona spoke about adding individual therapy for parents as a consistent support, recognising that speaking out in group sessions is not always sufficient.

> “I think it’s important that, that people have access to some sort of talking or, and the groups thing doesn’t necessarily work well. I know certainly that’s part of the Incredible Years, is just the other people in your situation and yeah, it’s somewhat helpful but I mean everyone’s situation is so different that you know it’s kind of hard to get a lot of solid from it... So sometimes the group thing doesn’t work, so I think individual therapy is what people probably need, or couples.”
Very practical and accessible supports were proposed by Caroline, who has contemplated taking on the role of service provider by creating the necessary resources herself.

“I suppose in terms of care I’ve often thought about it and then I have great intentions but I never have time to do these things but I’ve often thought it would be good for service providers to maybe produce a booklet that could be given to parents of children who’ve been diagnosed and, I don’t know even if there was an online support system that was just even a series of printed documents like it doesn’t even have to be manned by anybody. But em I think useful things like how do you talk to your family about giving you more help? How do you talk to your family about doing this or here’s some things you could try. I’ve kind of learned it over the years but it would be nice to dip into a resource.”

Participants are clearly expressing a need for additional support, and suggesting practical and accessible avenues through which this support could be provided. The fact that these needs are unmet by services and that parents are striving to fill that void communicates a sense of deficiency and inadequacy regarding supports that are available to participants.

4.8 Chapter Summary

Mothers of children with ASD have a huge amount of stress in their day-to-day lives. This stress is inextricably linked to their child with ASD, and manifests itself in various ways, but stress remains a constant companion for these parents. Reaching out to ID services for support in managing their stress appears to have disappointing outcomes for mothers. These results will be discussed in the following chapter in relation to existing literature, explored in Chapter Two.
5. Discussion

5.1 Chapter Introduction
This chapter provides a detailed discussion of the study’s findings. The research question is reiterated and the primary findings are summarised. The existing literature as presented in Chapter 2 is discussed with reference to the current research findings. The strengths and limitations of the current study will be explored. Potential implications for clinical practice, education, and policy are discussed as well as possible directions for future research. A critical reflection of the overall research process is presented. Finally, the chapter concludes with a summary of the study overall.

5.2 Review of the Research Question
The existing literature states time and again that parents of children with ASD experience greater levels of stress and mental health difficulties than parents of typically developing children or parents of children with other neurodevelopmental diagnoses or disabilities. The majority of this literature is quantitative in nature and lacks an in-depth exploration of the lived experience of parents of children with ASD. In addition, extant policy promotes a family-based practice approach to intervention in disability services; however, recent studies suggest that such policies are not always implemented into practice, leaving parents to often seek their own supports away from services provided by the state. The present study sought to engage more thoroughly with parents of children with ASD and provide a clearer understanding of their experiences. Thus one overarching research question was developed: “What are the experiences of stress, support, and self-care in mothers of children with ASD?”

5.3 Summary of Findings
As detailed in Chapter 4, this study elicited five super-ordinate themes common to participant’s narratives of their experiences of stress and support as parents of a child with ASD. These themes are: “Experiences of ASD”; “Interacting with Services”; “Experiencing ASD in the Family”; “Recognising Mental Health”; and “Aspiring for Change”. Embedded within each super-ordinate theme are descriptions of events and circumstances which could be understood as once-off or ongoing stressors in participants’ lives. In addition, alongside these experiences of stressors, participants engaged in various forms of support for themselves, their child, and/or their family, demonstrating a range of resilience, adaptive and protective factors in their roles as mothers, caregivers, and individuals.
5.4 Findings in the Context of Previous Literature

This section explores the findings of the current study in the context of existing literature. In the interests of clarity, superordinate theme headings are used to help structure the discussion of previous literature and its application to the current study’s findings.

5.4.1 Experiences of ASD

All participants explored in great depth their thought processes around ASD in a general sense. Each individual explored their own personal conceptualisation of ASD, and how having a child with ASD has altered their perspectives on ASD as a whole. Some research has shown that the majority of parents adapt well to receiving a diagnosis of ASD for their child, while a small but significant proportion of parents struggle with this (Poslawsky, Naber, Van Daalen, & Van Engeland, 2014). The current study reflects this finding, where the majority of participants spoke about ASD as an integral part of their child that they have come to accept, despite fear and dread in the stages before a diagnosis was confirmed. However, two participants also explored their desire to take away the ASD and leave the child without the diagnosis, living a neurotypical life. This has been explored previously in related disability literature, with the loss of the “ideal child” part of the complexities of diagnosis and early stages of coping with the severity of disabilities (Fernández-Alcántara et al., 2015). These feelings of loss mirror a grieving process seen often in parents of children with ASD, and emphasize again the importance of emotional support for parents at the time of diagnosis and beyond.

Parents described their concerns around how the manifestation of ASD impacts their child and the child’s integration in society, as well as their concerns on how ASD may influence their child’s development and future potential. These experiences are echoed throughout the literature, with mixed feelings on ASD and fears for the future a common finding (Lutz et al., 2012; Nealy et al., 2012). Parents of children with disabilities have expressed concerns that their child may be seen as “less than” (Landsman, 2008) or “other than” (Maguire, Wilson, & Jahoda, 2018; Esdale, Jahoda, & Pert, 2015), and there is a possibility that these feelings may become intertwined with the parent’s sense of self, or sense of efficacy as a parent. Research has shown that the attitudes of other parents towards behaviour difficulties in particular serve to highlight the differences between the child with ASD and the neurotypical child (S. Ryan, 2010). Parents in the current study provided examples of times when they have heard comments or witnessed behaviours from parents of neurotypical children which emphasized the difficulties their own child can live with. These experiences can be stigmatising, hurtful, and lead to a sense of being different from others for both the child with ASD and their parents.
This again reinforces the need for services to provide structured interventions which recognise and address emotional needs in the families they support.

5.4.2 Interacting with Services

Participant narrative universally explored parental experiences with disability services available to the family, be it solely public or supplemented with private interventions. Participants described frustrations with systematic failures such as insufficient resources, struggles to experience family-centred practices, and their experiences of pressure and responsibility in delivering interventions in the home. Families are faced with poorly resourced services exacerbated by an embargo on staff recruitment put in place during the recession which services are still recovering from, alongside a reliance on Home Tuition for some families who don’t have access to Early Intervention services (National Council for Special Education, 2013). Services are fragmented and lacking in coherent structure or service delivery. Frustrations borne of interacting with services are not unique to this study cohort; research in Ireland and further afield have found similar narratives, with parents finding themselves in a position of vulnerability and needing to advocate for sufficient supports in order to meet the basic needs for their child with ASD (Nealy et al., 2012; Nicholas et al., 2016; Twomey & Shevlin, 2017).

While there has been some international research on the importance of involving parents as partners (Hornby, 2011), parental experiences of this type of relationships is limited. Participants in the current study described frustration and powerlessness in the context of home-based interventions and the idea that the parent is the expert. This would seem antithetical to fostering a sense of partnership. The experiences of these parents leads one to wonder if home-based interventions are emphasized truly because they are in the best interest of the child or because it can fill a wide chasm left by lack of appropriate services (Gorman, 2017)?

In the context of resilience theory, frustrations with services could be conceptualised as another type of adversity or disturbance. While the ASD in itself may be seen as a disturbance which threatens the equilibrium of a system, the lack of appropriate resources is a disturbance which prevents the return of equilibrium. Participants communicated these experiences – either implicitly or explicitly – as stressful. Parents have been shown to be able mitigate their own stress when appropriate levels of supports from services are available (Derguy et al., 2015). Accessing private therapies or seeking alternative social supports to address shortcomings in
public service provision alongside delivering interventions at home could be viewed as harnessing resources to sustain wellbeing or adapting to disturbances that threaten the system.

5.4.3 Experiencing ASD in the Family
Narratives around the impact of ASD all focused at some point on the participants’ immediate family. The need for structure and routine to help the child with ASD, as well as the perception of such structure as imposing and controlling, was explored. These adjustments to family life may also be seen as part of the resilience process, harnessing resources and adapting to disturbances despite the stress inherent in making such changes. The needs of the wider system and the wellbeing of the child with ASD are seen as paramount to the needs of the individual parents within that system. The impact of ASD on the child’s siblings was described in depth by many participants with concerns around the mix of positive and negative connotations that exist for neurotypical children who grow and develop alongside a sibling with ASD. The variable impact on siblings appears to match what has been previously demonstrated in the limited existing literature (Cridland, Jones, Stoyles, Caputi, & Magee, 2016) and have been discussed in a small amount of recent studies (Lovell & Wetherell, 2016; Walton & Ingersoll, 2015; Ward, 2016), all of which recommend interventions be put in place to support siblings of children with ASD.

The impact of ASD on marital relationships, parenting style and family planning were also touched on by participants. These are themes which have been observed in previous research (Cridland, Jones, Caputi, & Magee, 2015; Saini et al., 2015; Wood et al., 2015). Participants modified their way of thinking and behaving as a direct consequence of ASD, by adapting their parenting style and reconsidering their options around expanding their family. These actions could be seen from multiple perspectives; a stress response, whereby parents retreat and attempt to prevent any further stressors from impacting upon their life by limiting their exposure to potential stressors in future; or conversely it could be seen as an act of resilience with adaptive coping skills engaging in re-establishing harmony within the family unit.

5.4.4 Recognising Mental Health
All participants openly and unguardedly explored their own mental health in the context of raising a child with ASD alongside typical life stressors. Participants describe their understanding of how they do or do not engage with self-care, why and how they prioritise elements that impact their mental health, and the various sources of constant stress which they are faced with on a daily basis. Self-care was almost universally experienced as a luxury which
participants could not afford to engage in, usually due to lack of time and energy. Some participants detailed experiences of maladaptive self-care such as over-reliance on alcohol or food. Others described experiences of depression, suicidality, and physical manifestations of stress. This suggests that participants are living with the ramifications of long-term chronic stress (Lovallo, 2015), that the demands of parenting their child with ASD outstrip their available resources (Liles et al., 2012), and parents therefore are unable to adapt successfully to the stressors in order to maintain sustained well-being. Some parents may experience symptoms of post-traumatic stress following a diagnosis of ASD for their child (Casey et al., 2012); in addition, studies have found that the impact of this trauma may be further-reaching and could require on-going support from services which may need to adopt a trauma-based framework to adequately understand the perspectives of the families they work with (Roberts, Koenen, Lyall, Ascherio, & Weisskopf, 2014; Stewart, McGillivray, Forbes, & Austin, 2017).

The idea of resilience as a process was a clear concept for participants. While all participants showed a degree of resilience, their journeys certainly involved varying degrees of resilience over time and circumstances. The levels of stress being experienced by participants and the lack of accompanying supports or resources to adequately tackle these stressors means the process of resilience is hampered insofar as participants, despite their best conscious efforts, are arguably unable to sustain well-being, recover to baseline functioning or achieve enhanced adaptation above and beyond existing levels of functioning.

5.4.5 Aspiring for Change

Participant narratives explored parent’s desires around changing the system to which they and their child and family are inextricably linked. Reflecting on their own experiences with services, participants describe the need for supports at the time a diagnosis is received, as well as continuous on-going support for the child and their family. For all participants, receiving a diagnosis of ASD for their child was a significant event with many far-reaching consequences rippling out into the future. This resonates with one recent study which demonstrated the existence of post-traumatic stress symptoms in some mothers following a diagnosis of ASD for their child, indicating a need for recognition and support for families at this pivotal moment (Casey et al., 2012). Each participant in the current study was remarkably eloquent in describing exactly how services could adapt to meeting the needs of their child and the larger family system. This indicates that participants are consciously aware of the resources required to bolster their resilience and allow them the necessary assistance and agency to manage their stress effectively. The expertise that parents carry regarding their own needs and the needs of
their families is reminiscent of a recent study into the challenges of parenting a child with ASD, where a dominant theme emerging from that dataset was the need to “live it to understand” the challenges of mothering a young person with ASD (Nicholas et al., 2016). Additionally, past research has recognised the need for services to address the real and desired need of parents, and to not forget how important parents feel it is for professionals to work well together as a team (Carlhed, Björck-Åkesson, & Granlund, 2003).

While the grief process has often been referred to in research on parents of children with ASD, a recent study looked at an addition to that process where post-diagnosis and in a stage of acceptance, parents proactively seek to de-stigmatize ASD and reposition ASD in a more positive light (Russell & Norwich, 2012). Several parents in the current study described actions they have taken in order to inform people around the realities of ASD and aid other families in similar situations. These participants described coherent and meaningful changes that they see the need to make for the betterment of society in general, while also lamenting their perceived lack of support from services in this regard. It may be that parents can feel the desire to proactively seek changes because they do not feel as though anyone else with a vested interest will do so.

5.5 Strengths and Limitations

The findings in the current study represent the experiences of the twelve participants only. The majority of participants were based in the greater Dublin area and some bordering counties. These are areas where disability services are currently awaiting reconfiguration under Progressing Disability Services and Children’s Disability Network Teams are not yet established. Parents of children with ASD living in areas where reconfiguration has occurred in early intervention services only, or parents of children with ASD living in areas where reconfiguration has been completed, may have somewhat different experiences of the services they engage with and as a result their experiences of stress and self-care may also be different to those who participated in the current study. Consequently, the findings of the current study cannot be generalised to the experiences of other parents of children with ASD or be said to definitively represent the experiences of other parents of children with ASD in Ireland.

The use of IPA in the current study facilitated the exploration of rich data from all participants on their subjective lived experiences. Other similar qualitative approaches, such as Grounded Theory or Thematic Analysis, may not have allowed for such a thorough engagement with the data. IPA also allows for transparent acknowledgement of the researcher’s inherent biases and
preconceptions when interpreting the data. Maintaining a clear audit trail alongside a reflective journal throughout the research process allowed the researcher the space to consider with curiosity the potential impact of pre-existing biases, and thus minimise that impact.

Due to time restrictions and the anticipation of busy lifestyles on the part of participants, each participant was interviewed at only one timepoint. It is possible that interviewing participants over multiple timepoints may have led to development of deeper rapport and consequently more detailed and richer data. However, all participants were given open-ended timeslots within which the interviews were conducted. In addition, all participants were asked at the end of the interview if they would like to add anything that they felt would be important but hadn’t been touched on already. The majority of participants took this opportunity to either re-state some issues that they felt were personally important to their own experience, or that they viewed as important for the general knowledge of the researcher and anyone who may read the resulting written research. Participants were also provided with contact details of the research and invited to email any additional comments they would like to include following the interview, as sometimes it can be difficult to articulate oneself in the moment and additional time to contemplate and process can be beneficial in gathering one’s thoughts. Participants were also welcomed to use this avenue of communication to request a retraction of data if they felt uncomfortable with anything they had said during the interview. No participant contacted the researcher following the interviews to provide additional data, therefore it can be surmised that participants were satisfied with the level of information they provided and did not feel the need to provide an appendage or recant any comments.

In order to facilitate the busy lives and demands on participants time, each participant was given the option to conduct interviews in person at an office provided by the field supervisor, or to conduct the interviews over the phone at a time convenient to the participant. Two participants opted to conduct interviews in person, while the remaining ten interviews were conducted over the phone. While the lack of consistent interview space is not always ideal, the current study was entered into with the understanding that participants may well have limited free time to travel for participating in a research interview. Thus providing the option of phone interviews allowed participants to engage in the research from the comfort of their own homes at a time and date convenient to their busy schedules. This approach to data collection reflects the researchers position of flexibility and openness to working with the needs and preferences of a group of caregivers whose voices often go unheard or unacknowledged.
While the current study sought out parents of children with ASD, only mothers responded to invitation to participate. This is a common theme in research with families and caregivers (Phares, Fields, Kamboukos, & Lopez, 2005), possibly as mothers tend to be the primary caregivers and therefore tend to engage with services and research more so than fathers. However, the important role fathers play in their children’s lives and the experiences and perspectives of fathers of children with ASD is arguably under-researched and deserves further attention. It is possible that explicitly recruiting a mix of mothers and fathers may have yielded a more diverse representation of parental experiences. Nevertheless, the researcher is confident that this study provides an accurate and thorough representation of the lived experiences of the participants who did volunteer to participate.

The sample in the current study raises some theoretical considerations. Two of the participants had children with ASD who were significantly older than the other participants’ children; one participant had a 17 year old child while another had an adult child of 24 years. It is therefore reasonable to assume that these mothers may have different experiences and perspectives than the parents of younger children. It may have been prudent to include these two participants as a subsample with contrasting viewpoints to the larger sample. Additionally, the children of the participants would span across different intervention teams based on their ages, i.e. Early Intervention, School Age, or Adult services. The children of the participants also had varying degrees of severity of ASD, some children also had co-morbid diagnoses e.g. ADHD, and some children were non-verbal or were limited in their verbal abilities. All of these variabilities lead to unique characteristics in the individual child and consequently individual experiences for their parents. Despite the potential for grouping participants together based on the age range, co-morbid diagnoses, severity of ASD presentation and other potential categorisations, data analysis revealed a striking level of shared experiences across all participants. While participants recognised that no one child is exactly the same as another, and that this is especially true when discussing children with ASD, the participants experiences of stress, self-care and support were ubiquitous and pervasive. As a result, the 12 participants were not segregated into subgroups but remained part of one larger group with individual yet relatable experiences.

No strong inclusion/exclusion criteria were imposed on potential participants for this study. A more homogenous group may have been found by restricting inclusion to parents with children who had an ASD diagnoses only, or had been diagnosed at a certain age or during a certain timeframe. The final sample recruited for the study could be argued to be lacking in
homogeneity when the details of the sample demographics are taken into account. The unifying aspect that makes this group homogenous is simply the fact that all participants were mothers of a child with ASD. The double-hermeneutic aspect of IPA research certainly comes into play here, as the researcher’s own lens is key to interpreting the participants’ lived experiences as distinct voices while allowing these voices to be unified under shared emergent themes.

With a group that may lack in homogeneity, it may be difficult to find emergent super-ordinate and sub-ordinate themes that relate to the overall group, or that emergent themes may not be representative of the individual lived experiences of all participants. It is also possible that any emergent themes and their subsequent implications may be lacking in transferability and thus limit our understanding of the particular lived experiences under scrutiny. However, given the heterogeneity of individuals with ASD, it was envisioned that families of children with ASD would be similarly heterogenous and thus imposing strict inclusion/exclusion criteria would unnecessarily and artificially constrain the research process. In addition, with the study’s use of IPA which is idiographic in nature, the aim was to explore the individual experiences of parents and not develop generalisable claims about all parents of children with ASD.

The analysis and interpretation of the data was conducted by the researcher, with support from the supervisor. Participants were not invited to be an active part of the analytical process. The concept of involving participants in the analysis of data is a relatively recent concept, the rationale being to ensure data are accurate and that the research is in line with the process of ongoing informed consent (Dockett, Einarsdottir, & Perry, 2009). Including participants in data analysis has its benefits and drawbacks (Cridland et al., 2015). Benefits might include providing participants with space to reflect upon their interviews and identify their own themes emerging from the data. Participants may also find it therapeutic to be involved in such a reflective and introspective process. Drawbacks may include a desire to withdraw some data from the analytical procedure following a period of reflection, thus potentially compromising the integrity of the collected data. Due to time limits on the researcher’s end, it would not have been possible to include participants in the analytical process. However, it is worth keeping in mind the potential richness such a method may contribute to a research study and contemplate its use for future investigations.

The current study used semi-structured interviews, a common method in qualitative research. Semi-structured interviews allow for in-depth conversations between researcher and participant, and while the interviews have an overarching goal with the research question in
mind, the process of the interviews are strongly guided by the participant and their opinions, perceptions, and experiences (Cridland et al., 2015). A key strength of the study is that it has managed to foster an open discussion on the experiences of parents of children with ASD, a process which is beginning to emerge as a central factor in providing adequate care regarding disability services. It is hoped that the inclusion of in-depth qualitative data will encourage future research to utilise similar methods and continue to gather rich datasets, which can in turn influence policy and clinical practice towards fully embracing the needs of the family as a whole on an individualised basis.

Potential limitations associated with the interview schedule used in the current study may include the fact that parents were aware that they were included in the study because they had a child with ASD, and thus their explorations of their experiences of stress, support and self-care may have been discussed only in the context of ASD while other stressors or reciprocal stressful processes may have been overlooked. Despite the author’s best efforts to mitigate such bias, it is possible that participants focused only on stress related to parenting a child with ASD and did not explore unrelated stressful experiences, which may have yielded rich data worthy of its own consideration. Participants may have viewed their role in this study as an avenue to advocate for their child and by extension the wider family unit, and may subsequently have focused singularly on stress associated with limited available supports or resources from services. Nevertheless, providing such an avenue for mothers of children with ASD to explore these experiences and express their frustrations undoubtedly provided a great deal of valuable and insightful data.

5.6 Implications for Clinical Practice

The current study found that mothers of children with ASD are acutely aware of the importance of minding their own mental health, but struggle to access adequate resources to manage difficulties they may experience in this area. Mothers reported that they found it difficult to speak to healthcare providers around their mental health, and they perceived the disability services that ostensibly provide support to their child and wider family do not extend that support to maternal mental health. An important implication for clinical practice arising from this study would be development of mental health support specific to mothers and other primary caregivers of children with ASD, and the available of this support to remain open as the child progresses through Early Intervention, School Age, and potentially even Adult services.
The current study also found that mothers of children with ASD are acutely aware of the importance of advocating for the needs of their child, and appear to have high levels of empathy towards other parents undergoing the assessment and diagnostic process. This is clear through the emergence of “Aspiring for Change” as a super-ordinate theme. Some participants described in detail how services could alter their processes in order to help mothers and their families adjust to diagnosis and access appropriate services, with participants going so far as to develop their own information and resources pack in the hopes that services would provide this to other families in similar circumstances. The importance of services listening to and truly hearing the voices of those supported by the service, taking on board suggestions for adaptive change, and being open to review and further consult with these individuals, could lead to enormous positive change not only in how services are provided to children with ASD and their families, but also to mother’s perceptions of their ability to cope with the stress inherent in raising a child with ASD and navigating the often complicated systems that govern the support they are entitled to. Any increase in a perceived buffer against psychological stress may help to mediate mothers’ experiences of stress and consequently bolster their resilience, self-efficacy, and overall mental health.

Available social and family support may be important factors in managing parental stress and mental health in parents of children with ASD (Yorke et al., 2018). In order to fully understand support available to the family system and as a consequence assess the family’s capability of managing and implementing interventions at home, an assessment of available supports may be a necessary part of clinical procedure, including perhaps an assessment of resilience in terms of family functioning. The outcome of this assessment should then ideally involve specific recommendations on where to access additional supports if needed, including supports for siblings of the child with ASD, providing a clear and comprehensive pathway towards appropriate services in a collaborative and respectful manner. Participants in the current study and in other related research studies have lamented the lack of clear guidance from services, indicating an obvious avenue for development which would benefit the individual experiences of families but also their relationship with services which is likely to continue for many years. It is possible that this may improve with the implementation of PDS across Ireland, but this remains to be seen.

There is a huge focus on standardised measures and subjective clinical observations when assessing the severity of behaviour in ID services. However, this approach neglects to take into account the parental perspective on their ability to cope with the behaviours. Parents of a child
with objectively severe behavioural difficulties my perceive themselves as quite able to manage, while parents of a child with objectively milder behavioural difficulties may not perceive themselves as adequately equipped to cope, for a variety of potential reasons. It is possible that parents who experience more psychological distress perceive the same behaviours as more difficult that do other parents (Najman et al., 2000). This again highlights the need to emphasize the individuality of parental experiences, and to provide individualised supports and resources to parents and families, as opposed to attempting to coordinate all services within a one-size-fits-all framework.

It has been posited that parental use of coping strategies to manage their stress may have beneficial impact on the relationship between a child’s behavioural difficulties and parental stress (Benson, 2014). As such, it behoves services to provide parents with coping strategies that are specific to their individual circumstances and abilities. Individual therapeutic support or the provision of parental support groups facilitated by clinicians which focus on practical and achievable coping strategies could be beneficial. Some participants in the current study did state that while some groups similar to this are made available by some services, childcare is not provided and the groups are often in the evenings when there is no one else available to care for the child. This again highlights the need for services to recognise the pragmatic barriers that exist for parents in accessing support, and take practical and timely steps to address these barriers. It would be ineffective and arguably unethical to continue to recognise the deficits in current clinical practice without taking any action to address these deficits.

Research in Child and Adolescent Mental Health Services (CAMHS) has shown that longer waiting times for initial assessment is associated with lower levels of engagement by families (Mitchell & Holdt, 2014; Schraeder & Reid, 2015). Seeing families at the earliest stage possible and taking time to develop individualised interventions could have hugely positive benefits for children, their families, and their relationship with the services (Gorman, 2017). Clinicians and service managers should be encouraged to examine ways in which they could potentially intervene earlier, provide better support to families, and adequately assess coping strategies and resilience regarding family life in order to provide the best supports possible for each individual child and their family unit.

5.7 Implications for Education

It has been shown that in the case where behavioural difficulties are the primary cause for concern in the pre-diagnosis stage, some health care professionals dismiss this symptomology
as being due to poor parenting (Nealy et al., 2012). Significant investment and development in Early Intervention Services has been cited as a priority for government spending this year (HSE 2019), but this development could go to some waste if referrals are not made and children and their families are not provided with the support they require at the earliest possible stage. It is vital that all health care providers receive up-to-date training and education so that the early signs and symptoms of ASD can be recognised and appropriate referrals are made in a timely manner.

Children from lower socio-economic backgrounds and rural areas tend to receive later diagnoses (in Bonis 2016). While the causes for this are unclear, it may be useful to introduce a general nationwide awareness campaign so that parents from all backgrounds are familiar with early signs of ASD. This would accompany the above-mentioned education for health care providers in recognising signs of ASD at early stages and thus lead to provision of support as soon as is required.

It may be useful to utilise educational spaces as forums for discussion and idea generation on how best to tackle the ongoing chronic difficulties involved in providing sufficient services to children with ASD and their families. Clinical Psychologists in Training, for example, may be learning about the inherent struggles in Intellectual Disability service provision in detail for the first time while on training and in placement. Individuals in this position have the privilege of being somewhat naïve to any administrative and managerial barriers which may exist. This may be a great advantage in regards to innovative thinking, as trainees would not be constrained by concerns around barriers, but instead would be free to brainstorm and develop creative ideas around service development, provision and implementation with impunity.

Individuals with ASD can have a unique and complex combination of strengths and difficulties. When it comes to medical care, there has been a push in recent times to increase mandatory training for clinicians so that doctors can be well-versed in how an individual with ASD may present with physical or mental health issues. Clinicians have been recognising a gap in their knowledge and are recommending an increase in training for the benefit of individuals attending their clinical practices (Marrus et al, 2014; Warfield et al 2015). An extension of such mandatory training to other professionals and care staff may lead to positive changes in the way individuals with ASD are perceived and treated by wider society. This may be especially useful for recognising and appropriately responding to girls with ASD, who can present
differently to and at a later stage than boys with ASD, and as such a recognition of their individual needs may require specialist training.

5.8 Implications for Policy

As discussed in Chapter 2, the Progressing Disabilities Services for Young People (2010) is a national policy which recommends equal access to services for all children with a disability. Participants in the current study described varying levels of intervention from services, often explaining that they desire more contact from services while recognising that the required resources do not appear to be available. It is noted that Early Intervention Disability Services in Ireland are currently in a period of transition (Carroll, Murphy, & Sixsmith, 2013); a recent report states that the Progressing Disabilities policy is still in the process of being implemented (HSE 2019). The lengthy timeframe for implementation arguably causes additional distress for parents of children with ASD. Lack of timely implementation of important policy can lead to negative implications and consequences for some of the most vulnerable in our society, and thus needs to be addressed as a matter of urgency. Based on the experiences of participants in the current study, it is clear that the Progressing Disabilities Act is not yet providing equitable access to services for all children with a disability. Indeed, several participants mentioned the Progressing Disabilities policy with a sense of frustration and disappointment. Current policy and legislation aim to bring a nationwide uniformity to disability services to eradicate the existing “post-code lottery” that exists across the country. Time will tell if these policies have the desired effect.

A recent government report into estimating prevalence rates of ASD in Ireland concluded with the sentence “Unmet needs of adults with ASD requires to be documented in Ireland” (HSE 2018). The genuine and pragmatic fears for the future described by participants in the current research reflect a lack of information, knowledge, and planning on the part of the Irish government and by extension the disability services for adults with ASD. Greater emphasis needs to be placed on creating sufficient policies and clinical practices which serve those individuals, an issue which is likely to become more pressing as the diagnosis rate for ASD continues to rise and a greater pressure on adult ID services is applied as those with a diagnosis of ASD reach maturity.

Given the lack of resources available throughout the HSE as a whole, and disability services more generally, change needs to occur at a higher level in order for services to provide adequate support in response to need. This will become especially more evident as the HSE strives to
move away from diagnostic and medical model-based approaches towards a needs-based approach. Greater numbers of resources need to be provided to the Health Service in order to meet the needs of individuals supported by the service and their families/caretakers. Resources include funding for greater numbers of staff, particularly psychologists, as a lack of psychologists is commonly cited as a reason for a delay in the completion of AoNs. Services do not always provide cover for maternity or parental leave, even in the form of short-term contracts, which may leave a service without a key member of its multi-disciplinary team for up to a year at a time. Introducing maternity/parental leave cover may provide some continuity of care for individuals and their families supported by services, and prevent a backslide in waiting list numbers for AoNs and other time-sensitive assessments and intervention services. Greater resources may also include funding for more suitable buildings with therapeutic space to engage with parents, siblings, extended family members and other caregivers in order to provide support rooted in a family-centred practice model.

In the Spring of 2018, the HSE outlined a proposal to introduce new Standard Operating Procedure in an attempt to deal with the existing backlog of families awaiting assessment from Disability Services. One key element of the proposed new procedure included a Preliminary Team Assessment model, which should “be completed in a maximum of 90 minutes, regardless of the child’s needs”. This type of assessment would in essence be nothing more than a brief screening tool at best and would potentially ignore the rights and provisions set down in the Disability Act of 2005 at worst. The Psychological Society of Ireland stated that introducing such an assessment model would “significantly reduce the level of assessment provided to a child”. While one might argue that a reduced assessment completed in good time is better than no assessment despite months of languishing on a waiting list, children and their families deserve to receive the gold standard of assessment and intervention procedures. A lack of resources does not get resolved by implementing strategies which do not fit with best practice guidelines. Policies which address the dearth of resources and allow for funding or allocation of resources to services so that children and their families can receive the quality of intervention they require would be a far preferable solution than attempting to implement a below-par model simply to reduce waiting lists. It may be necessary for the HSE to have more open communication with the PSI and other similar organisations while drafting policies, in order to ensure that those policies are effective and allow clinicians to adhere to best practice guidelines. At the time of writing, implementation of the Team Assessment Model has been deferred (Baker, 2019).
5.9 Implications for Future Research

Participants with multiple children spoke at length around the impact of having a child with ASD on the wider family. Several of these participants were very aware that there is a possibility that their other children may become caregivers in future for their sibling with ASD. Research into the roles and expectations of neurotypical siblings could provide fascinating insight into how major elements of life choices such as further education, career choices and family planning are impacted upon for siblings of individuals with ASD who require varying levels of care throughout the lifespan.

The majority of research on parenting in ASD focuses overwhelmingly on mothers, while the research conducted with fathers is comparatively sparse. Specific focus on the role of fathers is required in order to develop a more thorough understanding of the interplays within family systems where a child has a diagnosis of ASD. Efforts in this regards are ongoing and can be found in the current available research (Cheuk & Lashewicz, 2016; Meadan, Stoner, & Angell, 2015), although research focusing on the experiences of mothers as the primary caregivers remains dominant. Continued focus on incorporating the voices of fathers into the research may yield fascinating and much-needed insights into the models of stress and resilience in families who live with ASD.

A range of variables related to parenting stress may certainly impact the experiences of parents of children with ASD. Socioeconomic status, marital discord, coping styles of parents, emotional and behavioural difficulties in parents are some potential influencers of parental stress. Integrating these variables could provide a comprehensive overview of the unique and individual experiences of parenting a child with ASD. The importance of conducting such thorough research with a longitudinal design was highlighted by a recent review (Yorke et al., 2018) which stated that establishing the structure of child-parent relationships along with the various factors which mediate said relationships may provide further insight into the increase of mental health difficulties in children with ASD and their parents. This could be an interesting avenue for a future, larger study.

Although beyond the scope of the current research, it would appear as though there is a discrepancy between service ethos as mandated by governmental policy, and the lived experiences of parents of children with ASD who are supported by those services. Several parents spoke of a lack of partnership with services, a dearth of information regarding available interventions, and an absence of individualised and timely supports. In order to thoroughly
evaluate the efficacy of disability services in Ireland, an IPA approach may be hugely beneficial. For example, studies which include service management, clinicians delivering interventions, other services such as schools which are directly and indirectly influenced by the work of disability services, and individuals and families supported by the service could potentially uncover a wealth of subjective information from a variety of vested parties. While there are a number of qualitative studies exploring the experiences of service users and service providers in Ireland, to the researcher’s knowledge there is no IPA-based evaluation of services available.

At the time of writing, disability services across Ireland are in a state of flux with the process of reconfiguration of services at various stages around the country. It may be useful to explore the experiences of parents where reconfiguration has occurred and compare this to the experiences of parents who are in areas where reconfiguration is yet to occur. Additionally, it may be useful to conduct a repeat of the same investigation a few years after reconfiguration has been completed nationwide, to see if family-centred practice has been established under PDS.

There does exist some research into the positive parental factors that may mediate or ameliorate stress in families where a child has a diagnosis of ASD. Future research which expands on this topic may serve to broaden our understanding of family functioning and dynamics in adaptive ways, and in turn aid the development of interventions which focus on positive interactions and a reduction of parenting stress (Cridland, Jones, Magee, & Caputi, 2014).

The impact of the child’s perceived quality of life on parent’s perceptions of their parenting skills has only been partially explored (McStay et al., 2014). The concept of parenting stress being mediated by factors perceived to be within parental control is a fascinating one, and may have links to studies in resilience. Further investigations into parents’ perceptions of their available resources to cope with stress, muster resilience in the face of ongoing stressors, and the impact of their perceptions on their child’s and their own quality of life may provide interesting insights and future avenues for intervention. For example, counselling support for parents in the wake of receiving a diagnosis of ASD for their child could focus on building resilient coping skills and challenging negative or unhelpful cognitive patterns which may otherwise prevent successful adaptation to this new set of familial circumstances.

A number of participants in the current study made reference to family planning and the impact of having a child with ASD has had on their current thought processes around having more
children or retrospective thoughts around having children at all. As genetic factors relating to ASD continue to be explored, it might be interesting to see if a genetic link to ASD is associated with feelings of responsibility, guilt, or control for parents. This may have implications for the future of genetic screening and its utility in family planning.

5.10 Critical Reflection

I began exploring the potential for this research project due to my own personal interests in families of children with ASD, and my preconception that parents and siblings of individuals with ASD may themselves be potentially vulnerable or at-risk for mental health difficulties. While this preconceived idea has not been disproven, as several participants disclosed their own struggles with mental health and maladaptive coping strategies directly and indirectly related to raising a child with ASD, the concept of resilience in the context of this study did not emerge for me until much later in the research process. Only after immersing myself in the data did resilience reveal itself as an appropriate lens through which participants experiences could be viewed and understood. This represented to me a shift in my way of thinking, a change in my perspective of my participants’ journeys. I moved from viewing parents of children with ASD as being vulnerable, towards viewing them as individuals with their own inherent strengths, adaptive capabilities, ability to survive and/or thrive in the face of adversity. Having spent a great deal of time with the raw data and the emergent themes, I find that my perspectives on participants has shifted slightly from a place of quiet despair and sympathy, towards a stance of admiration and determination. I feel that these parents has managed to cope and thrive because of their own inherent resilience, often in spite of the services offered to them as opposed to in conjunction with services. I continue to feel quiet despair but this is now directed towards the lack of available resources and service capabilities instead of being directed at the general circumstances of the lives of parents of children with ASD.

I struggled a good deal during the stage of data analysis, as I felt it would be close to impossible to accurately represent the diverse experiences of my participants. Picking and choosing quotations from long reams of transcripts came with it a sense of discarding and ignoring the overall experience of my participants, as parts of their narrative could not pragmatically be included in the final written version of this research. I felt that by discarding some quotes, I was discarding their experience, perhaps mirroring the disrespect with which they had been experiencing in their struggles to have their voices heard and receive the appropriate services for their child and for themselves. I felt a weight of responsibility to do justice to their experiences and concisely but thoroughly portray their experiences, in an attempt to provide
an avenue through which their voices could be heard. It was in reflecting upon this process that I began to feel a true kinship with the participants, as I may have felt some fraction of the responsibility that weighed on their own shoulders as they fought to advocate for their child’s needs in a health service which acknowledges that it does not currently have sufficient resources to meet the needs of families with children who have ASD.

5.11 Study Conclusion

With regard to the current research study, there were no attempts to check that the data was reliable. This was due to the fact that IPA studies are idiographic in nature i.e. they are concerned with the particular and the specific. An IPA researcher does not set out to generate consistent data across research participants but instead is interested in what is salient about the subjective experiences of each individual participant. Nevertheless, it does appear as though the themes generated from the data gathered in the current research are similar to findings of previous related research.

Through extended family and close friends, I have some experience of families with ASD and have witnessed from the outside the struggles that some families endure when trying with all their power to access the best and most appropriate services for their child. These experiences have led to the observation of a myriad of complicated emotions, from sadness, fear, and desperation, to anger, determination, and commitment to continue on. The child with ASD at the heart of these experiences has always been held first and foremost, with their potential and ability to thrive at the forefront of every interaction with health services.

I consider it a privilege to have been exposed to such lived experiences, both through my personal life and through the process of completing this research. It is always a privilege to be granted permission to experience the inner workings of someone’s consciousness, to gain access to thoughts and emotions that may not be shared with others or be otherwise admitted even to the individual themselves. Alongside this, it has also been difficult to be exposed to such experiences as a clinician, from the other side as it were, with friends, family members, and participants in the current study describing the battles they have gone through while I have the insight and experience to see the dearth of resources from the inside of services. It can be difficult to empathise fully with families when you know that some service providers would love to offer more but simply don’t have the resources available to them to do so; concurrently it can be difficult to agree with service providers that lack of resources is the main issue when
some policies and practices may not appear to conform with the ideals of family-centred practice.

I would like to echo the sentiments expressed by another researcher in the field of qualitative ASD research (Cridland et al., 2015): Just as we attempt to do justice to the significance of participants’ experiences during the write-up of empirical research, we aim to honour the significance of our research practices by sharing our experiences with other researchers. The importance of sharing knowledge through dissemination which includes active reflective practice, may hopefully resonate with parents, researchers, and clinicians alike. It is hoped that the issues explored in this research will contribute to the growing body of knowledge around the experiences of parents of children with ASD and lead to positive changes in how services respond to those oftentimes challenging experiences.
References


relevant issues for support programs. *Journal of Intellectual and Developmental Disability, 40*(2), 156-166.


Appendices

Appendix A: Interview protocol

1. How has your child with ASD impacted on your life and your family’s life?
   a. What are the positives and negatives about having a child with ASD?
2. Were any supports offered to you when the diagnosis was received? Is so, what were they?
   a. What kind of supports would be helpful to you now?
   b. What types of supports do you avail of? E.g. parent groups, social media networks?
3. What are your main sources of stress at the moment?
4. Do your child’s ID team ask you about your own stress or health issues?
   a. Have any services who support your child ever asked about your wellbeing?
5. What are your main concerns for your child?
6. What are your main concerns for yourself?
7. What do you do for self-care? E.g. exercise, time with friends, “you” time?
8. Do you have anyone to talk to about your worries?
9. Do you feel as though you have enough support in life?
10. Is there anything we have not talked about that you would like to add?
Appendix B: Information Sheet for Participants

Study Title: The Experiences of Stress, Support, and Self-Care in Parents of Children with ASD

Dear Parent,

I am a Clinical Psychologist in Training, and as part of my studies I am conducting research with parents of children with ASD. I am interested in learning more about the experiences of parents, especially how parents manage stress and take care of themselves.

Taking part in this study involves meeting with me for about 90 minutes, to talk about your experiences of stress and self-care. The audio of this meeting will be recorded.

Please note there is a very small chance that talking about your experiences of stress may be upsetting for you. You can withdraw from the study at any point if you wish.

How many people are taking part?

I will be recruiting 12-15 parents of children with ASD.

Who has access to my information?

The main researcher, Dr Joanna Connolly, has access to the audio recordings of your interview. The project supervisor, Dr Barry Coughlan, will have access to the transcripts in order to guide Dr Connolly in her analysis. These transcripts will have had all names removed to preserve confidentiality.

Can I withdraw my consent?

Yes, at any point during the study you can decide you no longer want to participate in the study. You can request that any data we may have collected be destroyed. Please note that if your data has been published as part of a thesis or a research paper, that data cannot be withdrawn after publication.

If you would like to participate in the study, please contact me at the following email address:

09000395@studentmail.ul.ie

Lead Investigator Contact Details:
Joanna Connolly, Clinical Psychologist in Training
09000395@studentmail.ul.ie

Supervisor Contact Details
Dr Barry Coughlan, Assistant Director of Clinical Psychology
Barry.coughlan@ul.ie
Appendix C: Consent Form

Consent form for participating in research study

Title of Study: The Experiences of Stress, Support, and Self-Care in Parents of Children with ASD

Name:______________________________________________

The research project has been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the researchers listed on the information sheet.

I consent to:

Audio recording of my interview(s) with Dr Joanna Connolly, Clinical Psychologist in Training

Yes  No

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

__________________________________  ______________________________________
Signature of Participant               Signature of Researcher

Contact details:
Joanna Connolly, Clinical Psychologist in Training
09000395@studentmail.ul.ie
Appendix D: Example of IPA Analytic Process

<table>
<thead>
<tr>
<th>Stressed</th>
<th>So when your son got his diagnosis, how has that impacted your life, and your family's life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed</td>
<td>P: Em, it’s… I suppose it’s made it heightened, and stressed about what he needs to have done and what I should be doing. So I suppose it led us to speech therapy, it led us to psychology, it led us to all these things. And then we got loads of recommendations and strategies. Em but not being able to do all them in normal life, just, I think it led to stress.</td>
</tr>
<tr>
<td>Hope</td>
<td>I: It sounds like maybe it was a bit overwhelming?</td>
</tr>
<tr>
<td>Sadness</td>
<td>P: Em, yeah. It gave us hope as well because it meant that he would get what he needed because before the diagnosis there was nothing. But I was, then, I suppose a lot of sadness because now I was worried about his whole future and I suppose I was flashing ahead (voice breaks) sorry now, to what we were going to face. And usually actually what was most on my mind when he was diagnosed was how good would he be or how bad would he be. And I think there’s no answers in the diagnosis, everything’s quite vague. They don’t even want to tell you the level, you know, because some parents wouldn’t know the level. I did so I asked, but they wanted to get away from that, and they don’t want, they can’t I suppose but, I suppose I had a huge worry of is he going to be good? Is he going to be bad? Good autism or bad autism? (laughs) Or what would he be able to do, what would he achieve? And that was just, I was just overcome by, you know, is he going to be ok? And there’s no answer and there’s no solution. There’s no, you know, you only know every day what’s going to happen.</td>
</tr>
<tr>
<td>Worry for future</td>
<td>I: He’s 5 now. How old was he when he got his diagnosis?</td>
</tr>
<tr>
<td>Conflicting emotions</td>
<td></td>
</tr>
</tbody>
</table>
P: He was 3, maybe 3 and a half.

I: Ok. It sounds like it was a big source of stress for you. A little bit of hope, because you were getting some services. What about the wider family, like are there grandparents or cousins or anything like that?

P: Yeah. They didn’t really want to, em, they wanted, they kept saying there’s nothing wrong. They didn’t really want, they didn’t know what it was all about, and they only saw him as a person. Like his grandmother, I don’t have much family because I’ve three brothers and his dad lived with us at the time but his dad is from [other country] so there was a huge stress around, em, you know in [other country] things like that wouldn’t go down really well so my husband would not have been telling his family that there was something like this. But my husband, I mean my ex-husband, he was a loving father and he wanted to help and wanted to do things but there was no support on his family’s side. And then I have three brothers and my mother, his grandmother, so his grandmother would have said, they would have said he’s grand, he’s grand, ah sure he’s just a little bit different. So I felt the stress of having to break it to them. Like it was hard enough for me to, I’ll deal with it myself but also trying to teach them that no, this isn’t nothing, this is a real thing. And he was a toddler so they all just said, they all just took him as the person he was and they didn’t really…my mother hadn’t dealt with a child in years so she just thought, ah he’s grand, he’s a bit, and it was more heart-breaking for me to actually kind of destroy that and say no, this is real, it is something. And there wasn’t any…most people around my social circle would have…I had worries from when he was a tiny baby, and most people would always say that they didn’t think, he’s grand he’s grand, I
Lack of acceptance

Friends not knowing the impact

Happiness
Taking pleasure in his personality
Simple things are fun

Some aspects positive and negative

Fears for the future, the unknown

Autism and child as one

I: Can you talk about any positives and any negatives about having a child with autism?

P: Em, well positives are I think he enjoys things much more than a child typically would. Like bubbles could be just amazing to him. Colours are amazing. Sometimes I watch the way, the amount of fun he has over something so simple. Em, it’s quite nice. And he is really kind of, because he doesn’t have social interaction skills that he should have, some things are very funny. You know, you watch how he can just kind of walk into a room, not say hello to anyone, and grab sweets at the end of the room, you know, and sometimes things like that are funny. But yet negative when you think of him doing that as an adult. You know, it’s quite, he has a character, which is, he has a character anyway, he’s not a total black canvas, he has a character he’s cheeky, and like people in general do find him very funny. Yeah, there’s loads of, he’s very, very handsome, you know there’s lots about him. I couldn’t imagine him now without autism. I’d never know, I don’t know who the child is without autism. I can’t imagine him who he would be. I don’t think there is a personality of K without autism. I’ve never known that, I’ve never met that person so to me that person doesn’t exist. The only person that exists is the boy that I have.

I: It sounds like it’s just part of the package.

Struggling to express self
Uncertainty in “I suppose”
Support comes from not knowing the details? Support would include a more thorough understanding?
Some didn’t accept it. Not sharing or making known her actual worries.

Enjoyment: from his enjoyment – reciprocal in its own way
Getting pleasure in his personality
Overshadowed by fears of the future.

“A character” can be used positively or negatively.
Reassuring me that he has a personality – defensive?
Blank canvas – how she sees autism, or thinks other see ASD?

Sense of autism being integral to who he is as opposed to him being a person with autism.
<table>
<thead>
<tr>
<th>Isolation</th>
<th>Aggression</th>
<th>Control</th>
<th>Powerless</th>
</tr>
</thead>
</table>

P: Yeah, yeah, He is what he is and, I don’t, the negative things are, my social life is completely isolated because I can only go where he wants to go. He has aggressive behaviours. He leads my life, he controls my life. So I’m very limited on where I can go. I go to where he wants to go. So that would be the negative side of it. And I couldn’t go away for a long period. I work and he goes to school and I have my mother for short amounts of help but I couldn’t go somewhere, I couldn’t leave him with someone. Nobody would mind him, basically.

I: Ok. And it sounds like he wouldn’t want to be minded by anyone else.

P: No. He only, he’s sad unless it’s me, and that makes me not want to, like obviously I don’t want to make him sad even though people advise me, ah he’ll be grand! But I know how he feels.

I: Yeah. Ok. When you guys got the diagnosis, were you offered any supports?

P: Mmm, no. No, none at all. Well I was told about the parents….parent’s association…you know, the local autism group. They provide social activities for children actually, so, but they said that I would meet mothers of autistic children. And I suppose my answer to them was, that’s all well and good, but when I’m with my child at these social activities, I’m minding my child. I’m not, I can’t go and chat to people, I can’t. My child is the one climbing up on the ceiling. So when I go to social activities, as long as the children are there, I’m not, I won’t be the one having a cup of tea. You know, so that for me didn’t make me meet anybody.
I: Ok. And did you ever go to that meeting?

P: Yeah, yeah I did. I would go to several social meetings. No matter how difficult he is, I keep… from very early I suspected he had autism very, very early in his life, and I always brought him to everything, and kept going and kept going. But I could never really, I was in it for his benefit, I could never enjoy or have any peace at these things because of his behaviour.

I: Ok, so you’re more concerned about keeping an eye on him than developing social relationships.

P: Yeah, absolutely. And it wasn’t that I would choose that, but the level, like, he just needed constant, like he would be very physical, he’d hurt other children, he’s just a live wire in ways. So it wasn’t a choice, it wasn’t like I’m a real fussy mother, I had no choice but to be on him. If I was given the choice, if I had a child that didn’t have autism I’d be the mother that’d sit and have a cup of tea and leave them.

I: Ok, it just doesn’t make sense to do that with him. At the moment, what would your main sources of stress be?

P: Emotional stress I think because of the tantrums. Because I’m constantly apprehensive about what he’s going to do, what will his reaction be. My whole life and day is spent around avoiding upsetting him, and doing everything to make him happy. So it’s around, like if he gets angry, em, I’ll end up emotionally destroyed or like I have to be so careful to be nice all the time or to soothe him and nurture him. But if I was stressed about an outside stress, outside of him, like money, let’s say I was worried about money and he does something, has a tantrum, then I’m talking about total breakdown, you know I’m just I lose my mind,
<table>
<thead>
<tr>
<th>Coping with multiple issues impossible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed</td>
</tr>
<tr>
<td>Constant focus on child</td>
</tr>
<tr>
<td>Exhausted</td>
</tr>
<tr>
<td>Work as a break</td>
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</tbody>
</table>

I could be at home crying. And then it’s, I can deal with him being difficult but not him and something else, and something else. It’s when a few things...he takes so much attention that I can’t cope with any other stress at the same time. That’s what I find. Like if I was, em, if somebody knocks at the door, it could be as simple as that, and he was up and drowning all the bathroom, and something else happened, and something else happened, the fallout from it could be my ceiling leaking like it just, I have to keep, my focus has to be on him on him on him. And that’s when I get stressed, if there’s anything else going on besides him.

I: It sounds really exhausting.

P: Yeah, I’m exhausted but I work every day from 9-3 so that’s my, I love going to work.

Feels like a knife edge, reserve is almost completely depleted.

Things build so quickly, immediately. Drowning.

Unsaid – my break? My peace? Too afraid to admit?
Appendix E: Letter of Ethical Approval

13th December, 2016.

Re: Protocol Title:
An Investigation into Stress and Self Care in Parents of Children with Neurodevelopmental Diagnoses.
REC Ref: 122/16

Dear Dr. Connolly,

I am in receipt of your proposal as above submitted for review by our Research Ethics Committee. I have reviewed the contents of same.

I wish to advise that I have given your study Chairperson ethical approval.

You should note that your study cannot commence until you also receive AON approval which will issue from the Quality and Safety Department shortly. You are obliged to inform us as soon as your study is completed or if it terminates early for any reason.

I wish you every success with your study.

Yours sincerely,

Pat Dillon,
Consultant Anaesthetist,
Chairperson, Research Ethics Committee.

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Quality & Safety Department,
University Hospital Limerick
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