An Exploration of Parents’ Experience of Accessing Respite Care for their Child with Autism Spectrum Disorder

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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.

______________________________  ____________________________
Aisling McGrath  Date
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Abstract

Introduction: Research has found that respite care has a positive impact on the well-being of caregivers of children with disabilities and is associated with lower levels of stress, reduced levels of depression and anxiety, and more time for rest and rejuvenation. To date there has been limited research carried out with parents of children with autism spectrum disorder, so the aim of this study is to explore their experiences of accessing respite care for their child with ASD.

Method: Semi-structured interviews were carried out with six parents of children with a diagnosis of ASD, who were all in receipt of respite care from a children’s disability service. Interviews were audio-recorded and transcribed verbatim, before being analysed.

Results: Analysis of the interview data, using Interpretative Phenomenological Analysis (IPA), revealed five superordinate themes. These were: ‘Living with ASD’, ‘The Respite Worker’, ‘Role of Respite’, ‘Emotional Conflict’, and ‘Service Provision’.

Discussion: This study provided an insight into the unique, lived experience of parents accessing respite care for their child with ASD in Ireland. The findings of the current study are discussed in relation to the existing literature. Implications for clinical practice, education, policy, and future research are also discussed.
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Chapter One: Introduction

‘The true measure of any society can be found in how it treats its most vulnerable members’

(Mahatma Ghandi)

‘I believe that those we most often exclude from the normal life of society, people with disabilities, have profound lessons to teach us. When we do include them, they add richly to our lives and add immensely to our world’

(Jean Vanier)

1.1 Overview of the Present Study

Over the last number of years, there have been countless reports across the media, outlining the significant challenges facing parents of children with autism spectrum disorder, intellectual and physical disabilities when trying to access appropriate supports and services for their child in this country. Numerous articles have been written, detailing the lack of available services, insufficient funding, staff shortages and long waiting lists. Charities, advocacy groups and agencies across the country have launched numerous campaigns and petitions, lobbying for improved service delivery for individuals with disabilities and their families. Parents have also shared their stories on television and radio programmes, and on social media, to highlight the demands associated with caring for their child, and the lack of available support.

It is from this perspective that my interest in exploring parents’ experiences of respite services for children with ASD arose. Given the lack of published research in this area, I felt it was important to give this particular group a voice and allow their stories to be heard. By understanding the lived experience of parents of children with ASD in this country, I hope to gain an insight into how services are experienced by families. I hope the research will highlight specific barriers faced by families of children with ASD when it comes to accessing respite services, which may be helpful in the development of respite services for individuals with ASD in Ireland.

1.2 Thesis Structure

Chapter two will outline the existing literature in the field of respite care and children with intellectual disabilities and autism spectrum disorder. Chapter three will outline the methodology, including the rationale for the research design, data collection and analysis. Chapter four will discuss the main findings, supported by illustrative quotes and analytical comments. Chapter five presents a critical discussion of the main findings in relation to the
existing literature that was discussed in chapter two. Strengths and limitations, implications for clinical practice, education and policy, and future research opportunities will also be discussed.

1.2.1 Chapter Two: Literature Review

This chapter begins with a brief description of autism spectrum disorder, prevalence rates, and associated behaviours. Research relating to the impact of caring for individuals with intellectual disabilities and ASD will then be critiqued, as will the literature regarding respite care and the associated benefits and challenges for carers. The chapter will also explore the experiences and perspectives of carers, particularly in the Irish context. This chapter concludes with a short introduction to the current research project, and a brief discussion of the principle aims of the study.

1.2.2 Chapter Three: Methodology

The rationale for the research design and the adoption of the methodological framework will be presented. A comprehensive account of sampling and recruitment procedures, participant characteristics, data collection, and data analysis will be provided. Management of ethical concerns, trustworthiness and credibility of the research, and researcher reflexivity will be also discussed.

1.2.3 Chapter Four: Results

This chapter will outline the main findings from the six transcribed interviews. The five superordinate themes, and associated subordinate themes, that emerged from the data will be discussed. Illustrative quotes and interpretive comments will also be presented throughout the chapter.

1.2.4 Chapter Five: Discussion

This chapter will revisit and discuss the disseminated literature, presented in chapter two, in relation to the findings of the current study. The strengths and limitations of the research will be addressed, and a critical reflection of the research process provided. The main findings will be discussed in relation to clinical, policy and educational implications, and areas for potential future research will be identified. The chapter concludes with a brief summary of the general conclusions based on this research.
Chapter Two: Literature Review

2.1 Literature Search Strategy

Comprehensive searches of the following databases were carried out to identify relevant published articles: PsycInfo, PubMed, Web of Science, Embase, CINAHL Plus with First Text, Cochrane Database and Google Scholar. The question underpinning the literature search was ‘what do parents of children with autism spectrum disorder experience when accessing respite care for their child?’ Search terms and keywords included combinations of the following: Respite care and related terms (short breaks, home support, residential breaks), Parents (or caregivers, or families), Children, Autism Spectrum Disorder and other variants (autism, ASD, pervasive developmental disorder), Disability and related terms (intellectual disability, developmental disability, developmental delay, learning disability), and Lived Experience and similar terms (personal experience, insights, qualitative). Searching was limited to peer-reviewed articles in the English language. Initial search results were examined in order to determine their suitability and relevance to the research question. Titles and abstracts of each article were reviewed in order to identify literature for full reading and critiquing. Reference lists were also reviewed to identify any additional papers that were not returned during initial searches.

Due to the limited availability of literature related specifically to the experience of parents of children with ASD and respite care, it was decided that research involving parents and caregivers of children with intellectual disabilities or developmental disabilities would also be included in the literature review. As children with ASD tend to access similar services to children with other disabilities it was felt that this research was relevant to the current study. It is also likely that these studies included some parents/caregivers of children with ASD within the participant group. Literature related to the experience of parents of children with purely physical disabilities or with serious illnesses was excluded. As this research was taking place within an Irish service, it was also felt that it was important to include studies that had been carried out in this country, predominantly exploring the experience of parents and caregivers of individuals with intellectual disabilities. In addition to the relevant research literature, it was felt that it was necessary to provide some political, social and legislative context in order to understand the different models of disability, the nature of service provision and the relevant policies and strategies currently in place for people with disabilities. A number of government publications, policy documents, annual reports and newspaper articles were reviewed and also incorporated into the literature review.
2.2 Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a pervasive, neurodevelopmental disorder characterised by persistent impairments in social communication and interaction, and restricted, repetitive patterns of behaviour, interests or activities, both in varying degrees (American Psychiatric Association (APA), 2013; Bessette Gorlin, McAlpine, Garwick & Wieling, 2016). There is significant variability in the presentation and severity of ASD (Huerta & Lord, 2012; Bessette Gorlin et al., 2016), and individuals often display a range of co-morbidities including attention problems, oppositional behaviours, emotional difficulties, language impairment, epilepsy, and intellectual disability (Carlsson et al., 2013; APA, 2013; Posserud, Hysing, Hellund, Gillberg & Lundervold, 2018).

2.2.1 Prevalence Rates

The past number of years has seen a significant increase in the reported prevalence of ASD, with 1 in 59 children in the United States (1.68%) now estimated to have ASD (Baoi et al., 2018). Studies of ASD prevalence rates across Europe, Asia and North America have estimated that between 1% and 2% of the population meet criteria for ASD (Centres for Disease Control and Prevention, CDC, 2019). Recent research into ASD prevalence in Ireland has estimated that the incidence of ASD is at least 1-1.5% of the population (Sweeney, Staines & Boilson, 2016). This is similar to the findings of research in Great Britain (Baird et al., 2006; Brugha et al., 2012; Russell, Rodgers, Ukoumunne & Ford, 2014), but somewhat lower than Northern Ireland, where ASD prevalence is currently estimated at 2.9% (Waugh, 2018).

ASD frequently occurs with intellectual disability (Hoekstra, Happé, Baron-Cohen & Ronald, 2009), with research from the Autism and Developmental Disabilities Monitoring Network (ADDMN) showing that almost 40% of children with ASD also have an intellectual disability (CDC, 2012). According to the 2016 Census, there were 66,611 people with an intellectual disability in Ireland, representing 1.4% of the population (CSO, 2016). 24,459 of these were children and young people aged 0-19 years. Although there is currently no census data on the number of individuals with ASD in Ireland, it is estimated there are approximately 50,000 people diagnosed with autism in this country (Sweeney et al., 2016).

2.2.2 Living with ASD

Existing research has highlighted the challenges associated with caring for an individual with ASD. Behaviours commonly associated with autism, including sleep disruption (Devnani &
Hegde, 2015), feeding difficulties (Ledford & Gast, 2006), aggression and self-injury (Fodstad, Rojahn & Matson, 2012), tantrums or ‘meltdowns’ (Konst, Matson & Turygin, 2013), obsessional behaviours, rigidity or restricted interests (Richler, Bishop, Kleinke & Lord, 2007), and sensory sensitivities (Bonis, 2016), can impact family functioning, health and wellbeing, and relationships (Bessette Gorlin et al., 2016; Whitmore, 2016; Harper, Dyches, Harper, Roper & South, 2013). Many families report difficulties with providing sufficient care and accessing services (Bultas & Pohlman, 2014; Safe, Joosten & Molineux, 2012; Hodgetts, Zwaigenbaum & Nicholas, 2015; Desmarais, Barker & Gouin, 2018), securing appropriate educational placements (Bessette Gorlin et al., 2016; Derguy, M’Bailara, Michel, Roux & Bouvard, 2016) and have experienced stigma (Hoogsteen & Woodgate, 2013; Lutz, Patterson & Klein, 2012) or social isolation (Nicholas et al., 2016; Safe et al., 2012; Galpin et al., 2018). Parents of children with ASD have also been shown to have significantly higher levels of stress, anxiety and depression than parents of typically developing children, and children with other disabilities (Whitmore, 2016; Bonis 2016; Hayes & Watson, 2013, Zablotsky, Bradshaw & Stuart, 2013; Dabrowska & Pisula, 2010).

2.3 Changing Model of Disability

Over the last 50 years, there has been a political and social shift in the provision of care for people with disabilities from hospitals and institutions to community-based services, which promote social inclusion (Wilkie & Barr, 2008; Humpage, 2007). Historically, disability has been understood and defined in various ways. The most influential models of the 20th century are the medical and social models of disability (LoBianco & Sheppard-Jones, 2008).

2.3.1 Medical Model

Within the medical model, originally proposed by scientists, disability is understood and conceptualised as a biological product (Brittain, 2004). Disability occurs as a result of an individual’s physical and/or mental impairments, and can be caused by injury, disease, or other health conditions (Forhan, 2009; Haegele & Hodge, 2016). Similar to physical illness, disability is viewed as a problem that needs to be cured so an individual can fit within society (Haegele & Hodge, 2016; Brandon & Pritchard, 2011; Bingham, Clarke, Michielsens, & van de Meer, 2013). According to this model, the difficulties encountered by people with disabilities occur as a direct result of their impairments, and are independent of the wider physical, social, cultural and political environments (Brittain, 2004). Treatment, therefore, focused on fixing and eradicating their impairments, which would help them function within
society (Bingham et al., 2013; Roush & Sharby, 2011). It was felt this was best achieved by placing individuals with disabilities under the direct care of medical professionals in institutions, rehabilitation settings, and residential special schools (Humpage, 2007; Roush & Sharby, 2011; Palmer & Harley, 2012).

2.3.2 Social Model

The 1970s and 1980s saw the growing importance of the social model of disability, which argued that it is society that imposes disability on individuals (Brandon & Pritchard, 2011; Bingham et al., 2013). This model shifted the perspective from the individual to the environment, suggesting that it is not an individual’s physical and/or intellectual functioning that limits their abilities, it is society (Roush & Sharby, 2011; Haegele & Hodge, 2016; Forhan, 2009). Disability, according to this model, is imposed on individuals with impairments when they are disadvantaged or excluded from full participation in their community due to society’s inability or unwillingness to remove environmental barriers and accommodate differences (Haegele & Hodge, 2016; Roush & Sharby, 2011). Interventions, therefore, should not focus on the individual but instead society itself, with political action, social and cultural changes needed to decrease environmental barriers and increase understanding of those with impairments (Haegele & Hodge, 2016).

2.3.3 Provision of Care

Along with this ideological shift, there was an international movement towards deinstitutionalisation and community inclusion, whereby individuals with disabilities were moved out of large institutions into community-based care, either in smaller residential settings, supported accommodation, or their family home (Hamelin, Frijters, Griffiths, Condillac & Owen, 2011; Merriman & Canavan, 2007; Beadle-Brown, Mansell & Kozima, 2007; Noonan-Walsh et al., 2007; Doody, 2012). This was based on the principle of inclusion, which promoted equality, and recognised the rights of individuals with intellectual disabilities to experience a similar life to that of others in their community (Nirje, 1969, 1985; Wolfensburger, 1972; Doody, 2012). Community-based care aimed to provide those with intellectual disabilities with greater independence, privacy and choice, the opportunity to develop relationships, to participate in their community, and improve their quality of life, free from the negative factors associated with institutional living (Ericsson & Mansell, 1996; Hamelin et al., 2011).
2.3.4 Policy and Legislation

In 1965, the Commission of Enquiry on Mental Handicap in Ireland recognised that community-based care for people with intellectual disabilities was better ‘therapeutically’ than institutional care and recommended the provision of care within the community so that, where possible, individuals with disabilities could stay in their own home (Department of Health, 1965). This continued to be the focus of Irish policies in this area, with the Report of the Review Group on Mental Handicap Services (1990) and the Report on the Commission on the Status of People with Disabilities (1996) both recommending service provision within the community. The National Disability Strategy, launched by the Irish Government in 2004, aimed to bring together legislation, policy and services to support the equal participation of people with disabilities in Irish society (Merriman & Canavan, 2007). The elements of the strategy included legislation in support of social inclusion, namely the Education for Persons with Special Educational Needs Act (2004), the Disability Act (2005), and the Citizens Information Act (2007); sectoral plans for six government departments; and a multi-annual investment programme for disability services.

In the 15 years since the National Disability Strategy, several plans and policies have been introduced, each detailing recommendations and commitments to improve the lives of people with disabilities, and reform service provision in this country. These national strategies cover a range of areas including reform of children’s services (Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years, HSE 2009), deinstitutionalisation (Time to Move on from Congregated Settings, HSE, 2011), service provision (Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders, HSE 2018a), day services (New Directions: HSE Day Services Implementation Plan, HSE 2012), and carers (The National Carers’ Strategy, Department of Health, 2012) (Inclusion Ireland, 2013). The current National Disability Inclusion Strategy, which was released in 2017, restates the Government’s commitment to improving the lives of people with disabilities and providing them with the best opportunities to fulfil their potential (Department of Justice and Equality, 2017).

Internationally, there have also been significant legislative and policy developments in recent years. The Madrid Declaration declared disability to be a human rights issue, and advocated the social model of disability, recognising that change was needed on a societal level and putting forward recommendations in relation to service provision for people with disabilities.
The UN Convention on the Rights of Persons with Disabilities was adopted in 2006 and was ratified by Ireland in 2018 (Conneely, 2018). The aim of this Convention was to ensure that people with disabilities enjoy all the human rights and fundamental freedoms outlined in the UN Convention of Human Rights in 1948 (United Nations, 2015). The Convention recognised the right of people with disabilities to live in the community and to receive the necessary support to facilitate their full enjoyment and participation within the community. It also recognised the family as the fundamental group in society and outlined how society and the State should protect the family and ensure that people with disabilities and their family members received appropriate support and assistance where needed (UN, 2006).

Another important document is the UN Convention on the Rights of the Child, which is an internationally binding agreement on the rights of individuals under the age of eighteen years, first adopted by the United Nations General Assembly in 1989 (Children’s Rights Alliance, 2010). Within this UN Convention, Article 23 lays out the specific rights of children with disabilities. According to Article 23, it is important for States Parties to recognise that children with disabilities should ‘enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community’. It is necessary for States Parties to recognise the right of disabled children to special care and to ensure that support offered is appropriate to the child’s needs and to the circumstances of the parents or caregivers of the child. Supports should be offered free of charge and should be designed to ensure that the child has access to education, health care and rehabilitation services, preparation for employment, and opportunities for recreation that support the child in reaching the greatest possible level of individual development and social integration. Article 23 also outlines how States Parties should promote the exchange of information and research findings related to health care, medical and psychological treatment of children with disabilities, in order to allow them to improve their skills and build their experience in these areas (United Nations, 1989). Ireland signed the UN Convention on 30 September 1990 and ratified it on 28 September 1992, which committed the Irish State to promoting, protecting and fulfilling the rights of children in this country (Children’s Rights Alliance, 2010).

### 2.3.5 Caregiving in Ireland

As a result of this shift in the provision of care, an increasing number of individuals with intellectual, physical, sensory and developmental disabilities are now being cared for at home.
(Isaacs et al., 2007). In Ireland, families are the main providers of support for individuals with intellectual disabilities (Chadwick et al., 2013; Hourigan, Fanagan & Kelly, 2017). Since 1995, data has been collected on the number of people with intellectual disabilities availing of services in the Republic of Ireland. The National Intellectual Disability Database (NIDD) is a voluntary database used for gathering information to help with decision-making, planning and organisation of disability services (Hourigan et al., 2017). In 2017, the Annual Report of the NIDD (Hourigan et al., 2017) found that 28,388 people with intellectual disabilities were registered, with 27,985 (98.5%) of these in receipt of some type of service. 10,032 (35.3%) of these were children and young people aged between 0 and 19 years. Families were the main providers of support, with 69.0% (19,599) of those on the database reported to be living at home with their parents, siblings, relatives or foster parents. When looking to the 2016 Census data, 195,263 people (4.1% of the population) reported providing unpaid care to others. While it is clear that family carers are a hugely important resource when it comes to caring for people with intellectual disabilities, many have reported a lack of support and understanding from the government and service providers, inadequate income support, lack of home and community care services, and insufficient respite provision (The Carers Association, 2008; Lafferty, O’Sullivan, O’Mahoney, Taggart, & van Bavel, 2016).

2.4 Impact of Caring

2.4.1 Caring for Individuals with Disabilities

Research has found that caring for those with an intellectual or developmental disability can negatively impact the caregiver and the wider family. Although parents often report caring for their child to be rewarding and resilience building (Blacher & Baker, 2007; Kenny & McGilloway, 2007; Chadwick et al., 2013; Green, 2007), they are also at risk of physical and emotional burnout. In a review of the literature on the wellbeing of mothers of children with developmental disabilities, Lee (2013) found higher levels of stress than in mothers of typically developing children, with stress levels shown to remain high over time. Similarly, parents of children with intellectual disabilities have been shown to have an increased risk of psychological distress, anxiety and depression (Emerson, 2003; Feldman et al., 2007; Singer 2006; Gallagher & Hannigan, 2014). These parents also seem to be at greater risk of poor physical health, reporting more physical health issues such as headaches, back problems, sleep difficulties, gastro-intestinal complaints, respiratory illnesses, and elevated blood pressure (Allik, Larsson & Smedje, 2006; Gallagher & Whiteley, 2012, 2013).
Caring for a family member with an intellectual disability can also impact family functioning and relationships (Kenny & McGilloway, 2007). Due to the demands of caring, parents may not have as much time for their other children and may rely on them to help with their sibling’s care (Schuntermann, 2007; Harris, 2008; Phelps, Hodgson, McCammon & Lamson, 2009). Families often need to adapt or change their routine and may restrict social activities due to the needs of their family member with a disability (Povee, Roberts, Bourke & Leonard, 2012). This can lead to feelings of social isolation (Worcester, Nesman, Raffaele Mendez & Keller, 2008), which can have a negative impact on the family’s wellbeing (Galpin et al., 2018). Financial difficulties are common among families of children with disabilities, as parents often face considerable health care costs and may be unable to work, given the demands of caring (Resch et al., 2010; Worcester et al., 2008; Parish, Rose, Grinstein-Weiss, Richman & Andrews, 2008). Parents of children with intellectual disabilities are also more likely to experience marital problems (Al-Krenawi, Graham & Al Gharaibeh, 2011; Hatton, Emerson, Graham, Blacher & Llewellyn, 2010), with higher divorce rates among families of children with developmental disabilities (Risdal & Singer, 2004).

Several studies have explored the lived experience and personal insights of families and carers of people with intellectual disabilities. Research by Resch et al. (2010) found that parent caregivers identified several barriers to their wellbeing. Difficulties accessing important information and services, along with a lack of communication between different services, was very challenging for parents. Financial barriers to obtaining services and continuous efforts to ensure their child was included in their school and community also placed parents under significant strain. A lack of services and support for families, at the time of initial diagnosis and while caring for their child day-to-day, was also highlighted. Similar findings were reported by Kenny & McGilloway (2007) and Chadwick et al. (2013) in research with Irish caregivers. Additional difficulties were recognised by participants in these studies, including inadequate service provision, and societal and governmental attitudes towards people with intellectual disabilities. Parents reported concerns about their child’s future, and many described having to advocate and fight to access services (Chadwick et al., 2013).

2.4.2 Caring for Children with ASD

As discussed in the opening paragraphs, parenting a child with ASD has been associated with higher levels of psychological distress, than parenting typically developing children or children with other disabilities (Whitmore, 2016; Bonis 2016; Hayes & Watson, 2013; Zablotsky et al.,
This can negatively impact the parent’s ability to manage their child’s behaviours, their social relationships, and family functioning (Bonis, 2016). In a review of the existing literature exploring parents’ perspectives of raising a child with ASD, Ooi, Ong, Jacob and Khan (2016) identified numerous challenges facing parents. The psychological impact of receiving a diagnosis of ASD and difficulty managing their child’s behaviour appeared to impact parents’ wellbeing and stress, their health, career and financial position, and their leisure time. The impact of ASD on family life and relationships was also highlighted as families struggled to spend time together, which could affect the quality of their relationships. Parents have described their worries about their child’s future, and about the impact that living with ASD has on their other children (Preece, 2014). Additionally, the social impact of ASD, particular in relation to stigma, lack of understanding, and social isolation, is also frequently mentioned (Ooi et al., 2016; Preece, 2014).

Bessette Gorlin et al. (2016) identified specific challenges facing parents caring for a child with severe ASD. Parents described the complexity and mystery of ASD, noting their child’s behaviour was often unpredictable and could change dramatically. Families reported significant difficulties managing the challenging behaviours related to ASD, including self-injurious behaviours, meltdowns, severe sleep disturbances, aggression, and elopement, which seemed to get worse as their child got older. Parents also spoke about the challenge of caring for a child with little or no verbal and non-verbal communication skills. In line with the research with parents of children with intellectual disabilities, parents of children with severe ASD also reported extreme stress, social isolation, and financial difficulties. Additionally, parents described a sense of isolation from their child, due to the nature of their ASD, their difficulties with communication, and the lack of affection from their child.

Similar findings have been reported by Galpin et al. (2018), as parents identified the everyday challenges of living with ASD, managing their child’s specific needs and characteristics. Participants spoke about their sense of isolation from the community, a lack of understanding and awareness of ASD, and expressed their wish to feel more connected to others, including professionals and other parents. They described the adversarial nature of the system, with many stating that the existing systems did not meet the needs of their family. Parents highlighted the need for formal and informal supports, which should be tailored to meet the needs of the whole family, rather than just the child, and for more support to be provided post-diagnosis. The need for respite care was also recognised by many parents, in order to ‘recharge their batteries’ or
take care of everyday tasks and appointments. While support during school term was reportedly helpful, parents felt there was a need for greater flexibility, with more support needed during school holidays.

### 2.4.3 Influential Factors

A number of individual and environmental factors have been shown to contribute to increasing stress in parents of children with ASD. Child-related factors, such as ASD severity (Lyons, Leon & Roecher-Phelps, 2010; Picardi et al., 2018), challenging behaviours (Lecavalier, Leone & Wiltz, 2006, Harper et al., 2013; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014), and lower levels of adaptive functioning (Hall & Graff, 2011) have been reported to impact parental stress and wellbeing (Krakovich, McGrew & Ruble, 2016; Derguy et al., 2016). Parents’ own characteristics, including their coping style (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Benson, 2010; Hall & Graff, 2011), personality traits (Ingersoll & Hambrick, 2011), sense of optimism and self-efficacy (Faso, Neal-Beevers & Carlson, 2013; Lee, 2009; Meadan et al., 2010) can also influence their experience of stress (Galpin et al., 2018).

Meadan et al. (2010) has suggested that there could be a bidirectional relationship between individuals with ASD and their family members. While the child’s behaviours could lead to increased stress, family members could also negatively influence the child’s behaviour due to their own psychological distress, emotional difficulties or strained familial relationships (Meadan et al., 2010). Environmental factors have also been found to be influential in caregivers’ experience of stress, with lack of social support (Ingersoll & Hambrick, 2011; Hastings & Johnson, 2001), inadequate service provision (Galpin et al., 2018; Preece, 2014), and lack of professional support (Bishop, Richler, Cain & Lord, 2007) associated with greater levels of distress.

### 2.4.4 Impact on Siblings

Research examining the impact of having a sibling with ASD has been relatively inconsistent. Some researchers have highlighted the difficulties that siblings of children with ASD face in relation to developing a good relationship with their sibling, taking on caring responsibilities (Harris, 2008; Kaminsky & Dewey, 2001), and have reported negative outcomes including behavioural and emotional difficulties, and loneliness (Gold, 1993; Hastings, 2003; Verté, Roeyers & Buysse, 2003; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Ross & Cuskelly, 2006; Gau et al, 2010; Orsmond & Seltzer, 2007). Siblings have described some of the difficulties they are faced with, including restricted opportunities for activities or to have
friends visit, difficulties completing their homework, and embarrassment due to their sibling’s behaviour (Preece, 2014).

Conversely, other researchers have reported positive outcomes associated with having a sibling with ASD, with typically developing siblings shown to be emotionally and behaviourally well-adjusted, (Kaminsky & Dewey, 2002; Dempsey, Llorens, Brewton, Mulchandani & Goin-Kochel, 2012; Hastings, 2007; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004). Some siblings exhibit less conflict and greater admiration in their sibling relationships, (Kaminsky & Dewey, 2001), more accepting and supportive behaviours (Benderix & Sivberg, 2007), and have been found to have enhanced psychosocial and emotional development (Macks & Reeve, 2007). Qualitative research with siblings of individuals with ASD has supported these contradictory findings, with many participants acknowledging the difficulties associated with living with a sibling with ASD while also describing the positive impact of their relationship (Mascha & Boucher, 2006; Ward, Tanner, Mandleco, Dyches, & Freeborn, 2016).

2.4.5 Positive Aspects of Caring

Although a large proportion of the existing research has identified the difficulties encountered by carers, there is a growing body of literature focusing on the positive aspects of caring for children with disabilities. Kenny and McGilloway (2007) found that, despite a lack of available support services and clear evidence of strain, most parents of children with intellectual disabilities reported feeling fulfilled and satisfied with their lives, describing the joy that their child has brought to them and others. Some participants noted that having a child with special needs had encouraged them to be less judgemental, more creative and confident, and more appreciative of the ‘little things in life’ (Kenny & McGilloway, 2007, p. 225). Similar findings were reported by Chadwick et al. (2013), whereby family carers commented on the sense of pride and inspiration they gained from their family member with intellectual disabilities.

For families of children with ASD specifically, several studies have reported positive outcomes related to the experience of caring. Research with mothers of children with ASD found that many described the positive side, the ‘silver lining’, to caring for a child with ASD (Bultas & Pohlman, 2014). Participants identified increased empathy, a more positive outlook, improved self-esteem, and reported feelings of joy when their child reached developmental milestones. Similarly, Phelps et al. (2009) found that caregivers of children with ASD reported their role allowed them to develop greater compassion, selflessness, more patience, and described how advocating for their child led to a sense of fulfilment. Families of children with ASD have also
reported that caring for their child has led to greater cohesion and adaptability within the family (Luong, Yoder & Canham, 2009; Phelps et al., 2009; Bilgin & Kucuk, 2010).

2.5 Respite Care

Over the last number of decades, advances in medical and health care technologies have led to greater survival rates and improved life expectancy for individuals with disabilities and complex medical conditions (Thomas & Price, 2012; Strunk, 2010; Welsh, Dyer, Evans & Federev, 2014; Olsen & Maslin-Prothero, 2001). As discussed in preceding paragraphs, there has also been a change in the provision of services for individuals with disabilities, with the majority now being cared for by family members (Isaacs et al., 2007; Chadwick et al., 2013; Olsen & Maslin-Prothero, 2001). With the increasing number of individuals with disabilities now receiving home-based care, there is a significant need for additional support for families. Support services play a vital role in helping families to cope, enabling them to continue to provide care for their family member at home (MacDonald, Fitzsimons & Noonan Walsh, 2006).

Respite care is concerned with both formal and informal ways of providing parents, caregivers and families with support and a break from the demands of caring for individuals with physical, intellectual or developmental disabilities, or other special needs, including chronic or terminal illnesses (Wilkie & Barr, 2008; Whitmore, 2016; Ling, Payne, Connaire & McCarron, 2015). Treneman, Corkery, Dowdney and Hammond (1997) defined respite care as:

“The shared care of a person with learning difficulties and/or physical disabilities, either at home or in short-term residential settings, in order to give the family a break from routine care-taking.” (p. 548)

Traditionally, the main aim of respite services was to provide caregivers with a break from the responsibility of full-time caring in order to facilitate the continued care of people with intellectual disabilities in their home ( Cotterill, Hayes, Flynn & Sloper, 1997; McConkey, Truesdale & Conliffe, 2004). Carers who benefitted from respite care were believed to be more likely to continue to provide long-term care (Chesson & Westwood, 2004), which would allow families to stay together and postpone the need for long-term residential placements (Cotterill et al., 1997). More recently, the needs and wishes of the service user have been given greater consideration and it has been recognised that respite care can allow individuals with disabilities the opportunity to develop greater independence, participate in more activities and integrate
into their community (Cotterill, 1995, cited in Cotterill et al., 1997), while also providing relief for their carer.

2.5.1 Models of Respite Care

There are a number of different models of respite care described in the literature, which reflects the diversity in service provision across different geographical areas and services. According to Pollock, Law, King and Rosenbaum (2001), models of respite care vary across four dimensions: purpose, duration, location and provider. Services can be described as having a primary or secondary respite purpose. The goal of primary services is to provide the family with a break from the demands of caring while secondary services aim to meet the needs of the individual with the disability, which often involves some time away from the family (Robinson & Stalker, 1993). The duration of respite care can also vary, with short-term services providing relief for a few hours or overnight, and long-term services offering respite for a week or more or during holidays, to allow carers a more significant break. Respite care can also be provided in response to a crisis or emergency (Neufeld, Query & Drummond, 2001; Dunne, 2015; Whitmore, 2016; Jeon et al., 2005).

The third dimension associated with different models of respite care is location. Historically, respite care was provided on a residential basis, typically in an institutional setting (Cramer & Carlin, 2008), which was in line with the medical model of disability. The growing importance of the social model of care, and the shift towards the provision of services for people with disabilities in their own community, led to the development of alternative models of respite (O’Brien, 2001; Jeon, Brodaty & Chesterson, 2005). Respite care is now provided in a range of locations, including specialised residential facilities, community-based services, and in the family home (Wilkie & Barr, 2008; Corkin, Price & Gillespie, 2006; MacDonald & Callery, 2004). Residential respite offers overnight support away from the family home, in a purpose-built facility, which can provide specialised care for individuals with more significant support needs (Majkut, 2010). While traditionally this type of respite would have been provided in long-stay hospitals or institutions, now residential respite is commonly offered in smaller, community-based centres or units (Coll & Scully, 2011). In Ireland, the majority of respite care for children and adults with disabilities takes the form of short breaks to community-based residential services (McConkey, Kelly, Mannan, & Craig, 2010).

Out of home respite care is also available in a number of other community-based respite models which have been designed to address social inclusion and to support the active participation of
individuals with disabilities in their community. A wide of different programmes have been developed to offer respite care to individuals within the community, including day services, group activities, recreational clubs, before and after-school clubs, camps, holiday schemes, play and friendships groups (Merriman & Canavan, 2007; Neufeld et al., 2001; MacDonald & Callery, 2004; Majkut, 2010). Another approach to respite care is home-sharing, which offers individuals with an intellectual disability a short break or full-time placement with another individual or family in the community, specifically selected and trained for this role (HSE, 2016). In-home respite care, on the other hand, is provided in the family home, and is designed to be more flexible, in order to allow families to avail of a service that is tailored to meet their needs.

The final dimension associated with different models of respite care is that of the service provider. Some respite services utilise paid or professional caregivers, nurses or other healthcare staff, many of whom have special training in providing support and care to individuals with disabilities (Pollock et al., 2001; Health and Social Care Board, 2017). This model of service provision is typically constructed more formally and is less flexible. As mentioned above, respite services are also offered by host families through the home-sharing initiative, who are specifically recruited and trained for this role. Additionally, respite care can be provided on a more informal basis by friends, family members or relatives of the individual with the disability (Whitemore, 2016). Much of the research on respite care focuses on respite services as a whole, rather than focusing on particular models, meaning it is difficult to determine whether one model of respite care is more beneficial than another (Ontario Centre of Excellence for Child and Youth Mental Health, 2013).

**2.5.2 Benefits of Respite Care**

Families of children with intellectual disabilities have consistently identified respite care as an essential source of support (Nishigaki, Yoneyama, Ishii & Kamibeppu, 2017; Champagne & Mongeu, 2012). In a review of the literature, Robertson and colleagues (2011) found that overall, respite care can have a positive impact on the wellbeing of carers, their family, and their children with disabilities. Parents reported more time for rest and rejuvenation, a sense of relief, and freedom to do things for themselves (Robertson, et al., 2011). Respite care has been associated with lower levels of fatigue, a decreased risk of psychological distress and decreased stress levels (Chan & Sigafoos, 2001; Cowen & Reed, 2002; Whitmore, 2016; Strunk, 2010; Nankervis, Rosewarne & Vassos, 2011; Norton, Dyches, Harper, Roper & Caldarella, 2016; Mullins, Aniol, Boyd, Page & Chaney, 2002; Chapman, 2013). Respite allows parents to catch
up on sleep, re-energise themselves, and experience a sense of normality (Robertson et al., 2011; Nankervis, et al., 2011; McConkey et al., 2004). Regular access to a high-quality respite service has also been shown to positively impact the caregiver’s ability to continue in their role as a carer (Mansell & Wilson, 2009; Wilkie & Barr, 2008; Collins et al., 2014).

Research carried out by Whitmore and Snethen (2018), exploring parental perceptions of respite services, found that respite was like a ‘gift’ for parents, allowing them a break from the constant demands of caring. Parents described how respite gave them hope, allowed them time to themselves, and special time with their other children (Whitmore & Snethen, 2018). Some parents also stated that respite care has allowed them to relate better to their child (Joyce, Singer & Isralowitz, 1983; Marc & MacDonald, 1988). Studies have shown that respite care has a positive impact on family functioning (McDonald & Callery, 2004; Chan & Sigafos, 2001), allowing families to get along better, to spend time together and do a wider range of activities (Joyce et al., 1984; Marc & MacDonald, 1988; McConkey et al., 2004; Mannan et al., 2011). Families availing of respite services have been found to have an improved quality of life (Forde, Lane, McCloskey, McManus & Tierney, 2004; Sung & Park, 2012), with some research also suggesting that respite care is associated with improved marital relationships (Stalker & Robinson, 1994; Harper et al., 2013; Whitmore & Snethen, 2018).

Siblings of children with disabilities have described positive aspects of respite care, including more time and attention from their parents, opportunities to try new activities, to have a ‘normal’ life for a short time, and to have a break from their sibling (Welch et al., 2012). Respite care can also benefit children with disabilities as it allows them to experience new environments, mix with others, develop new friendships, build their social skills, and become more independent (McConkey et al., 2004; Shared Care Network, 2008; Wilkie & Barr, 2008; Neufeld et al., 2001; Chapman, 2013). According to parents, attending respite care promotes the development of their child’s self-esteem, their social, communication and daily living skills, and contributes to their physical development (Welch et al., 2014; Welsh et al., 2014). Research carried out with children themselves found that the majority enjoyed respite care and described numerous benefits, including new toys and activities, a sense of excitement and adventure, freedom from their parents, good relationships with the support carers, and the opportunity to meet other children (Minkes, Robinson & Weston, 1994; Welch et al., 2014). Similar findings have been reported for adolescents, with the majority reporting improved psychological wellbeing, a sense of belonging, less emotional difficulties, and improved social interactions (Spruin, Abbott & Holt, 2018).
2.5.3 Challenges for Respite Services

Despite the increasing demand for respite services and the numerous benefits that have been identified, carers are often disappointed with the supports available to them (McGill, Papachristoforou & Cooper, 2006; Doig, McLennan & Urichuk, 2009; Welsh et al., 2014). Across the literature, the most frequently identified unmet need for parents and carers of individuals with disabilities and ASD is appropriate respite care (Hodgetts et al., 2015; Meadan et al., 2010). Demand for respite services far exceeds the available supply and many families report waiting for long periods of time to access support (Caples & Sweeney, 2011; Nankervis et al., 2011; Mansell & Wilson, 2009). In a study carried out by Doig et al. (2009), parents described the process of obtaining respite care as ‘jumping through hoops’, and reported numerous difficulties navigating the system and ensuring their family met the necessary requirements. A number of other barriers have also been identified, including lack of information and awareness of services (Wilkie & Barr, 2008; Mansell & Wilson, 2009), lack of availability and flexibility, inadequate funding, staff-related issues (Welsh et al., 2014), and concerns about their family member’s eligibility for the service due to challenging behaviours (Southby, 2017).

Some parents have expressed a reluctance to use respite services for various reasons, including feelings of guilt or embarrassment (Wilkie & Barr, 2008; Neufeld et al., 2001; York Moore, 1994; Chapman, 2013), fear of leaving their child with strangers, anxiety about the separation, loss of privacy, fear of abuse, and uncertainty about the quality of the service and qualifications of the staff (Neufeld et al., 2001). Several studies have shown that respite care can lead to an increase in caregiver stress when it does not meet the individual needs of the family (Hoare, Harris, Jackson & Kerley, 1998; Treneman et al., 1997). Neufeld et al. (2001) found that many caregivers who accessed respite care did not feel the service offered them a sufficient break from caregiving. Similarly, MacDonald and Callery (2008) found that, while parents recognised their need for a break, their concerns about the quality of the care provided could impact their ability to switch off. Parents also described how their caregiving and need for respite evolved over time, as their child developed, and their family circumstances changed (MacDonald & Callery, 2008).

Although respite care has been associated with numerous benefits for carers and families, there is some research which suggests that the beneficial effects of respite are relatively short-lived (Chan & Sigafuos, 2001; McNally, Ben-Shlomo & Newman, 1999). A study by McLennan,
Doig, Rasmussen, Hutcheon and Urichuk (2012) found that a small group of parents reported a sense of relief having accessed respite care, but this was not associated with a reduction in stress levels over time. Similarly, Mullins et al. (2002) reported that, while psychological and parenting distress were reduced following respite care, this improvement in stress levels was not maintained long-term. This suggests that, while respite care is effective in providing temporary relief, it cannot fully ameliorate the stress of caring for a child with a disability. These findings show that, for carers to benefit as much as possible from respite services, they should be allocated well-planned, regular respite support, designed to meet their individual needs (Nankervis et al., 2011).

Overall, while parents appear happy to avail of respite services, the majority report a significant need for more services, greater flexibility, more frequent respite (Caples & Sweeney, 2011; Doig et al., 2009), and for more collaboration and greater communication between agencies and service providers (Thomas & Price, 2012). Parents have highlighted the need for respite to be more responsive and immediate where needed (Olsen & Maslin-Prothero, 2001), more consistent and organised, family-centred and tailored to ‘fit’ the needs of each family specifically (Whitmore & Snethen, 2018; Welsh et al., 2014). Carers have also expressed their wish for respite care providers to show that they really care for the children (Whitmore & Snethen, 2018; Welsh et al., 2014), and for additional supports to be offered alongside respite care (Mullins et al., 2002).

2.6 Respite Care in Ireland

2.6.1 Service Provision in Ireland

Respite care is defined by the National Disability Authority (NDA) of Ireland (2004) as

“Temporary residential care based either in a centre or community based, that is intended to support the upkeep of people with disabilities in their own homes. This temporary care can cover a crisis period, take place on a periodic basis to enable a caregiver to have a break, or it can provide the person with a disability with medical, therapeutic or support services” (p. 212)

In Ireland, the majority of respite services are provided by voluntary organisations and religious orders, partly financed by the Health Service Executive (HSE) (Hartrey & Wells, 2003; Mannan et al., 2011). In 1996, the Report of the Irish Commission on the Status of People with Disabilities stipulated respite care as a requirement in every health board area in Ireland and recommended that respite services should be expanded. This report acknowledged the crucial
role for respite in community support for people with disabilities and outlined how services should be flexible and include a range of options. It was also recommended sufficient funding be granted to ensure that respite services are suitable in terms of the quality and frequency of the service provided (Department of Health, 1996). Following this, the period from 1996 to 2004 saw an increase of 357% in the number of individuals with intellectual disabilities availing of centre-based respite services (Barron & Mulvaney, 2004).

Despite expansion of the services over the last number of years, respite remains a largely unmet need for many families in Ireland. According to the NIDD, 4,104 people with intellectual disabilities received respite services in 2017, which represented a decrease of 6.4% from those accessing respite in 2016 (Hourigan et al., 2017). There is also significant variability in the provision of respite services across different areas in the country (Hourigan et al., 2017; McConkey et al., 2010). Similarly, research exploring the experiences of family carers found that over half of those who required crisis respite care did not receive the service (Lafferty et al., 2016). Demand for respite continues to rise, with the NIDD predicting that, in the period from 2018-2022, 2,365 new residential support services will be required for those living at home or in the community. Additionally, 1,461 people with intellectual disabilities will need changes or enhancements to their existing residential support services, with the majority (67.2%) in need of more frequent centre-based crisis or planned respite breaks (Hourigan et al., 2017).

The economic downturn in Ireland a decade ago had a significant impact on funding within the voluntary sector, meaning cuts to funding for respite care, which has contributed to the shortage of services (Hanrahan, 2010; Inclusion Ireland, 2011). Over the last number of years, the Irish government has also made numerous cuts to funding for intellectual disability services and to the respite support grant (McConkey & Craig, 2018; Russell, 2016), with many carers left in crisis, with no access to support (Russell, 2016; Gittens, 2017). There have been numerous campaigns by various charities, advocacy groups and agencies across the country, calling for the government to reconsider these cuts and provide more funding for services nationwide (Russell, 2016; Cullen, 2014). In response to this, the government announced in 2016 that the respite grant would be restored to its original amount. In 2018, the HSE launched a new Respite Development Programme which granted additional funding of €10 million to fund new respite houses, increase the capacity in existing services, and to provide alternative respite services for people with disabilities (HSE, 2018b). While this is a welcome commitment from the
government, demand for respite is likely to continue to grow, increasing the pressure on services already stretched beyond capacity (Kelly & McConkey, 2012).

### 2.6.2 Experience of Irish Families

Previous research has explored parents’ experiences of respite services specifically in an Irish context. In their study of parents of children with intellectual disabilities, Wilkie and Barr (2008) found that parents reported numerous benefits to accessing respite care. Respite provided parents with temporary emotional and physical relief, a renewed sense of energy and level of confidence, and allowed them to spend time with their other children. Most parents identified that stress was their main reason for accessing respite care, with some noting feelings of guilt and embarrassment in relation to their need for additional support. Attending respite was also felt to be beneficial for the child as it gave them the opportunity to interact with other children, develop social skills, and increase their participation in activities in the community. Forde et al. (2004) found that accessing in-home family support was associated with a better quality of life, reduced levels of parental stress, more time to spend with other family members and opportunities for people with disabilities to participate in social and recreational activities.

In line with these findings, research evaluating the experience of a short break scheme for children with intellectual disabilities and their families found that parents reported reduced stress levels and improved family functioning (Ryan, 2011). Participants were largely positive about their experience, reporting that the quality of the service and care provided was excellent, and that they felt the family-based setting was beneficial for their child (Ryan, 2011). Similarly, in their case studies exploring the meaning of respite care for two Irish mothers of children with learning disabilities, Hartrey and Wells (2003) found that respite care relieved some of the social restrictions placed on families and provided relief from the burden of caring. Both mothers reported feeling a stronger attachment to their child with learning disabilities than their other children, and described the emotional conflict involved with accessing respite care. Respite allowed them the opportunity to rest, but their strong attachment to their child made this separation quite difficult and led to feelings of guilt. According to the authors, while the provision of respite care was beneficial for both families, it was not enough in itself to alleviate parent stress and tiredness. It was suggested that respite care could, in fact, be a stressor for some families and it was recommended that professionals acknowledge this potential distress and provide appropriate support and preparation for families ahead of respite care.
The emotional conflict facing parents when considering whether to access respite care was also evident in the findings of qualitative research studies carried out by Dunne (2015) and Mannan et al. (2011). While all parents interviewed reported feeling mentally and physically drained and recognised their need for support, the majority initially did not want to place their child in respite care. Parents expressed concerns about the ability of others to care for their child, their lack of knowledge about the services available, and many reported a sense of sadness about placing their child in the care of someone else (Dunne, 2015). Mannan et al. (2011) found that parents expressed a sense of ambivalence towards respite care and described the decision to use respite services as a moral dilemma. While many reported that the service gave them a sense of relief, they also experienced feelings of guilt and thought that other carers may have greater needs than their own (Mannan et al., 2011). It was felt by some that service providers did not recognise the dilemma caused by respite, with one parent in particular noting that she felt she couldn’t complain about anything as she had access to respite care (Mannan et al., 2011).

Although most parents appeared to be satisfied with the service they received and recognised the benefits of respite care, several issues have consistently been identified in relation to service delivery. Many parents have spoken about the lack of availability of respite, difficulties with scheduling due to respite being offered at very short notice (Chadwick et al., 2013; Caples & Sweeney, 2011; Dunne, 2015), and little opportunity to interact with other parents or become involved with the service itself (Dunne, 2015). Parents have highlighted gaps in service provision, particularly during the summer months, and have raised concerns about the level of funding as well as the transition process from child to adult services (Coll & Scully, 2011). Parents have also expressed concern about the quality of the service, calling for more appropriate settings for respite care, and for services to promote the independence and self-determination of the individuals receiving care (Mannan et al., 2011).

Caples and Sweeney (2011) carried out a survey investigating the quality of life of parents of children and adults with an intellectual disability who were availing of respite services. Overall, parents reported having a ‘good’ or ‘excellent’ quality of life, with most found to be satisfied with their family’s health, financial wellbeing, and family relationships. A lack of support from others was noted by many parents, however, which impacted their quality of life, as they reported social isolation and limited opportunities for social activities. In some cases, parents had to give up their career to take on the full-time care of their child. Similar to Dunne (2015), a number of barriers to accessing respite supports in Ireland were also identified by parents,
including long waiting times, lack of services in their locality, and insufficient levels of support from services.

2.7 Respite Care and ASD

In reviewing the experiences of parents and families of children with ASD specifically, there has been relatively little research carried out. Given the demands of caring for a child with ASD, there is a significant need for additional supports and services for parents and families, which can be provided informally, by other family members or the wider social network, or formally, by healthcare agencies and respite service providers. Studies have shown that parents of children with ASD who receive informal and formal supports show more positive adjustment and lower levels of stress, anxiety and depression (Chan & Sigafos, 2001; Hastings & Johnson, 2001; Benson, 2006; Dunn et al., 2001). Parents have frequently highlighted the value of both direct and online social support from other parents of children with ASD (Huws, Jones & Ingledew, 2001; Reinke & Solheim, 2015; Mackintosh, Myers & Goin-Kochel, 2005), with lack of social support shown to be associated with increased stress and psychological distress (Bromley, Hare, Davison & Emerson, 2004; Ekas & Whitman, 2010; Barker et al., 2011; Bishop et al., 2007). Across the literature, many parents have spoken about the benefits associated with informal respite, usually provided by their spouse, other family members, or friends, with recent research also highlighting the vital, and often unrecognised, role of grandparents in supporting families of children with ASD (Prendeville & Kinsella, 2019).

A review of the literature on respite care and stress among caregivers of children with ASD, carried out by Whitmore (2016), reported mixed findings. Harper et al. (2013) found that number of hours of respite care was positively related to improved marital quality for both husbands and wives, with more respite care also associated with reduced levels of stress. Cavanagh-Husseini (2015, as cited in Whitmore 2016) found an association between lower levels of maternal stress and availing of respite care during the holidays or in response to a crisis. Most mothers of children with ASD who had accessed respite services reported that the service was very effective in reducing their levels of stress, with some noting that respite was the most effective way to relieve stress. Similarly, a survey of caregivers of children with ASD found that respite care was viewed to be the most effective service in reducing caregiver, family and financial stress (Ruble & McGrew, 2007).

Qualitative research by Minhas et al. (2015) found that mothers of children with ASD frequently reported high levels of stress due to the constant nature of caring for their child’s
needs and the lack of respite care. While most researchers found that respite care was associated with lower levels of stress in parents of children with ASD, some have reported that respite was associated with higher levels of stress (Whitmore, 2016). Young, Ruble & McGrew (2009) found that availing of a larger variety or services, including respite care, was associated with higher reported levels of parental stress. Research with parents of pre-school children with ASD by Shamash (2012, as cited in Whitmore 2016) found that higher perceived stress was associated with use of respite services, which could reflect more significant needs of children who receive respite care compared to the general population of children with disabilities. Conversely, research by Dyches et al. (2016) found no significant relationship between respite care and maternal stress or level of depression.

Previous research has suggested that access to healthcare and support services is particularly problematic for families of children with ASD (Preece & Jordan, 2007; Kogan et al., 2008). A study by Hodgetts et al. (2015) found that the single greatest need reported by parents of children with ASD was locating and retaining a qualified respite provider, even with the appropriate funding in place. Parents spoke about the need for respite care to get a break, have some periodic free time for themselves, and to sleep ‘I have the skills, I need the energy’ (Hodgetts et al., 2015, p. 679). Similarly, research by Galpin et al. (2018) exploring the support needs of parents of children with ASD, found that many parents’ felt unsupported, with existing services not meeting their needs. Parents highlighted their need for respite care, particularly during the school holidays and in the evenings, and greater flexibility in the options available. They called for service provision to adopt a relational, family-centred approach, which is tailored to ensure the needs of the whole family are considered, builds close relationships, and offers support when families need it most (Galpin et al., 2018). According to Whitmore (2016), the adequacy of both informal respite provided by family members, and formal respite services is largely influential on parental stress levels, with inadequate support shown to be associated with higher stress. Parents have described the struggles they have encountered trying to request and receive appropriate services, with some noting that poor services exacerbated their families’ difficulties (Preece, 2014).

A diagnosis of ASD can also present specific challenges when it comes to availing of respite care. Children with ASD often prefer to adhere to a predictable routine and can become quite distressed when faced with change or transitions to new settings (Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011; Preece, 2009). Some children with ASD prefer solitary play so may not be comfortable in busy services or joining activities with other children (Preece, 2009). The
behaviours associated with ASD, such as aggressive behaviours, self-injury (Fodstad et al., 2012), and tantrums (Konst, et al., 2013; Bessette Gorlin et al., 2016) can result in children not being accepted (Barson, 1998, as cited in Preece, 2009) or being excluded from services (Van Bourgondien & Elgar, 1990). Conversely, given the broad nature of the autism spectrum, some children with less severe ASD may be considered too able to meet eligibility criteria for access to services (Oberheim, 1996, as cited in Preece, 2007). Additionally, respite providers may not have specific training or expertise in ASD, and the respite setting may not be suitable for children with sensory sensitivities (Preece, 2009).

2.8 Current Study

Respite care can be an invaluable support for parents and families of children with disabilities, however, to date there has been very limited research carried out involving parents of children with ASD accessing respite care. A review of the literature did not find any studies that have explored the experience of parents of children with ASD who avail of respite services in Ireland. Given the dramatic increase in the reported prevalence of ASD worldwide, it is hugely important that parents of children with ASD be given a voice to express their need for services and support, and for service providers to give this significant consideration when planning suitable interventions. The aim of this study, therefore, is to explore the experience of Irish parents availing of respite services for their child with ASD.

The primary research question for consideration is

‘To explore parents’ experiences of accessing respite care for their child with autism spectrum disorder.’

This research aims to provide an insight into the unique experiences of parents and families of children with ASD in Ireland. The study will endeavour to explore parents’ perspectives on respite services and identify any challenges they may have faced in relation to accessing respite care. It will also explore the meaning of respite care for the parents, the child, and on the wider family. By understanding the lived experience of parents and caregivers of children with ASD in this country, it will be possible to gain an insight into how services for children with ASD are experienced by families. This research may also highlight specific barriers faced by families of children with ASD when it comes to accessing respite services and may be helpful in the development of respite services for individuals with ASD in Ireland.
Chapter Three: Methodology

3.1 Chapter Introduction

This chapter outlines the rationale for adopting a qualitative research methodology in the present study. It will also outline the research design process and the rationale for the adoption of an IPA framework. The chapter will include a comprehensive account of the sampling procedures employed and a detailed description of participant characteristics. A step-by-step account of the procedures involved in data collection and data analysis will also be provided. Finally, the management of ethical concerns, trustworthiness and credibility of the research, and researcher reflexivity will be discussed.

3.2 Rationale for Research Methodology

The primary aim of the present study was to gain an insight into the unique lived experience of parents of children with ASD accessing respite services. It was felt that a qualitative research design was the most appropriate as it would support the exploration of participants’ experiences, allow the researcher an insight into their world, and explore the meaning that they have attributed to their experiences. From an epistemological perspective, qualitative research is concerned with meaning, understanding how people experience and make sense of the world (Willig, 2013). This type of research takes an inductive, interpretative, naturalistic approach, which aims to further our knowledge and understanding of social phenomena (Morse & Field, 1996; Denzin & Lincoln 2018).

The aim of qualitative research is to explore the lived experiences of people and to generate data that provides a true insight into their lives (Morse & Field, 1996; Silverman, 2014), fitting the central focus of the present study. In contrast, quantitative research is concerned with testing theories by deriving different hypotheses and carrying out experiments or observations to provide evidence to support or falsify these proposed explanations (Pietkiewicz & Smith, 2014). Quantitative research is generally concerned with establishing the number of occurrences, or the volume and size of the associations between factors under study, which requires phenomena to be measured and reduced to numerical values in order to carry out statistical analysis. Qualitative research, on the other hand, aims to collect data in more naturalistic settings, with the participant and the researcher engaging in a collaborative process to produce rich, descriptive accounts of the phenomena being investigated (Pietkiewicz & Smith, 2014).
3.3 Interpretative Phenomenological Analysis

Although several qualitative research methodologies were considered, it was felt that Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2012) was the most appropriate given the exploratory nature of this research. During the initial stages of this research project, the researcher considered utilising thematic analysis (Braun & Clark, 2006). Thematic analysis is a method of identifying, analysing and reporting on patterns or themes in qualitative data, and interpreting these themes to address the research topic (Braun & Clark, 2006; Clark & Braun, 2013). It is described as a flexible approach to qualitative data analysis, as it is not tied to any particular epistemological or theoretical framework, allowing the researcher to work within an essentialist or constructionist paradigm (Braun & Clark, 2006).

Looking to the primary aim of the current research, the researcher felt that IPA more appropriate than thematic analysis as the aim of the research was to gain an insight into the unique, lived experience of each of the participants.

Grounded theory was also given some consideration by the researcher. Grounded theory was originally developed to provide researchers with a systematic, sequential guide to qualitative research and analysis (Glaser & Strauss, 1967; Smith et al., 2012). It is generally concerned with using qualitative data to generate a theory and develop hypotheses to account for behaviours or particular phenomena (Ivey, 2017). IPA was felt to be more appropriate for this study as it would offer a more detailed and in-depth analysis of the lived experience of the participants, which was the researcher’s primary motivation for this project, rather than developing a theory which would account for their experiences. Discourse analysis was discounted due to its focus on the linguistic resources utilised by participants to construct accounts of their experience, rather than attempting to understand how participants are making sense of their experience, which is central to IPA (Smith, 2011). Narrative approaches to analysis were not utilised for the current study due to their central focus on the structure and content of the stories told by participants and how these are arranged chronologically (Creswell, 2013).

The adoption of IPA for this study provided the researcher with a qualitative methodology within which they could explore participants’ lived experience and examine how they make sense of this experience (Smith, 2004). The development of IPA has been informed by the fundamental principles of phenomenology, hermeneutics and idiography (Smith et al., 2012; Pietkiewicz & Smith, 2014). Phenomenology is a philosophical approach, originally developed by Edmund Husserl, which is concerned with the way things appear to individuals
within their experience (Pietkiewicz & Smith, 2014). Within this approach, experience should be understood as a lived process, which incorporates perspectives and meanings that change and evolve over time and is unique to each individual’s embodied and situated relationships to the world (Smith et al., 2012). According to Husserl, science was a ‘second-order knowledge system’, which was dependent on first-order personal experience. To adopt a phenomenological attitude, the researcher needs to move their focus away from objects in the world, and instead direct it towards individual’s associated perceptions and perspectives (Smith et al., 2012). IPA is phenomenological in its approach in that it attempts to explore personal, lived experience and is concerned with the individual’s perception or description of objects or events, rather than attempting to produce an objective account of the objects or events themselves (Smith & Osborn, 2003). In IPA, the researcher’s attempts to understand the participants’ relationships to the world are interpretative, and centre upon the meanings that people attribute to their activities and to the things that are happening to them (Smith et al., 2012).

The second theoretical underpinning of IPA is hermeneutics, which is the theory of interpretation, originally developed to provide in-depth interpretations of biblical texts (Smith et al., 2012). Key contributors in the area of hermeneutics include Heidegger, Merleau-Ponty, Sartre, Schleiermacher and Gadamer (Smith, 2007; Smith et al., 2012). A former student of Husserl, Heidegger built on his initial phenomenological foundations in his descriptions of the dual quality of appearance – with things having a certain, visible meaning on one hand, with hidden meanings on the other (Smith et al., 2012). According to Heidegger, our engagement with the world and understanding of the meaning of things is accessed through interpretation, and the process of interpretation will inevitably be influenced by our preconceptions, assumptions, and past experiences (Heidegger, 1962). Although these fore-conceptions enable our understanding, they can also act as an obstruction in the process of interpretation, where our focus should be on the encounter or event itself, rather than on our preconceived ideas (Smith et al., 2012).

Within IPA, an important concept to note is the hermeneutic circle, which is concerned with the dynamic relationship between the part and the whole, on a number of levels (Smith, 2007). In order to understand any given part of something, you need to consider the whole; to understand the whole, you need to look to the parts (Smith et al., 2012). This describes a non-linear approach to analysis, with the possibility of revisiting and delving further into one’s interpretations (Smith, 2007). In the context of IPA research, this is evident in the iterative
analytical process whereby the researcher moves back and forth between different ways of thinking about the data (Smith et al., 2012). Another important concept to highlight within IPA is the double hermeneutic. While IPA is centred around a person’s perception of events or objects, it also recognises the role of the researcher in the analysis and understanding of the participant’s experience. This involves a double hermeneutic, in that the individual is trying to make sense of their world while the researcher is trying to understand the individual as they are trying to make sense of their world (Smith, 2004). It is important, therefore, for the researcher to be aware of their own opinions, biases and preconceptions, and recognise how these can influence the interpretative process (Smith, 1996). This involves the practice of ‘bracketing’, where the researcher attempts to suspend their judgements and focus on what is actually presented within the data (Smith et al., 2012).

Finally, IPA is idiographic as it initially focuses on the in-depth analysis of one single case and examines the experience and perspectives of the individual in their unique circumstances (Smith, 2004; Pietkiewicz & Smith, 2014). The researcher then moves on to a detailed analysis of each of the cases, exploring them in turn before comparing and contrasting common themes, and producing general statements based on the analysis (Smith, 2004; Pietkiewicz & Smith, 2014). Given the focus on the particular and the emphasis on building an understanding of the meaning of something for an individual, IPA typically utilises small, homogenous samples (Smith et al., 2012) which allows for more detailed analysis (Pringle, Drummond, McLafferty & Hendry, 2011). The IPA framework allows the researcher greater flexibility in their approach to exploring the research question, and the potential to discover novel research areas and topics not previously addressed in the literature (Brocki & Wearden, 2006). The commitment of IPA to the idiographic approach enables the researcher to get an insight into the ‘life world’ of the participant and can help to answer in-depth questions about the individual’s unique experiences (Pringle et al., 2011; Shaw, 2001).

3.4 Application of IPA Methodology

The primary aim of this study was to gain an insight into the experiences of parents of children with ASD and explore the meaning that accessing respite care has for them, their family and their child. IPA was considered an appropriate framework for the current study as it would support the exploration of the lived experience of the participants, allow the researcher to gain an insight into their world, and explore the meaning that they have attributed to their experiences.
3.4.1 Semi-structured Interviews

The primary goal of IPA is to elicit rich, detailed stories, thoughts and feelings from participants about the phenomena under study (Pietkiewicz & Smith, 2014; Smith et al., 2012). Semi-structured interviews tend to be the preferred method for collecting this type of data (Reid, Flowers & Larkin, 2005), although IPA studies have used a number of other methods including postal questionnaires (Coyle & Rafalin, 2000), emails (Murray & Harrison, 2004; Turner, Barlow & Ilbery, 2002), focus groups (Flowers, Duncan & Knussen, 2003), observational methods (Larkin & Griffiths, 2002), and diary entries (Smith, 1999). It was felt that semi-structured interviews were suitable for the current study due to their flexibility which would allow the researcher to explore in depth any topics of interest while also allowing participants to discuss their own personal experiences (Pietkiewicz & Smith, 2014; Reid et al., 2005).

3.5 Sampling

3.5.1 Method of Sampling

A purposive, homogenous approach to sampling was adopted in this study. This involves consciously selecting participants due to their experience, perspectives and insight into the phenomenon being investigated (Smith et al., 2012). In this study, participants were recruited based on the criteria that they were a parent of child with a diagnosis of ASD and that they had availed of respite care for their child over the course of at least one year.

3.5.2 Sample Size

Six participants were interviewed in this study. While some qualitative studies have included large sample sizes, the value of a smaller sample in capturing a richer, more detailed account of individual experiences has been recognised more recently (Smith et al., 2012). Smith et al. (2012) have suggested that a sample of between four to ten participants is appropriate for professional doctorate research studies. For clinical psychology doctoral programmes, Turpin et al. (1997) have recommended that a sample of eight to ten participants is sufficient. As the present study aimed to gain an insight into the unique lived experience of parents and the meaning they attribute to these experiences, it was felt that a smaller size was appropriate.

3.5.3 Inclusion and Exclusion Criteria

Parents of children who had a diagnosis of ASD and who had availed of respite care over the course of at least one year were included in the research. Parents also had to be in a position to provide informed consent in order to take part in the study. Participants would be excluded
from the study if their child did not have a diagnosis of ASD or if they had availed of respite care for less than the minimum period of one year. Additional exclusion criteria were if parents had learning disabilities, verbal comprehension/receptive language difficulties, literacy difficulties, or were non-English speakers.

These additional exclusion criteria were included following feedback from the Research Ethics & Quality Committee (REQC) within the children’s service through which participants were recruited. The researcher consulted with the gatekeeper from the service who was appointed to coordinate the research and it was agreed that the service was not in a position to provide additional resources to support parents with learning difficulties, verbal comprehension/receptive language difficulties, or literacy difficulties to participate. The service was also not in a position to support the researcher in accessing interpreters/translator to allow parents who were non-English speakers to take part. As a result, it was agreed that these additional exclusion criteria be included in the amended ethics application, which was then submitted and approved by the REQC.

3.6 Research Context

This present study was carried out within a charitable organisation that provides support and services to individuals with physical, sensory and intellectual disabilities in Ireland. The service is provided in partnership with a number of organisations including the Health Service Executive (HSE) and various other voluntary agencies. Nationally, the service provides support to 7,500 individuals with disabilities and their families in 40 locations across 14 counties in Ireland. The mission of the organisation is to work in partnership with the individuals who use their services to achieve maximum independence, choice and inclusion in their communities. The organisation is based on the social model of disability in that it is focused on the person, not their disability. It recognises that access, inclusion and equality are basic rights for all people and places the responsibility on society to adapt in order to accommodate individual needs.

Participants in the present study were recruited specifically from the children’s disability services in the Mid-West, which provides therapeutic assessment, intervention and respite services to children with complex disabilities and/or developmental delays across three counties. The service has provided family support and respite services to children in this area since 1997 and currently provides services to over 500 children. The service was developed with the assistance of the HSE West and is provided free of charge. It offers various types of
respite services, including in-home, community-based or group activities, as well as residential respite breaks. The parents who took part in the present study availed of different types of respite care.

3.7 Participants

3.7.1 Recruitment

As mentioned above, participants in the present study were parents of children with ASD who were attending a children’s disability service, based across three counties in the Mid-West of Ireland. A gatekeeper from the service was appointed to coordinate the research and facilitate the distribution of recruitment material. During the initial phase of recruitment, the researcher discussed the project with the gatekeeper and sent Information Letters (Appendix A) to three service coordinators, who were responsible for coordinating and allocating respite services for children with disabilities in the Mid-West. The Information Letter outlined the proposed research project and the inclusion and exclusion criteria for potential participants.

Potential participants who met the inclusion/exclusion criteria were identified by the service coordinators from the list of families that availed of respite services. Invitation Letters (Appendix B) and Participant Information Sheets (Appendix C) were then sent to potential participants by the service coordinators. The Participant Information Sheet outlined the details of the study and what participation would involve. Parents who wished to participate were advised to contact the researcher and arrange a time and date for the interview. This approach to recruitment ensured that the researcher had no access to any confidential or sensitive information about the families attending the children’s disability service.

Participants were recruited to the study between October 2018 and January 2019. Six interviews were carried out, each conducted in one sitting. Given the lack of published research exploring the experiences of parents of children with ASD availing of respite care, the aim of this study was to capture the essence of the lived experiences of this purposive sample, rather than to draw conclusions and make broad generalisations representative of a wider population.

3.7.2 Sample Characteristics

Participants were six female parents aged between 40 and 52 years (mean = 45.7, SD = 4.5) of 7 children with ASD (2 females, 5 males) who were aged between 7 and 21 years (mean = 13, SD = 4.9). Further details on participant demographics are outlined in the table below.
<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Parent Pseudonym</th>
<th>Gender of Parent</th>
<th>Age of Parent</th>
<th>Child Pseudonym</th>
<th>Gender of Child</th>
<th>Age of Child</th>
<th>Child’s Diagnoses</th>
<th>Accessed Respite Care</th>
<th>Type of Respite Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Brenda</td>
<td>Female</td>
<td>44</td>
<td>Molly</td>
<td>Female</td>
<td>7</td>
<td>ASD &amp; Chromosomal condition</td>
<td>2016 to present</td>
<td>In-home</td>
</tr>
<tr>
<td>2</td>
<td>Lisa</td>
<td>Female</td>
<td>52</td>
<td>Thomas</td>
<td>Male</td>
<td>19</td>
<td>ASD &amp; ID</td>
<td>2003 – 2018</td>
<td>In-home</td>
</tr>
<tr>
<td>3</td>
<td>Teresa</td>
<td>Female</td>
<td>45</td>
<td>Luke</td>
<td>Male</td>
<td>13</td>
<td>ASD, ADHD, ODD &amp; Anxiety, ASD</td>
<td>2011 to present</td>
<td>After school group Residential, In-home, Community-based/group</td>
</tr>
<tr>
<td>4</td>
<td>Kate</td>
<td>Female</td>
<td>40</td>
<td>Lauren</td>
<td>Female</td>
<td>13</td>
<td>ASD</td>
<td>2008 to present</td>
<td>In-home</td>
</tr>
<tr>
<td>5</td>
<td>Carol</td>
<td>Female</td>
<td>43</td>
<td>Sean</td>
<td>Male</td>
<td>9</td>
<td>ASD &amp; ID</td>
<td>2017 to present</td>
<td>In-home Residential</td>
</tr>
<tr>
<td>6</td>
<td>Rachel</td>
<td>Female</td>
<td>50</td>
<td>Michael</td>
<td>Male</td>
<td>9</td>
<td>ASD &amp; Chromosomal condition</td>
<td>2014 to present</td>
<td>After school group</td>
</tr>
</tbody>
</table>
3.8 Procedure

3.8.1 Data Collection

Potential participants who met the inclusion criteria and who were interested in participating were advised to contact the researcher. This would allow them the opportunity to discuss the project in more detail and to arrange a suitable time, date and location for an interview. Some interviews took place in a quiet room in one of the services while others took place in the participant’s home.

Prior to commencing the interview, participants were provided with another copy of the Participant Information Sheet (Appendix C) and were given the opportunity to ask any additional questions. Participants were asked to provide written consent by signing the Participant Consent Form (Appendix D) and the limits of confidentiality were discussed. The researcher explained to parents that their participation in the study was completely voluntary and they had the right to withdraw, at any stage of their participation, without any consequences. The procedure for the interview was then discussed and permission was sought to record the interview using a Dictaphone.

3.8.2 Interview Schedule

Semi-structured interviews were carried out according to the interview schedule (Appendix E). Preparing a schedule allowed the researcher to set a loose agenda for the interview, to anticipate any issues that may have the potential to cause distress, and to ensure questions were framed in an open, expansive manner (Smith et al., 2012). The interview schedule was piloted during an initial interview with the first participant. This afforded the researcher the opportunity to become familiar with the schedule and to review the schedule on completion of the interview, in relation to the suitability of questions, the flow of conversation, and opportunities for the participant to speak freely and expand on their responses. Some adjustments were made to the schedule following the pilot interview, with the inclusion of some additional questions and changes to the phrasing of others. When carrying out the interviews, the researcher did not adhere too rigidly to the interview schedule, instead the schedule served as a guide during conversation with participants.

Before commencing the interview, the researcher set out to establish rapport with the participant and ensure they were as comfortable as possible. The researcher attempted to maintain an open, conversational tone throughout the interview, and ensured their role was that of an active listener in the conversation. At times, the researcher probed the participants to gain
a more detailed account of their experiences and follow up on topics of interest. On completion of the interview, participants were given the opportunity to ask any questions they had about the interview process. They were provided with the researcher’s contact details and advised to contact the researcher should they have any further questions. The researcher also informed participants that they could contact their local service coordinator should they have any questions or concerns about their participation.

All interviews were recorded using a Dictaphone and were transcribed verbatim. Interview duration ranged from 46 minutes 22 seconds to 62 minutes 17 seconds (mean length = 54 minutes 44 seconds). Reflective notes were also kept by the researcher throughout the course of the project (see Appendix F for extracts). These reflective notes proved to be useful during the data analysis and final write-up stages of the project, allowing the researcher to personally reflect on the research process.

### 3.9 Data Analysis

Once the interviews had been transcribed, each transcript was formatted using Microsoft Word, in preparation for the analysis stage. The format suggested by Smith and colleagues (2012) was utilised, which consisted of three columns for each transcript. The middle column contained the text from the original transcript. The right column contained exploratory comments from the researcher. The left column was dedicated to the documentation of emergent themes. An example of this layout can be seen in Appendix G. Exploratory comments included descriptive, linguistic and conceptual comments. As suggested by Smith and colleagues (2012), comment types were differentiated using different types of text, with descriptive comments in normal font, linguistic comments in italicised font, and underlining conceptual comments.

The process of data analysis in IPA is a dynamic, inductive, iterative process of description and engagement with the transcripts (Smith et al., 2012). The IPA framework is multi-directional, in that it requires the researcher to continuously shift between different analytical processes, involving flexibility, revision, and creativity (Smith et al, 2012). In order to become familiar with the data and ensure the participant remained the focus of the analysis, the researcher read each transcript several times, listened to the audio-recordings and noted their own reflections. The different stages involved in the analytic process are outlined below.
| Stage 1: Familiarisation with the transcripts | Reading and re-reading each individual transcript and listening to the audio recordings. |
| Stage 2: Exploratory commenting | Initial noting to examine the content of the transcript, identify topics of interest and comment on their meaning. Descriptive, linguistic and conceptual comments are noted. |
| Stage 3: Development of emergent themes | Development of categories, or emergent themes, by mapping the interrelationships and connections between the researcher's exploratory notes and comments and the transcripts themselves. |
| Stage 4: Connecting themes | Emergent themes are drawn together, according to patterns and connections, in order to produce a number of subordinate themes. |
| Stage 5: Moving on the next case | The remaining transcripts are analysed following the same process. In line with IPA's commitment to idiography, each case should be analysed in detail on its own terms before moving on to the next one. |
| Stage 6: Searching for patterns across cases | Patterns across all of the interview are identified. Subordinate themes may be reconfigured and relabelled. A number of superordinate themes are identified. |

*Figure 3.1. IPA Analytic Process (adapted from Smith et al., 2012)*
3.10 Research Trustworthiness and Credibility

In order to ensure the quality and validity of the current study, the researcher consulted Yardley’s four principles (Yardley, 2000) of establishing trustworthiness and credibility in qualitative research, as recommended by Smith et al. (2012). While there are numerous approaches to assessing quality in qualitative research, Yardley’s framework is felt to take a more refined and pluralistic stance, offering an accessible, broad range of criteria which can be applied to different theoretical orientations (Smith et al., 2012). The trustworthiness and credibility of the current study was considered in terms of the following principles: (a) Sensitivity to context, (b) Commitment and rigour, (c) Transparency and coherence, and (d) Impact and importance

3.10.1 Sensitivity to Context

The researcher demonstrated sensitivity to context throughout the research process. During the initial stages of research development, an extensive review of the available literature in relation to the experiences of parents and caregivers of children with disabilities and ASD, and the impact of respite care was undertaken. To gain an understanding of the socio-cultural context experienced by families of children with disabilities and ASD, the researcher engaged with relevant documents, publications and newspaper articles in relation to policies, legislation, funding and service provision in Ireland. The researcher also demonstrated a commitment to understanding the theoretical underpinnings and central concepts of IPA before commencing with recruitment of participants and data collection. Sensitivity to context was maintained during the recruitment and interview process. The location for the interviews was considered, with participants encouraged to choose the location they felt most comfortable with in order to minimise any potential distress. During the interview, the researcher acknowledged the socio-cultural context of the participant at the outset and noted the unfamiliarity of the researcher to the participant, in an attempt to establish rapport. Sensitivity to context remained an important consideration during the data analysis stage of the study. Given that IPA is idiographic in its approach, each interview was analysed in detail individually before findings were collated across all six interviews (Smith et al., 2012). In order to demonstrate sensitivity to the data that was collected, the researcher ensured to include a considerable number of verbatim extracts from participants, to support the interpretations being made.
3.10.2 Commitment and Rigour
The researcher demonstrated commitment to the research process through their continued engagement with the research material and the literature, and their efforts to develop their competence and skills in the IPA methodology, endeavouring to achieve a robust application of the methodology. Throughout the interviews, the researcher attempted to ensure that the participant was comfortable and attended closely to what each participant was saying. The researcher demonstrated rigour in their design of the research, including the selection of an appropriate sample, the development of the interview schedule, and in their approach to data analysis. The researcher allowed appropriate time to immerse themselves in the transcripts, in order to engage fully with the data collected and draw conclusions based on these interpretations. Attendance at research workshops and discussions with other researchers utilising IPA for their doctoral research further enhanced the researcher’s commitment and rigour over the course of the project.

3.10.3 Transparency and Coherence
The researcher attempted to ensure transparency and coherence in this study by detailing every aspect of the data collection and analysis stages of the project, as well as providing extracts of the analytic process (Appendix F) within this report. Coherence was demonstrated through the researcher’s efforts to ensure a ‘good fit’ between the primary research question, the underlying theoretical principles of IPA, and the methods of data collection and analysis. The researcher also attempted to present the findings of the research in a coherent manner, with a clear narrative style used throughout the report, and descriptions of the themes and associated interpretations presented logically to the reader. The researcher remained cognisant of the importance of transparency and coherence throughout the course of the project and ensured that all of the data was filed in a logical, consistent manner. This ensured there was a clear chain of evidence which could be followed from the project development stage right through to the final report. In order to further enhance transparency and coherence, an independent audit of the data trail was carried out by a peer, which examined the accuracy of transcripts and the credibility of the final report. The completion of a reflective journal throughout the research project was also helpful as it allowed the researcher to note their thoughts, reflect on the process, and was consulted during the preparation of the finalised report.
3.10.4 Impact and Importance

The aim of this study is to provide an insight into the lives of parents of children with ASD in Ireland, particularly in relation to their experiences of accessing respite services. Given the lack of published literature in this area, it is hoped this study will serve as an initial step towards a greater understanding of the lived experience and support needs of this particular group. This research can give rise to a greater understanding of what it is like for parents of children with ASD and how they experience availing of additional support to care for their child. As the rates of ASD diagnoses continue to rise, services will likely face a significant increase in the demand for additional support from families living with ASD. Exploring parents’ perspectives of service provision may also be helpful when looking towards the planning and development of services for individuals with ASD in the future.

3.11 Reflexivity

As previously discussed, although the primary concern of IPA is centred around a person’s lived experience and the meaning they give to this experience, it also recognises that analysis is a ‘joint product of the participant and the analyst’ (Smith et al., 2012). IPA acknowledges the impact that the researcher’s own beliefs, preconceptions and past experiences can have across all stages of the research process, and that this has the potential to act as a barrier in the analysis and interpretation of data (Smith, 1996; Smith, 2004; Berger, 2015). By engaging in reflexive analysis of their own role in the research and openly acknowledging their assumptions and understandings at the outset, the researcher hoped to minimise the impact of this during data collection and analysis.

The researcher was conscious of their role as a Trainee Clinical Psychologist, and the potential impact this may have had on the interview process and on their interpretation of the data. The researcher’s own personal interest in the topic arose from their previous experience working with parents and children with ASD in an educational setting. The topic of additional supports for families of children with ASD had resonated with the researcher due to their experience of working closely with families and experiencing first-hand many of the challenges they faced. This curiosity into how parents manage caring for their child and how they experience accessing respite supports may have influenced the researcher during the analytic stages of IPA. As a result, the researcher felt it was beneficial to consider the present study in relation to Yardley’s four principles (Yardley, 2000), in order to minimise the impact of this and ensure trustworthiness and credibility of the research.
3.12 Ethical Considerations

Ethical approval for this study was obtained from the Research Ethics & Quality Committee in the children’s service through which the participants were recruited (see Appendix H).

3.12.1 Informed Consent
Informed consent was sought from participants prior to data collection. Participants were given a copy of the Participant Information Sheet (Appendix C) to read and were asked to sign the Participant Consent Form (Appendix D). The consent form ensured that parents had given permission to participate in the study and have their interviews audio recorded. In addition to the signed consent form, the researcher ensured that verbal consent was sought from each participant prior to the interview, and that participants were given the opportunity to ask any questions they may have had in relation to their participation. Participants were informed of their right to withdraw from the study following the completion of the interview, by contacting the researcher and having their data removed. Participants were also assured that their decision to participate in the research was entirely voluntary and would have no impact on the service they received.

3.12.2 Confidentiality and Anonymity
Participants were informed that all data collected would remain confidential and anonymous, as both themselves and their child would be allocated a unique pseudonym and only the researcher would have access to the coding sheet which noted each pseudonym. Any identifiable information in relation to the participant, their child, their family or the service providers was removed from transcripts. The researcher also discussed the limits of confidentiality with participants, in relation to their own safety and that of their family and any others involved. Following each interview, the audio file was transferred on to a password-protected computer, where each file was encrypted, and password protected. The audio file was then permanently deleted from the recording device. Transcripts were reviewed by the primary researcher only, apart from the independent audit of analysis in which a review of transcripts was carried out by a peer.

3.12.3 Potential Distress
Given the focus of the research, the potential for distress during the interview process as well as in the immediate aftermath, was recognised by the researcher. At the outset of the interview, the researcher advised participants that they could request the termination of the recording at any point if they felt distressed and offered them the opportunity for breaks during the process.
if needed. During data collection, the researcher attempted to remain sensitive and responsive to the participant, in order to recognise any signs of emotional distress. On completion of the interview, the researcher carried out a verbal debrief with each participant. At this point, participants were reminded of the researchers contact details and advised to get in touch should they experience any distress. They were also advised to contact the respite service coordinator should they have any concerns or experience any distress following their participation.

3.13 Conclusion of Chapter

This chapter has provided a detailed account of the qualitative research design, the IPA framework, and data collection and analytical procedures employed in the current study. Ethical concerns, trustworthiness and credibility of the research, and researcher reflexivity have also been addressed in the context of this research.
Chapter Four: Results

4.1 Introduction

Following an extensive period of familiarisation with the data, involving transcribing, re-reading, listening to the audio files, and analysing the data, the researcher identified several themes within the six interviews. The following chapter will discuss each of these in detail and outline how they relate to the primary research question, which aimed to explore the lived experience of parents accessing respite care for their child with ASD. Quotes are included throughout to provide the reader with an opportunity to hear the voices of the participants while analytical comments outline the researcher’s interpretation of each theme. Direct quotes are italicised, with a sequence of three dots used to indicate the removal of any additional, unnecessary text. Some minor changes have also been made to improve readability, including the removal of some repetitions, minor hesitations by the speaker, and utterances such as ‘eh’. It is hoped this will enhance the clarity of quotes, highlight the meaning associated with each, and provide readers with a view into the lived experience of the participants. Any potentially identifying material has been altered or removed and the pseudonyms noted in the Method chapter have been used consistently to preserve the anonymity of participants. This chapter also includes several reflective boxes, which aim to give the reader an insight into the researcher’s personal thoughts and reflections throughout the analytic process.

4.2 Overview of Research Findings

Five superordinate themes emerged from the interview data. These were ‘Living with ASD’, ‘The Respite Worker’, ‘Role of Respite’, ‘Emotional Conflict’ and ‘Service Provision’. Each of these superordinate themes incorporated several interrelated subordinate themes, which are outlined in the figure below. Exploration of these superordinate themes and their associated subordinate themes will form the basis of the following chapter, with the inclusion of illustrative quotes from the transcripts throughout.

It is important to acknowledge that the identified themes provide one possible account of the experiences of parents of children with ASD who avail of respite care. The themes presented do not fully account for each individual participant’s entire experience as they are discussed in relation to their relevance to the research questions under exploration. These themes represent one researcher’s subjective interpretation of the data, and it is important to recognise the potential influence of the researcher’s preconceptions and experience on this interpretation.
Figure 4.1: Graphical Representation of Research Findings
4.3 Living with ASD

Although the primary focus of this study was parents’ experience of accessing respite care, many participants spoke at length about the challenges associated with living with ASD. For some, the diagnostic process seemed to have stayed with them, with parents recalling their initial shock and their subsequent struggle to adjust. The demands of caring and the impact of ASD in day-to-day life were also frequently discussed.

4.3.1 Diagnosis and Adjustment

During Brenda’s interview, she described how receiving a diagnosis of ASD for her daughter Molly came as a total shock:

‘It actually never dawned on me that autism would be an issue and I thought they were going to tell us that we were very bad parents … When they said it, they just whipped a blanket from under me, a rug’

This captures the enormity of this moment for Brenda and highlights the stark contrast between the expectation of being told she was a bad parent and a diagnosis of ASD. While things appear to have improved for Brenda’s family, the period surrounding the initial diagnosis was ‘up there with death with stress’.

The diagnosis also seemed to have a negative impact on Brenda herself, causing a shift in her own perspective and behaviour towards her child:

‘I was just in a complete bad place … because of it, and … then I was very protective over her because, I just, I just, I changed’

She described her continuing struggle to adjust to Molly’s ASD, which is likely impacted by the doubt that exists in her mind:

‘I don’t think I’ve adjusted yet … having that thought in your head always puts a doubt in’

For Rachel, the initial suggestion of ASD was met with similar shock, even though she acknowledged some concerns about her son’s development:

‘And I was in shock. Didn’t want to accept it … I was terrified … there’s no way he could be. Even though I did think there was something wrong’
The process of adjustment was also described by Lisa, as she recalled her efforts to find a treatment that made a difference for her son:

‘I travelled to the North, to England, to the States ... I went on courses, training courses, workshops, and I sought every intervention that I thought would make a difference ... I suppose in one sense you don’t verbalise it, but you’re looking for the cure’

After years of trying every different type of intervention she could, Lisa recalled the moment of realisation that there was no magical cure:

‘And there isn’t one, you know. Autism isn’t going away’

This led to a shift in her perspective and Lisa expressed regret that she had focused on the search for the ‘cure’ rather than accepting her son’s ASD and trying to build a meaningful life for him:

‘If that was what somebody told me when he was diagnosed, that’s the end game ... that would have been the kindest and most informative thing somebody could have done for me. Instead of giving me a list of therapies’

Carol, on the other hand, appeared to take quite an active role in seeking a diagnosis for her child. While she described a similar reluctance to accept an initial suggestion of ASD, it appears she adopted a very proactive approach:

‘I was just scrawling autism across everything, even though I had no diagnosis ... I said, you know, time is the essence, you need to get a move on there’

She expressed her frustration with the service in their reluctance to confirm the diagnosis of ASD and acknowledged the contrast between her approach and that of other parents:

‘I said, it’s not much good when I’m trying to get him in somewhere ... Here we are pushing for it and most parents wouldn’t be ... I’m not here for the craic of it’

This could reflect a strategy for coping with her concerns about her child, as it allowed Carol to feel like she was doing something to help.

Following their diagnosis, some participants expressed a sense of isolation and abandonment, evoking the image of a door being closed in their face, leaving them on the doorstep:

‘And then they walk out and that’s what you’re left with’ (Brenda)
‘You get your diagnosis, you’re out the door … surely to god they could have a booklet there’

(Carol)

Brenda spoke about how overwhelmed she felt when she was told about her daughter’s diagnosis:

‘I was completely blank on that day … I was like, nah, I don’t care what’s happening’

Once she was ready to talk about the diagnosis and look for support, she felt there was nobody there to give advice or guidance:

‘I think that when a child is diagnosed, there is no … there’s nobody there to help you’

Similarly, Teresa recalled the sense of initial confusion, outlining how valuable it was for her to have an advocate to guide her through the process:

‘Overwhelmed, the amount of information … where do I even start … I don’t know what I’d have done … if I didn’t have … an advocate’

4.3.2 Challenge of Caring

A common thread throughout the interviews was the significant challenges parents faced in caring for their child with ASD. The initial sense of isolation that some parents felt following their child’s diagnosis seemed to continue.

‘It can be a bit isolating … generally, disability does kill off a lot of your own social life … literally having no life’

(Teresa)

Similarly, Kate described the sense of isolation she experienced caring for a young child with ASD:

‘When the child was young, it felt very isolating but as they go to school, they are staying longer in school, so you are not left just you and the child’

Many parents spoke about the need for constant vigilance due to their children’s behaviours, and the impact this can have on their wellbeing and relationships:

‘You have to watch him 24-7 … he could do anything … you literally cannot sit down … you’re wrecked, you haven’t got sleep and it’s a full day ahead with him’

(Carol)
‘You are … completely stuck with Lauren … the room where she was is where you had to be because if you are not there, she will turn the place upside down’  (Kate)

‘If I took my kids to some place, like a play area, I had to patrol’  (Lisa)

Teresa described how her son’s high level of activity often left her completely exhausted:

‘He’s squeezing you, he’s slapping you, he’s rocking on the chair, he’s falling back … and that could go on all night … by the time 9 o’clock comes, you can’t string a sentence to each other, my brain is shutting down’

For Kate, the need to constantly watch her daughter also presents a challenge when it comes to spending time with her son:

‘When they were very young, they could really want attention … Lauren might not look for it, but my son would be looking for it, but you’d just have to be there … because you have to watch her’

With such constant demands on their personal strength and caring abilities, things can get too much for parents. Brenda described how frustrated she can feel with her daughter and the need to take herself away to manage this:

‘I’ll go out the back to calm down coz I just itch to shake her and then she’ll come out and she’s like ‘what’s wrong with you’ and I’m like go away. Just go away. I’ll be outside holding the door just saying leave me alone, just leave me alone … she’s hard work’

This is an incredibly honest account of her struggle to cope with her daughter’s behaviours and highlights how close parents can get to breaking point when faced with the constant demands associated with their child’s disability.

Similarly, Rachel described high stress levels in her home, due to her son’s emotional lability:

‘It’s stressful at home, it is, I’m constantly tense. It depends on Michael’s mood, my God, it can turn into hell’

She noted that the family is on ‘eggshells constantly’ waiting for Michael to hit off, which she acknowledged was very difficult at times.

The following quote from Teresa gives a humbling insight into the reality of caring and the heavy burden that this can place on caregivers:

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‘For everything that I do that’s taken the life out of me, taken all my mental energy, all my mental strength, my physical strength, it’s taken its toll’

4.3.3 Impact of ASD

A number of participants spoke about the impact that ASD can have on everyday life, with many noting the differences between their child’s life and that of a typically developing child. Kate described how her daughter’s tendency to run away means that she can’t visit friends:

‘She can’t go to a friend’s house ... you couldn’t trust her, she could run away out of the house, she’s a danger of running, even now that she’s 13’

Similarly, Teresa recognised the difficulties her son has in relation to participation in social activities, which she feels is the reason that he needs respite:

‘If he’d no issues ... he could be over at friends’ houses and off doing football ... but sure that was the whole reason he needed the break out ... coz he doesn’t have that capacity to be able to take on those things’

During her interview, Carol mentioned the day-to-day struggles she faces, trying to find appropriate activities and places to bring her son:

‘There is nowhere for them ... the day was so long, there was nowhere you could bring him in the middle of the day because every place was too busy’

The sensory sensitivities and behaviours associated with ASD can also present difficulties for children in school, as Rachel noted in her interview:

‘He couldn’t cope with that size of class, he couldn’t cope with the noise ... it was all too much for him ... one day he had to change seat and he just went under the table screaming and roaring ... he found it very traumatic’

Brenda, on the other hand, expressed her frustration with the lack of understanding of her daughter’s teacher:

‘It’s trying to make her teacher understand that, because she’s keeping it together in school, she breaks down at home and it’s because she needs more in school ... She just doesn’t get it’

It seems that there is often a mismatch between the environment and the child, which in some ways could add to the sense of isolation already mentioned above.
For Kate, the behaviours associated with her daughter’s ASD mean that she is not comfortable with anyone else taking her:

‘Going to park or going to the shopping like, you know, I couldn’t let her go with someone else ... Even now, she’s 13, she couldn’t go with anyone else, because she’ll walk away’

As a result, Kate herself is unable to get a break. Without the option of informal support, it is up to the parent to take sole responsibility for the care of their child, which is likely to be interrelated with the burden associated with caring.

 Reflective Box
Throughout the interview process, I was struck by the level of emotion that parents seemed to continue to experience in relation to their child’s diagnosis of ASD. While the impact of diagnosis was not necessarily the primary focus of the project, it was mentioned by many parents during their interviews, so I felt that this was a particularly important area to explore in more detail. It appeared that parents felt that it was important for these experiences to be heard and acknowledged. Despite the time that had passed since some of the parents had gone through the assessment process, there was still a sense of doubt for some, or a reluctance to completely accept the diagnosis and hope that professionals may have got it wrong. For me, this raises important questions about the diagnostic process and the quality of the information that parents are given. It also caused me to reflect on the importance of parents feeling ready to accept what they are being told and the need for support through the process of adjustment to their child’s diagnosis.

4.4 The Respite Worker

The second superordinate theme to emerge from the data related to parents’ perspectives of the person providing respite care for their child. This theme contains three interrelated subordinate themes: Trusting Relationship, Awareness and Understanding of ASD, and Caring Nature, which will be discussed below.

4.4.1. Trusting Relationship

Almost every parent referred to the importance of building a close, trusting relationship with their respite worker.
‘You don’t hand over a 3-year-old, your 4-year-old who’s non-verbal very easily ... it’s very necessary to actually know each other very well and to have that kind of comfortable relationship’

(Lisa)

Kate highlighted the importance of the bond between the carer and her child:

‘I knew she would be safe with the lady ... Lauren was attached to her. The lady knew Lauren’s ways. I knew if they went away somewhere that she’s going to look after her’

For both parents, the respite worker also acted as a source support for them as well as providing care for their child:

‘She was a great support just in terms of parenting him. She was a young girl but she was still very helpful in that sense’

(Lisa)

‘This lady, I could talk to her, we could talk ... And she totally understood me, understood Lauren’

(Kate)

Given the demands associated with caring for a child with ASD and the sense of isolation experienced by many parents, this additional support is likely to be an invaluable resource.

A common cause of frustration was the frequent turnover of staff with no warning:

‘The change of personnel was another massive problem. Constantly changing people’

(Lisa)

‘My God, they came and went like the weather it was shocking ... it was just disruptive for Luke ... it was putting him off, he had to get to know a new person all over again’

(Teresa)

Lisa spoke about how the respite workers rarely said goodbye to her son:

‘It was actually Thomas who showed me ... people came and went and never said goodbye ... they were people who were important in his life at the time and he never got to say goodbye to them’

She described how children with disabilities, like her son, seem to constantly have different people coming in and out of their lives, which for her feels quite ‘intrusive’.

During her interview, Kate expressed her own reluctance to have a new respite worker:
‘I got so used to this lady … if someone else comes … They might not get along and I don’t want someone taking her out if they don’t get along … I didn’t want someone to come and then I didn’t like that person’

(Kate)

There seems to be a real contrast between the attitudes of the families and that of the service, who seem to disregard the important position respite workers hold in the lives of families and children with ASD. According to Lisa, it’s quite an ‘intimate relationship’, so an unexpected ending or the absence of any goodbye is likely to cause some distress for both parent and child.

Carol expressed concerns that there did not appear to be any attempt made to match suitable carers with specific children:

‘The person that’s taking them, they just assign whoever to you … This is the person you’re getting, off with you’

While she believed that most carers were trustworthy, she did express concerns that parents were not given any opportunity to get to know their respite worker.

Many parents spoke openly about their sense of reliance on their respite worker, highlighting the importance of having a close, trusting relationship with them. Teresa described the challenge of having to work around her respite worker’s schedule:

‘Very much working around her timetables and college schedule … over time there was no routine and we couldn’t plan anything … You were always waiting to see would it change’

She expressed her worry that the respite worker would leave if she raised these issues with her:

‘What will we do, if we say it again she’s going to be gone because that was just the way it was going. There was no continuity of care, it was turnover after turnover’

Similarly, Carol spoke about her reluctance to ‘rock the boat’ due to her reliance on her care worker:

‘You’re relying on them, so you are trying not to rock the boat either as well … you couldn’t make an appointment for something, because it’s not, it’s up to them to show up’
The importance of the respite worker in the lives of many parents and children with ASD is captured in this quote from Brenda, who outlined how, if the respite worker ‘isn’t there, and something huge comes up, there’s nobody’.

4.4.2 Awareness and Understanding of ASD

Many participants highlighted the importance of the respite worker having training and experience in the area of ASD. Participants spoke about their need to feel confident in the respite worker’s skills and described the difficulties they had encountered when the carer was not familiar with ASD.

On several occasions, Kate mentioned a lack of understanding of ASD in others. Due to the variability in its presentation, ASD is often overlooked and misunderstood, and Kate feels that the lack of any obvious physical symptoms adds to this:

‘Nobody understands because I think, with autism, because the children, they look so normal physically that people think … the parent is being overprotective … so they just think, oh maybe the mother is too protective…so they really, really don’t understand’

Her repetition of ‘protective’ suggests Kate has heard this before from others, which could lead to a need to justify her concerns about her daughter and the level of vigilance she feels is required when watching her. It seems the full extent of her child’s needs is not always acknowledged by others, and she herself may also feel misunderstood in her role as a parent and carer of a child with ASD.

For Kate, it is essential that the respite worker accepts her daughter’s behaviours are part of her ASD and does not judge her or assume she is intentionally misbehaving:

‘You need somebody who understands the child or somebody might give out to her … you don’t want the child to go away with someone who doesn’t understand … who might be thinking what a bold child this is’

According to Teresa, some of the workers ‘didn’t have the best skills for the job’, as she recalled negative experiences with one particular care worker who didn’t seem to fully understand the nature of her son’s diagnoses:

‘She had … no real understanding of ASD. She was pulling me out there when he would come back and she was saying his manners were very rude today … he has autism. You’re lucky if he grunts’
Teresa acknowledged the impact this had on her, and her discomfort with such negative views of her son:

‘I was just so used to it over the years but draining … first I felt like my child was being referred to like he was a monster of sorts … It sounds dramatic now, but we all know what his issues are, that’s disability, it’s ASD’

This conveys the sense of disappointment and frustration that parents like Teresa must experience, when the service that is there to offer them support displays such a lack of understanding towards their child.

For Carol in particular, the fact that her current respite worker has a child with autism herself is very beneficial, as she feels that ‘you can’t explain it, you have to live it’. If people ‘don’t have any dealings with autistic kids’, she feels they really struggle to understand it and can find the associated behaviours very difficult to manage.

She also expressed concerns about the recruitment process and training offered to respite workers, and outlined that the role of a respite worker is not a job that just anybody can do:

‘They really need to … train a bit better you know … I just think it’s too serious a job to just let anyone do it … It’s not just a case of, oh Garda vet them, and they’re grand’

Similarly, Lisa outlined her views that the range of skills needed to provide respite should be acknowledged by the service and that the role of respite worker should be respected and valued accordingly:

‘The person who works in the respite service really shouldn’t be the lowest grade, minimum wage person. This is somebody who needs to be highly skilled, who needs to know what it is that motivates that person, hooks them, keeps them on task, grabs their interest … It needs to be a highly, highly observant person who can use all of that in order to use the four hours highly effectively’

For parents who devote all their time and energy to the care of their children, it is clear that the role of respite worker is a hugely valuable and privileged position to hold, as they are handing over the care of their child. As Kate outlined, very often the respite worker is the only form of additional support that parents can avail of, so the hope is that this person is trained and capable of providing the necessary care:
‘Anyone who has children with special needs needs a break and the only break you can get is with someone who knows your child. You cannot drop your child to a friend … You just need respite by professional people who know how to deal with children with special needs’

4.4.3 Caring Nature

Several of the parents mentioned the importance of their respite worker demonstrating a caring nature and having the right personality to fit the role. According to Teresa, the respite worker is ‘gold dust’:

‘Getting the right workers into the right jobs because some of them, they really just have no business working in special needs’

Speaking about her experience with a previous respite worker, Brenda expressed the concerns she had about her attitude and behaviour towards her child, which seems to suggest the worker may have been impatient and was not willing to tailor her approach to suit Molly’s needs:

‘She wasn’t, she didn’t come across kind…so when you’re harsh…if you correct Molly in a critical way, it will send her into a spiral’

Similarly, the following quote from Lisa shows how important it is for parents to feel that their respite worker will devote their complete attention to the child, and give them the appropriate level of consideration and respect:

‘They’re my focus so they should be your focus, for those 4 hours that’s your focus. And some people are great at that and some people are not so great at that, they can be disrespectful in the way they might address them’

A couple of the parents expressed their views that providing respite care is not just a means to earn money, that workers need to possess the right qualities and show dedication to their role:

‘I just think they need to get someone whose made for it, you know, that has the personality and that’s able, not someone who just wants the money … who just needs a bit of a job’

(Carol)

‘Deep down I feel they weren’t able for the challenge of managing Luke … they weren’t cut out for it, it was just money on the side for them’

(Teresa)
According to Teresa, the two respite workers her son has now are like ‘angels sent from heaven’ as they are ‘passionate about what they do’ treating their role ‘like a vocation’.

While parents have highlighted the importance of having a good relationship with the respite worker and having a worker with a good understanding of ASD, one of the most important qualities is undoubtedly a caring nature, so parents can feel confident that their child is being appreciated, respected, and taken care of:

‘That cares about him, that’s the most important thing. Someone that cares’ (Carol)

4.5 Role of Respite

The third superordinate theme to emerge from the data was concerned with the role of respite in the lives of families and children with ASD. Parents spoke at length about the importance of respite for themselves and their family, allowing them to get a break, but also recognised the opportunities it presented for their child. Three interrelated subordinate themes were identified; A ‘Break’, Opportunities for Learning and Development, and Evolving Role, which will be discussed in the following sections.

4.5.1 A ‘Break’

For many parents, respite offers them a break from the demands of caring for their child:

‘It was a good break ... you could go and lie down and read a book or just leave them. Go to another room and just close the door’

(Kate)

‘It’s an absolute life saver ... to know that you’ve 3 hours there, that he’s gone ... you can do whatever you want to do ... It makes such a difference’

(Carol)

‘The respite care is a chance for me to relax as well’

(Rachel)

During her interview, Brenda expressed how important respite is to herself and her husband, as it allows them to spend time together:

‘It’s really important actually to us ... asking for an overnight ... Oh my god, it was just bliss! It was awful to come home ... we can go and have a conversation and not worry that we had to come home’

For couples raising children with ASD, balancing the needs of their child with other responsibilities can be very difficult, and often their relationship can suffer. Having time away allowed Brenda and her husband to reconnect with their roles as adults and as a couple, without
the worry of going home to resume their caring role again. Her acknowledgement that it was ‘bliss’ to be away and ‘awful’ to come home, gives an insight into the reality of caring for a child with ASD and how important it is for parents to experience a sense of relief from time to time.

Some of the parents outlined how respite not only acts as a break for themselves, but also for their other children, allowing them time together while their sibling is with their respite worker:

‘It meant time for him ... Lauren took most of the time, all of the time, even now ... because there are so many things to deal with with her ... the brother is not getting as much time’

(Kate)

‘Having the 3 of them ... it was a lot of work so it was completely respite, one was gone and I could do something with the other two’

(Lisa)

Additionally, Kate recognised how respite can also provide a break for the child themselves, giving them time away from their parent:

‘I could have time for myself, not constantly watching her ... she needed it. A break for her to go somewhere, to be with someone else instead of being with me’

For Teresa’s family, respite care was initially granted when the family was at breaking point:

‘I suppose would you use the word crisis ... everybody needed a break and we were definitely a family that was right for respite’

In situations such as these, respite can offer carers and families the opportunity for rest and rejuvenation and, according to Carol, helps carers to feel that they can carry on:

‘It makes life so much easier ... you’re better able to cope, mentally like. You aren’t as cross and as angry, as tired. You know you’re going to get a break from it, it keeps you going’

She expressed how much of a difference even a few hours can make to parents, as it gives them a ‘breather’ from having the child there:

‘It’s unbelievable. I know people would say oh god, it’s only 3 hours but I mean, even mentally, to know you’re getting that break is just, it’s just unreal’
Similarly, Rachel outlined how she looks forward to respite every week as it allows her one
evening when she does not have to do homework with her son, which is particularly stressful.
This break enables her to feel as if she can keep going when things are difficult:

‘So what I think to myself, right, you’re facing a hard week ... I say okay Monday, I
 can do Monday, Tuesday, I have a break, and then it’s only Wednesday and Thursday
coz they don’t get homework on a Friday, I can do this Lord. It’s that hard’

This series of quotes illustrates how vital this service is for parents who are feeling
overstretched in offering a sense of relief, even temporarily, which can help them to continue
in their role as carer for their child.

4.5.2 Opportunities for Learning and Development

While many of the parents acknowledged the role that respite plays in giving them a break,
they also recognised the potential for respite to provide opportunities for their child to learn
and develop new skills.

A common thread throughout the interviews was the idea that respite care could allow a child
the opportunity to develop friendships and build social skills. Several parents spoke about the
struggles their child experiences in relation to their social-emotional development, compared
to typically developing children:

‘He’s never been invited to a birthday party, he doesn’t have friends that same way as
other people’ (Lisa)

‘She doesn’t really have any friends, just like other teenagers so I just think the friends
she can make are other kids with autism’ (Kate)

‘He wasn’t coping with neurotypical children as such, he wasn’t making friends with
them in Junior and Senior Infants. He was on his own and they were out in the yard’
(Rachel)

For both Kate and Rachel, respite care is viewed as a means of supporting their child to interact
with other children with ASD, while also allowing them to have fun:

‘He might meet children who are similarly affected ... which as the reason I went for it
... give him some support’ (Rachel)
‘The way people meet up, go to friend’s house, she can’t do that … if she got respite where she went somewhere with an adult … and met with other kids with autism and maybe do activities, it would be good for her’

(Kate)

It seems that there is a sense of security or safety in interacting with other children with autism, particular since these parents have witnessed the significant struggles their child encountered when trying to relate to typically developing children.

In contrast, Lisa identified respite care as an opportunity for her son to develop his independence, and to build a relatively normal life:

‘Those respite hours should have been used for him to have a more normal life, as an independent child … learning about independence and learning about separating from your family … developing skills out there in the world, almost as an anonymous person’

According to Lisa, her son does not need a break through respite, instead he needs opportunities to spend time away from her, ‘to meet other people, try new skills’. She appears reluctant for her son to be grouped with other children with ASD, instead she feels that he should be supported to become an independent individual, who is an active participant in the world.

Teresa expressed similar goals for her son, hoping he would have the opportunity to become more involved in his community, but she feels that the service is not structured to support this:

‘Respite’s job would just be to facilitate him linking with the community through meeting friends, I think if they could take away all that red tape in and around that, it would be brilliant’

During her interview, Kate discussed the role of respite in building her daughter’s daily living skills and teaching her how to behave in various situations:

‘It trains her, it’s good for her … they were part of, kind of therapy for her. How to behave in a shop, how to behave in the playground … she had to be out there, doing all these things to learn’

Lisa also recognised the therapeutic role of respite, in consolidating and practicing skills that the child is learning in school, or through various interventions:

‘Respite could play a massive, massive role in that. In terms of being out there and translating skills from the classroom or that are being taught at home or through therapies, in a natural environment’
It seems that parents value the break they get during respite care, while also hoping their child’s time at respite is enjoyable and beneficial to their wellbeing and development. The following quote from Kate highlights the hopes that many parents likely have for their child with a disability, and how respite can support this:

‘They should be able to do anything which other teenagers do but what they need is to be minded ... because they are still struggling. So ... if people are providing respite, they should be taking them out and about ... so that they know how to work their way in life’

4.5.3. Evolving Role

Participants also spoke about the evolving role of respite, as their child grows and their needs change. For Lisa, respite initially acted as a break for her, when her son had more significant care needs. Now that her son has grown, Lisa feels the focus needs to shift away from her needs to those of her son:

‘When they’re 3, 4, 5, and you’re in the middle of a separation, it genuinely is respite ... before he got out of nappies and all of that, it was a break for me. But ... it’s not about a break for me, it’s about building on skills for him’

The service should look different at various stages of the child’s development and should aim to respond to the changes over time, offering meaningful support to the child and the wider family:

‘I think, that what it is, is going to look very different throughout 0-18 ... whatever system of respite there is should be well able to manage that but in a very structured way. That it doesn’t come as a surprise that, at age 6, he doesn’t want to go to the play centre anymore ... like all the learning that should have been gathered at this point, should be put into a system that should be highly responsive’ (Lisa)

When children are younger and their care is more physically demanding, respite can offer parents a much-needed break to relax and recharge; as they get older and need less physical care, the focus of respite should shift to their own needs.

The evolving role of respite care was also recognised by Kate. Now that her daughter is a teenager, she feels that the type of service she receives should change to group respite, which would facilitate the development of social skills:
'There has to be age-related respite ... when the children become teenagers, it’s more about social skills, more meeting with other kids ... They should try to bring them together as part of the respite'

For teenagers to benefit from respite care, the goal should be to meet their needs and support them in whatever way they feel would be most helpful:

'Teenagers with a disability, do not want respite ... so, that needs to be much more about them ... maybe what they want is to go to the local GAA club but the GAA club won’t have them unless they have somebody there to supervise ... so maybe it needs to be something like that, that is supported'  

(Lisa)

For Teresa, however, the rigidity of the service and their failure to respond to her son’s evolving needs meant that respite no longer served a purpose:

'David ended up not really needing it or wanting the service anymore, he kinda found his feet ... so the hours at that time for David were just not really ... whether they were necessary or not suitable, I don’t know which word you’d use ... He could have done with getting something but ... the rules around it were too rigid'

This quote illustrates a certain level of confusion for Teresa, as she felt that her son could have benefitted from respite but was unsure whether the service was necessary or suitable for his needs. Her statement about the rules being too rigid, on the other hand, has quite a definitive quality to it, and relates to her earlier point about the ‘red tape’ surrounding the provision of services.

According to Lisa, a responsive respite service that recognises the need to evolve with the child would allow families and the service itself to monitor and review the child’s progress, and plan towards the future:

‘Taking someone for 0-18 and actually being able to say at the end of the day we started here, this is where we ended up, and look at the progression we made ... There should be reviews, there should be meetings, there should be regular consultations’

4.6 Emotional Conflict

The fourth superordinate theme to emerge from the data was related to the emotional conflict that many parents seem to experience when accessing respite services for their child. Parents described a sense of fear associated with respite care, and some expressed feelings of guilt for
choosing to avail of respite services. Many of the participants also referred to episodes of inner conflict and uncertainty about their decision to avail of respite care. Finally, some of the parents described feeling as if they had to ‘toe the line’ to avoid jeopardising their respite care.

4.6.1 Fear

While accessing respite care is viewed positively by many parents, some have described the sense of fear that accompanies this. The lack of clarity about the allocation of respite hours appears to cause unease in parents, who report being afraid that their respite will suddenly be taken away. Brenda described how she is reluctant to ask any questions of the service due to her fear that they could change their decision about her eligibility for respite care:

‘I don’t know how that works. I’m not actually going to ask that question...that information should be given to you at the very beginning, so you know where your comfort zone is’

Similarly, Carol spoke of her relief at finally getting access to respite services, but acknowledged there was a level of fear associated with this:

‘If you get any bit at all you’re afraid they’re going to take it off you ... take what you’ve got and say nothing in case they take it off you’

The ambiguity surrounding the allocation of services was also mentioned by Teresa, who described the sense of dread she experiences every year:

‘I qualified for respite but every year now it hangs over me ... I’ve had it 7 years now and I’m thinking, are they going to start making cuts again? ... Everything is like that in the world of special needs. It’s uncertainty’

She described feeling uncomfortable at times when she has asked the respite worker to reschedule days as she feels that, if she upsets them, this could negatively impact the service she receives:

‘If you text them and ask them will we do a swap this week, you were always feeling that you were exposed, that you were putting yourself out there’

Due to the extent of her own physical health issues, another worry for Teresa is that she should not be eligible to be a carer for her son:
‘I’m half afraid ... if you looked at the policies up close, I probably shouldn’t be considered a carer... it’s scary you know, you’re never really comfortable with the system’

These quotes capture the vulnerability of parents, who are dependent on the services for additional support, and who fear the consequences if these supports were suddenly withdrawn. It evokes an image of a mountain climber hanging off a cliff, with only one rope protecting them from the sheer drop below.

According to Lisa, the service should recognise parents’ fears and reassure them that respite is available if needed, instead of leaving them feeling as if they are hanging on, about to be dropped off the cliff:

‘Let people know that respite, when they need it it’s there, but they don’t have to have this fear that you’re going to be dropped and back to the bottom of a list again?’

4.6.2 Guilt

Brenda frequently referred to the sense of guilt she experiences when availing of respite care for her daughter. Comparing her situation to that of other parents of children with disabilities, Brenda reported finding it difficult to justify that she has access to respite:

‘We don’t have it hugely difficult, like it is difficult but it’s not ... and it’s very hard to justify then that I am getting respite... Because I feel that I’m taking it from somebody else that needs it more’

There is a level of uncertainty in this quote, as Brenda alternates between saying things are difficult for the family, and then saying things are not that difficult. This captures the fluctuations that can occur in a person’s capacity to care, as sometimes the demands of caring can seem manageable while on other occasions, particularly when the carer is experiencing burnout, it can be very difficult to continue.

Brenda could feel as if other parents would look at her situation and judge her for needing additional support. It appears she is struggling to justify accessing respite care to herself, as with this there comes an admission that she can’t manage things alone.

In spite of these feelings of guilt when thinking about other parents, Brenda acknowledged her reluctance to give up respite care:
‘I do feel a bit guilty though, there are other people who have very severe behavioural problems with their children and they probably need it more than I do. But I’m still not willing to give it up’

While she feels that the family ‘could completely survive’ without the hours, she recognises that this would be ‘very difficult’. There is a sense of solidarity with other parents who are caring for children with ASD, as Brenda frequently referred to other parents and compared her experience to theirs. While she recognised her need to protect her hours, for the benefit of her family, this leads her to feel selfish for not sharing the information with others who may need:

‘I feel really selfish not saying it to other people, that this is available but then, I need to protect the hours we have for us’

For Teresa, there is a level of guilt associated with the break away from her son provided by respite:

‘Getting the odd night off ... there’s guilt associated with it ... You’re thinking of him ... is he okay, should I ring later to see did he go down to bed okay?’

Brenda also spoke about feeling guilty at the thought of sending her daughter away for respite:

‘I would love a place where I could send her for a week ... when she gets way too much. And then I feel really bad about thinking about it’

For both parents, it appears that their dedication to their role as carer for their child means that they feel they should have sole responsibility for their care and are uncomfortable handing this over to anybody else.

4.6.3 Inner Conflict

Several parents spoke about the inner conflict they experienced surrounding their initial decision to access respite care, with many describing how this uncertainty continued as their child attended respite.

Rachel described her initial uncertainty about respite services, stating that she was ‘split’ as she didn’t want her son to be ‘labelled’ but she felt that respite would provide him with the opportunity to develop social skills.

She recalled the initial struggles in the early stages of respite care as her son did not want to go and the respite club was a significant distance away:
‘I didn’t tell them at the actual service themselves, but this year is the first year that he’s actually enjoying it, right? I wanted him to go ... Oh my god, it was so difficult’

Despite these difficulties, Rachel outlined how she felt the need to prioritise her son’s attendance in the hope that it would become ‘somewhere that he’ll be happy’ and allow him the chance to develop friendships.

Teresa described similar experiences with her son, as she outlined the challenges associated with the service, and questioned why herself and her husband had agreed to the service:

‘I don’t know why we even entertained that notion, we took it out of desperation ... there was so many rules, regulations ... it just seemed very short, and then it was hit and miss for him’

As in Rachel’s experience, Teresa’s son was unhappy attending respite initially, which left her feeling conflicted and questioning whether they should continue with the service:

‘I don’t think he was ever 100% happy ... eventually he was really not enjoying it and it was leading to meltdowns ... I don’t think he was getting on awful lot out of it and we kept at it because we were told we were giving him skills to cope’

These quotes capture the inner conflict experienced by parents who are trying to do what’s best for their child while feeling uncertain about the choices they have made and the options available to them.

In Brenda’s interview, she spoke of her initial concerns about the respite worker that was allocated to her family. Although she wasn’t completely confident with the carer, Brenda described how she ‘went ahead with it’:

‘I wasn’t hugely comfortable with her but also, are you ever hugely comfortable when you leave a child somewhere in the first place?’

While many parents are likely to feel some sense of unease at the thought of leaving their child, for Brenda this inner conflict was heightened due to the nature of respite care. She seemed to feel that she had to go along with the service, despite her reservations about the person providing respite:

‘It feels like you have to live with it...And it’s a big, it’s a big difference from going in somewhere for an hour and you’re in there as well but if you’re not going to be there, you can’t just live with that’
Similarly, Lisa questioned the appropriateness of allocating a respite worker to a child, when it was clear that they were not a good match:

‘Why are you giving me somebody that you know ... it’s not the right person, like why are we doing that? This is 4 hours where he has to go off with an individual he’s not comfortable with’

In Carol’s experience, having a respite worker with little knowledge of ASD caused her to feel very conflicted about the purpose of the service, as it appeared to add to her stress rather than offering her a sense of relief:

‘Every single time she took him, she came back whinging. You were just like, honest to god almighty, this is just causing me stress. There’s no point in having this’

As highlighted in the following quote from Rachel, it seems that parents of children with ASD are faced with a constant state of uncertainty about whether they are making the right decisions and doing what is best for their child:

‘You’re constantly thinking am I doing the right thing, am I giving him every opportunity. I still don’t know’

4.6.4 ‘Toe the line’

Throughout many of the interviews, parents described feeling like they needed to ‘toe the line’ to avoid jeopardising their respite hours.

Brenda questioned how much say parents have in the service they receive and spoke about the need to ‘bite your tongue’ in order to keep the hours that you have:

‘How much can you reject, can you say no, I don’t want this person. I don’t know that you can. Because basically you’re looking for a service and they’re telling you that’s what I have. Do you get much say?’

Teresa outlined the difficulties she has experienced in the past when she felt unable to discuss any issues with the respite service:

‘I’ve always found it difficult ... if you had a problem with respite. Like if you have an issue with a worker ... that, feeling like, I can’t say anything, it’s going to jeopardise my respite if I do’
She expressed how she felt that she could never say anything but would eventually have to ‘bite the bullet’ and speak to a manager, when the issues had not been resolved.

For Lisa, there is a ‘power relationship’ between parents and the services, as parents try to avoid drawing attention to themselves for fear their respite could be pulled. She described how parents are reluctant to express any concerns they may have as they want to avoid appearing like they are difficult:

‘If you start kicking up too much, you get a name in the system as being difficult … and the impact is on you and your son or daughter’

As a result, parents tend to ‘smile and accept a lot, because the alternative is nothing’.

Parents seemed to feel like they were expected to be grateful for the service they received, with no consideration given to their needs or what would be best for their child:

‘You’re given what you’re given, and you’re expected to be grateful for it’ (Lisa)

‘You’ll take what you get, whatever’s going you’ll take it and you’re thankful for it’

(Teresa)

Teresa described feeling as if she had to ‘crawl and beg’ to be given an extra hour of respite, and that the service did not want to communicate with parents at all:

‘You felt you were to be thankful for the scraps you were being thrown and shut your mouth and toe the line was a little bit of the feeling’

This is a very evocative description, presenting an image of a dog begging for scraps of food. For Teresa in particular, this appears to highlight the lack of respect she has felt in her interactions with the service providers.

**Reflective Box**

I was struck by how frequently parents mentioned that they were grateful or thankful for the respite they got, even when they were describing negative experiences with respite services. It suggests that, even in the interview setting, there was still a sense of fear about jeopardising their respite and a reluctance to appear as if they were being difficult or complaining.
4.7 Service Provision

The final superordinate theme to emerge from the data was related to parents’ experiences of the provision of respite services. Parents spoke about three interrelated areas related to service provision: Segregation, Adversarial System and Tailored Family Support, which will be discussed below.

4.7.1 Segregation

Several of the parents discussed the model of service provision for people with ASD, which they feel promotes segregation rather than encouraging and supporting inclusion.

Carol and Lisa raised questions about the appropriateness of the respite care that was available, and whether parents of typically developing children would be as willing to send their child off with an unfamiliar adult:

‘Do many people with typically developing 3 or 4 year olds ... do they willing say off you go now ... for a night. It’s a big deal to build up to that’ (Lisa)

‘Would a child from mainstream, would their parents be as willing to hand them over? ... They wouldn’t, they wouldn’t be sending him off with a stranger’ (Carol)

This presents an interesting contrast between what is expected of parents of children with disabilities accessing respite services, and what would be considered unusual for parents of neurotypical children.

Brenda expressed discomfort with the idea that children with disabilities should be grouped together with other children with disabilities:

‘While a child has special needs, just because they have special needs, doesn’t mean that they have to be surrounded by other people that have special needs’

She spoke about a respite club that the service had offered her, which she felt was ‘a dumping ground’ for children with disabilities and didn’t ‘rest easy’ with her.

In her eyes, the service seems almost disrespectful in the way it views and treats children based on their diagnosis, ‘dumping’ them in a respite club instead of valuing them for their individuality and tailoring the service to meet their needs.

For Brenda, her concern was that this approach to respite provision was based on exclusion, which could make her daughter feel as if she is a burden:
‘That makes her feel like she’s a burden, in my eyes and sometimes she is a burden, but I don’t want her to feel like that’

Similarly, Lisa questioned why services seem to strive to keep people with disabilities together, rather than trying to include them in the community:

‘Like all the services, this segregation … in the respite world, does that have to be like that? Does it have to be, we’ll take them to Special Olympics, but we mightn’t take them to the regular swimming club down the road?’

She reflected on the potential impact that this could have on the person with the disability:

‘Support the family to do regular stuff, not take the child out of that situation so that you can do the regular stuff and the child can do the segregated stuff over here … How does that make the person feel valued?’

In Lisa’s own experience, this segregation can permeate the child’s self-image, leading them to feel different from others, without the same levels of expectation or ambition:

‘He doesn’t see himself as an adult in the world … so the expectations haven’t been set and I think all these kids are unconsciously or subconsciously not seeing themselves like everybody else’

She also spoke about the impact that this model of service provision has had on her son, taking him away from his own community:

‘Nobody knows him … They know nothing about him and he had no development throughout the community. He didn’t go to school in the community. Taken out, you know, that’s been his life experience’

Carol, on the other hand, felt that there were positive aspects to this model of respite care. She described her difficulties finding appropriate places to take her son, so she feels that a dedicated respite centre is beneficial, as it offers her son a sense of belonging:

‘There’s nowhere really to bring them… That’s what I find great about the house … It’s kind of his place, that he can go to. You know the way you say my kid goes to camogie or whatever … And he loves it there’
Several parents expressed their views that respite workers should welcome the inclusion of siblings or friends, in order to make respite a more natural, integrative experience, and more enjoyable and beneficial for the child:

‘They would organise a child and sibling ... something like that. Rather than let’s all be special needs together, yay ... that’s not an integrative system ... I don’t see how that is proclaiming inclusion at all’

(Brenda)

‘There can’t be any plan to take Luke and a friend of his choice into the community to do something age appropriate or related’

(Teresa)

‘Why does it have to be just him and his care worker? Could it not have been more of a family outing, with his brother, who would have enjoyed it’

(Lisa)

A common thread throughout the interviews was parents’ wish for their child to be treated like a neurotypical child and to have the same opportunities that they would have without a diagnosis of ASD. For Brenda in particular, the focus on keeping children with special needs together seems to be almost patronising and counteracts the work that has been done in the world of disability towards a model of social inclusion.

### 4.7.2 Adversarial System

Another aspect of service provision that was frequently mentioned by parents was the adversarial nature of the system. Both Carol and Teresa referred to the ‘battle’ to access support, with Teresa describing how services try to ‘protect their pie’ and parents fight to be given a slice.

A number of participants spoke about the lack of information from services, describing respite care as a ‘secret’ that not many parents seem to know about:

‘It’s not a proclaimed service that’s available ... it’s like it’s a big secret’

(Brenda)

‘I have met so many parents, with kids at 16, 18, didn’t even know it existed’

(Lisa)

‘This secret place that no one can know about’

(Carol)

Carol expressed her confusion and frustration with the lack of information from the service, and the fact that she only found out about respite from another parent:

‘What I find odd is, you go in to the HSE ... you get your diagnosis and some parents are told about respite, and more parents, like myself, are not told about respite’
She outlined the obstacles that parents face when trying to access services, including the volume of paperwork, needing multiple reports from different professionals, and having to give a ‘boohoo story’ to the service, almost to prove that they need respite care. This creates an image of the service as quite a hostile environment which, instead of supporting parents, seems to place numerous barriers in their path:

‘It’s kind of like the less people that know about it, the better, the less they have to help’

The adversarial nature of the system appears to create a sense of competition between parents themselves, as they almost have to battle each other to get access to respite.

‘You’ll be told what you’ll be given and you’ve to wait for it and its limited, so you’ll be fighting with other parents to get your share’ (Lisa)

In Carol’s experience, it seems to be the parents who shout the loudest that ultimately get access to respite hours:

‘Whoever shouts the loudest, that’s what it boils down to … whoever shouts the loudest and who is the biggest drama queen will get the most respite’

This raises questions about fairness in the allocation of services, and also about the potential pressure this could place on parents who could already be at breaking point. The use of the term ‘drama queen’ conveys Carol’s discomfort with this style of interaction, as she had previously spoken about her tendency to take a proactive, pragmatic approach to the care of her son.

After a prolonged fight to get access to services, it seems parents are left feeling lucky to receive anything, and a sense of obligation to agree to whatever they are offered:

‘Nobody knows about it ... nobody knows about it. It was just pure luck on our part, pure luck’ (Carol)

‘And I said yes to everything at the beginning, coz I knew so little’ (Rachel)

Several of the parents described feeling that they need to protect their hours, so they are reluctant to mention to anyone that they receive respite:

‘I’ve never said anything ... to them since ... I don’t say whether I have hours or I haven’t the less you say the better ... or they’ll take it off you’ (Carol)
‘I’d be afraid to say to anyone that we get respite ... I suppose I’m protecting our hours one, and the other part of it is that, I know with some of the other children, that their behaviours are much more difficult than Molly’s’

(Brenda)

Following the battle for services, parents are also reluctant to take themselves off the list, even if respite is not particularly helpful:

‘It was never officially done, we just ... pulled back or just stopped taking the days ... we kept our options open, left our names on the list but he never really went back’

(Teresa)

‘It wasn’t filling any function, but I wouldn’t take his name off the list coz if I did really need it again I wouldn’t be able to get it, so you play the game’

(Lisa)

Lisa’s reference to the system being like ‘a game’ captures what many parents seem to experience, that you have to play by the rules of the service and it very much seems that there is an element of luck involved.

The following quote from Carol illustrates the impact this can have on parents, adding to the fight they already face in caring for their child with ASD:

‘It’s constant stress for parents ... as if they haven’t enough problems, it’s just constant stress. It’s one thing after the other the whole time ... that’s what I would take from it, to be quite honest, just the nightmare’

4.7.3 Tailored Family Support

All the parents interviewed made some reference to the need for respite care to be more tailored to meet the unique needs of the child and their family.

Lisa expressed some discomfort with the term ‘respite’ itself, as she felt it could be considered disrespectful to the person or child with the disability:

‘I also feel it’s a bit disrespectful for the person with the disability, that somehow I need a break from you’

For her, the term ‘family support service’ is more appropriate and fits better with what families of children with ASD need from services:

‘The landscape of your life is important. It has to be more than just the person presenting, it is a family support ... that’s how it should be operated’
In her eyes, services are more responsive to the needs of the parents, rather than considering the whole family, and she seems to feel a sense of frustration with the lack of opportunity for collaboration between parents and the service:

‘The services respond more to what I need … which is not actually what I need either, I’m not asking for what I need either, they’re telling me what I need’

The lack of involvement of parents in decision-making and planning for the provision of their own respite hours was also identified by Kate in her interview:

‘The thing is you get what you’re given, I think that was the way it was … You get what you are given’

For Teresa, there is a need for respite services to be more individualised and tailored, depending on the needs of each family:

‘It really needs to be tailored to each family … a care plan needs to be very specific. They need to come away from the institutional style thinking when it comes to respite’

Several parents also expressed a need for greater flexibility with the respite that was offered:

‘The hours had to really be on terms of who the worker was, rather that suiting the family’

(Teresa)

‘No it wasn’t convenient … Going, coming, going again … you have to coordinate the whole thing but it was so worth it thinking I was doing something positive for Michael. It wasn’t respite for us … It wasn’t at that time’

(Rachel)

Teresa described the restrictions associated with inflexible respite hours, as parents are unable to get a break when they feel it is really needed:

‘You’d see behaviours and meltdowns … when they happen they’re bad … it’s always nearly after that you’d say, Jesus we really need a bit of headspace. And it doesn’t come, you’re tied into your hours’

Similarly, Brenda recognised the lack of responsiveness in the current system of respite care, whereby parents could be left unsupported in a crisis:

‘We’re missing something where, when it gets overwhelming, you don’t have any clawback to getting out of the situation’
Additionally, an individualised respite service could offer parents support with other responsibilities they may have, aside from direct care for their child, as Brenda described how parents could benefit from help around the house:

‘Respite should include a homecare service… do you know like they give to elderly people? … That it’s a proper full assessment of what is needed within a family’

For these parents, the importance of their voices being heard and having input into the design of their own respite care is clear and seems necessary in order to ensure that the service they receive is beneficial, with the potential to make a significant difference in their lives.

4.8 Conclusion of Chapter

This chapter has presented each of the superordinate themes related to parents’ experiences of accessing respite for their child with ASD. Each of these themes has been discussed in detail, along with the interrelated subordinate themes, with illustrative quotes and interpretive comments included throughout the chapter. The following chapter will discuss the findings from this section in the context of the existing literature.
Chapter Five: Discussion

5.1 Chapter Introduction

This chapter presents a critical discussion of the main findings of the present study. Relevant literature, initially presented in Chapter Two, will be revisited and discussed in relation to the current findings. Novel contributions and findings unique to this particular study will also be considered. The strengths and limitations of this study will then be addressed, and a critical reflection of the research process will be provided. The main findings will be discussed in relation to clinical, policy and educational implications, and areas for potential future research will be identified. Finally, the chapter will end with a brief summary of the general conclusions based on this research.

5.2 Summary of Findings

The primary aim of this study was to explore the experiences of parents accessing respite care for their child with autism spectrum disorder. To date there has been very limited research carried out with parents of children with ASD so it was hoped this study would add to the existing knowledge in this area. Semi-structured interviews were carried out with parents, which were then analysed and interpreted using IPA. It was hoped that this study would provide a unique insight into the lived experience of Irish parents availing of respite services for their child with ASD, exploring their perspectives of service delivery and the meaning of respite care for their family. In fulfilling this aim, the elements of respite care that are important to parents and the barriers and challenges they face were also identified and explored.

As outlined in the previous chapter, this study identified five main themes in participants’ accounts of their experience of accessing respite care for their child with ASD. These were: ‘Living with ASD’, ‘The Respite Worker’, ‘Role of Respite’, ‘Emotional Conflict’, and ‘Service Provision’. Parents spoke about their experience of receiving a diagnosis of ASD for their child, with many noting their initial shock and the associated process of adjustment. Several of them described the challenges associated with caring and highlighted how respite plays a very important role in offering parents a sense of relief from these demands. Although parents recognised the value of having a respite service, many also expressed reservations they had in relation to some aspects of service delivery, their respite worker, and spoke about their own emotional conflict with respect to accessing respite care. In the following sections, these key findings will be discussed in relation to the existing literature.
5.3 Discussion of Results

5.3.1 Living with ASD

Many of the participants in this study described their experiences of living with ASD. While the primary focus of the research was parents’ experiences of accessing respite care, it became apparent that another important aspect of the lived experience of parents is the impact that ASD has had on their lives. The current study conceptualised living with ASD as having three interrelated components for parents: diagnosis and adjustment, challenge of caring, and the impact of ASD.

A review of the literature of parents’ perspectives of raising a child with ASD by Ooi et al. (2016) found that many parents spoke about the psychological impact of receiving a diagnosis of ASD, which was echoed in the current study. Participants in this study described their struggle to adjust to their child’s diagnosis and the sense of abandonment they felt at this time, as they struggled to access information about support services. Similar experiences were reported by parents of children with intellectual disabilities in studies carried out by Resch and colleagues (2015) and Kenny and McGilloway (2007). Parents identified a lack of support at the initial time of diagnosis, and a need for more information to be provided about ASD and services that are available (Resch et al., 2015; Kenny & McGilloway, 2007; Galpin et al., 2018). A recent review of services for individuals with ASD in Ireland carried out by the HSE echoed these results (HSE, 2018).

In this study, many of the parents spoke about the challenges associated with caring for a child with ASD. Some described their own sense of social isolation as their role as a carer had impacted their ability to work and to spend time out of the house. This is consistent with previous research, which has shown that caregivers of children with intellectual or developmental disabilities often report feeling isolated (Nicholas et al., 2016; Safe et al., 2012; Worcester et al., 2008; Preece, 2014) due to restricted opportunities for social activities (Povee et al., 2008), which can negatively impact their wellbeing (Galpin et al., 2018).

A study by Bessette Gorlin et al. (2016) identified a number of challenges facing parents of children with autism, including difficulty managing the unpredictable nature of the behaviours associated with ASD. This is similar to the current study in which many parents described the need for constant vigilance when caring for their child, with one parent noting that the family is constantly ‘on eggshells’ due to the unpredictability of her son’s behaviours. The impact of the constant demands associated with caring has also been consistently demonstrated in the
literature, as caregivers have been shown to have high levels of stress (Lee, 2013; Whitmore, 2016), an increased risk of emotional and psychological distress (Emerson, 2003; Singer, 2006), and poor physical health (Alik et al., 2006; Gallagher & Whiteley, 2012, 2013). The current study found similar results, as participants referenced the impact that caring had on their wellbeing, with one parent describing the toll caring for her son had taken on her physical and mental strength.

A number of participants in this study discussed the impact that ASD has on day-to-day life, particularly in relation to their struggle to find suitable activities or educational placements for their child, and the lack of understanding they had experienced from others in relation to their child’s needs. This mirrors findings reported by Derguy et al (2016) and Bessette Gorlin et al. (2016), who also reported that parents of children with ASD struggle in relation to securing appropriate school places and services for their child. Similarly, research by Galpin et al. (2018), found that parents of children with ASD frequently spoke about their sense of isolation from the community and identified a lack of understanding and awareness of ASD.

5.3.2 The Respite Worker

Participant narratives within this section focused specifically on the respite worker, with many acknowledging the importance of developing a close, trusting relationship with the person providing respite care for their child. Parents described their need to get to know their respite worker, to ensure they were a good fit for their child, and many referred to their sense of reliance on their respite worker. Similar findings were reported by Welsh et al. (2014), in their research with parents caring for children with complex care needs. Parents spoke about the importance of developing trust with the respite worker, in order to feel comfortable leaving their child, and reported experiencing emotional distress when there was a change of respite provider. The importance of the respite provider having a caring nature and passion for their supportive role was also highlighted by parents, which was mirrored in the findings of the current study.

A study by Neufeld et al. (2001), involving caregivers of children with chronic medical conditions and/or disabilities, found that the biggest concern in relation to respite care was the availability of qualified staff. Participants spoke of their need for a respite worker who is reliable, available and comfortable with the challenges associated with this role. They also highlighted the need for more training and educational opportunities for respite staff. Similar results have been found with parents of children with ASD specifically, who reported that their
In the current study, parents also highlighted the importance of respite workers having training and experience in the area of ASD. Participants acknowledged the challenges they had encountered when their respite worker was not familiar with ASD, with some expressing concerns about the recruitment process and training provided for respite workers. In line with these findings, Wodehouse and McGill (2009) found that mothers of children with ASD frequently expressed concerns about support professionals’ lack of knowledge, understanding and expertise in the complexities of autism. Similar results were also reported by the HSE in a recent review of services for individuals with ASD in Ireland (HSE, 2018). For parents to feel comfortable leaving their child, it appears they need to feel confident in their respite worker’s skills and qualifications. Recent research by Ackermann and Sheaffer (2018) found that family caregivers provided more favourable ratings of their well-being when receiving respite from a trained provider.

5.3.3 Role of Respite

Participants in the current study spoke at length about the role respite plays in their own lives, as well as that of their child and their family. Many parents identified the importance of respite for themselves, offering them a break and allowing them time to spend with their partner and other children. Recent research by Whitmore and Snethen (2018), exploring the perspectives of parents of children with special healthcare needs, reported similar results. Parents described respite as a ‘gift’, allowing them a break from the constant demands of caring, and allowed them to spend time with their other children. A review of the literature by Robertson et al. (2011) also presented consistent results, with respite shown to provide parents with time for rest and rejuvenation, a sense of relief, and freedom to do things for themselves.

In this study, parents also described how respite enabled them to feel as if they could go on caring when things became difficult. Similar findings have been reported by Collins et al. (2014), and by Wilkie and Barr (2008), with regular access to high quality respite care shown to positively impact a carer’s ability to continue in their role as carer. In line with this, Whitmore and Snethen (2018) reported that respite care was important in offering parents a sense of hope when faced with the challenges of caring.

While many of the parents acknowledged the role that respite plays in giving them a break, they also recognised the potential for respite to provide opportunities for their child to learn,
develop new skills and build relationships with other children. A number of parents described the difficulties their child had experienced in terms of their social-emotional development, so it was hoped respite would support them to interact with other children while also allowing them to have fun. This is in keeping with research carried out by McConkey et al. (2004) and Wilkie and Barr (2008), which recognised the benefits associated with respite for children with disabilities, allowing them to experience new environments, mix with other children, build their independence. Previous research has also identified a role for respite in promoting the development of children’s social, communication, and daily living skills, and building up their self-esteem (Welch et al., 2014; Welsh et al., 2014), which was echoed by parents in the current study.

The evolving role of respite over time was frequently mentioned by participants in this study. Parents described how respite initially provided them with a break but outlined how the focus of respite care should shift as the child grows older, in order to meet their needs. Services should recognise and respond to these changes in order to ensure the support that is offered is appropriate and meaningful for the child and their family. The evolving role of respite was also recognised in research carried out by MacDonald and Callery (2008). This study presents a developmental map of caregiving over time, based on parents’ accounts of caring for their child with complex needs. It describes the trajectory of care for children with complex needs from infancy to adulthood, and recognises parents’ evolving need for respite care in line with these changes.

5.3.4 Emotional Conflict

Several participants in this study referred to the emotional conflict associated with accessing respite care for their child. While parents acknowledged how valuable respite was to themselves and their family, they also described feeling a sense of guilt about placing their child in respite care in order to get a break. This is in line with the existing literature, with many parents admitting feelings of guilt and uncertainty with regard to respite care (Neufeld et al., 2001; Dunne, 2015; Chapman, 2013). In their studies with Irish parents of children with intellectual disabilities, Wilkie and Barr (2008) and Hartrey and Wells (2003) found that parents expressed a reluctance to avail of respite services due to feeling guilty about placing their child in the care of someone else.

Similarly, Mannan et al. (2011) found that parents expressed a sense of ambivalence towards respite, with the decision to avail of respite described as a ‘moral dilemma’. In comparing their
needs to that of other carers, parents seem to feel that others’ needs were greater than their own, which is mirrored in the results of this research. Participants in the current study expressed the continuing sense of uncertainty they felt about their decision to avail of respite services and the inner conflict they experienced, particularly when they were unsure about the value and appropriateness of the service for their child. Previous research has found that respite care which does not meet the individual needs of the family can ultimately lead to an increase in caregiver stress (Hoare et al., 1999; Preece, 2014). Similarly, Hartrey and Wells (2008) recognised that respite could act as a stressor for parents, so it was recommended that professionals acknowledge this potential for distress and provide appropriate support for families ahead of respite care.

In the current study, parents also expressed a sense of fear associated with respite care and feeling as if they had to ‘toe the line’ in order to avoid jeopardising the service they receive. One parent described the ‘power relationship’ between the services and parents, while others spoke about feeling as if they had to be grateful for the service they received, whether they were satisfied or not. Similar results were reported by Mannan et al. (2011) in their research with family caregivers of individuals with intellectual disabilities. This study found that carers often felt that they couldn’t complain about the service they received as they were getting something, while other families did not have access to any respite. The existing literature did not appear to contain any specific reference to parents’ fears that their respite could suddenly be taken away. This could be a reflection of the particular social and cultural context that the parents in the current study are in, their challenges in securing respite care and their subsequent fear that they could lose it.

5.3.5 Service Provision

Participant narratives within this final section focused on their experiences of the provision of respite services. Parents questioned the model of service provision for individuals with ASD, which they feel promotes segregation rather than inclusion. Many of them shared their hopes for their child to have similar life experiences as a typically developing child and felt that the respite service that was provided did not always support or acknowledge this. Similar to this, Chadwick et al. (2013) and Kenny and McGilloway (2007) found that families of individuals with intellectual disabilities felt there was a need for a shift in societal and governmental attitudes towards people with disabilities, who they felt were often an ignored and misunderstood group. For some of the parents in the current study, it was important that their
children were supported to build their own independence and integrate into the community as much as possible. This was echoed in research by Mannan et al. (2011), which found that parents wanted services to promote the independence and self-determination of individuals with disabilities.

Another related aspect of service provision that was frequently mentioned by parents was the adversarial nature of the system and the ‘battle’ they faced trying to access support services. Many expressed their frustration with the lack of information and secretive nature of services, with parents left feeling as if they had to protect their hours, even if the service was not meeting their needs anymore. Doig et al. (2009) outlined the struggles parents faced when navigating the system, having to ‘jump through hoops’ in order to find and retain respite care. The ‘fight’ to access services was also recognised in research carried out by Chadwick et al. (2013) and Mannan et al. (2011). In both studies, parents described having to advocate and fight to access appropriate services for their child with disabilities. Galpin et al. (2018) reported similar results for parents of children with ASD, with many describing how they felt it was the people who shouted the loudest who got access to respite care. This was echoed exactly by a parent in the current study.

Across the literature, parents have consistently highlighted the need for respite care to be more family-centred and tailored to fit the unique needs of the child and their family (Whitmore & Snethen, 2018; Welsh et al., 2014). Caples and Sweeney (2011) and Doig et al. (2008) found that parents frequently reported a need for more respite services and for greater flexibility in the options available to families, which is similar to the current findings. Galpin et al. (2018), presented consistent results, as they identified the need for services to adopt a relational, family-centred approach, which is tailored to ensure the needs of the whole family are considered and offers family support when needed. Additionally, parents in the current study outlined how they should have more of a say in the service they receive, and how respite care should be more responsive to the needs of families, and which is in line with findings of Olsen and Maslin-Prothero (2001).

5.3.6 Synthesis of Themes

Looking to the five superordinate themes that were identified from the data, it appears that there are two principle concepts within the narratives of the lived experience of parents of children with ASD. Although the goal of IPA is the identification and description of lived experience rather than producing a model to provide an explanation of a phenomenon, there
are some commonalities between the superordinate themes which could be synthesised further, to give an insight into two main areas of the parents’ ‘life world’.

This first of these relates to the parents’ experience of living with ASD and the impact that the diagnosis has had on their life, and that of their child and family. While this was not the principle focus of the research study, this topic featured strongly in each of the parents’ narratives throughout the interviews. In speaking about their experiences, many parents reflected on the diagnostic process and the associated emotional adjustment, which some were continuing to work through. Several parents also described the challenges they faced caring for a child with ASD and the impact of ASD on everyday life. Given the pervasive nature of ASD and the impact it can have across every area within a family’s life, this is a central component of the ‘lived world’ of these parents. It seemed to be important for parents, as part of their own reflections, to discuss this and the isolation they sometimes felt, from the service, the community, and from other people in their lives. In a way, this also appears to be reflected in the themes themselves, as parents spoke about ASD almost separately to the respite service, which seems to mirror the way they feel about the services – that they are not able to access information about services, that ASD continues to be misunderstood and that respite services are not tailored to meet the specific needs of children with autism.

The remaining four subordinate themes all appear to have a similar underlying message – that parents want to have a personalised, individually planned respite care that would allow them to have an input in designing a service that would meet their needs and that of their child and family. Parents spoke about the importance of having a skilled and caring respite worker, who they could develop a relationship with and who they would trust with their child. They also spoke about the hugely important role that respite plays in their life, in giving them a break and in allowing their child the opportunity to learn and develop new skills. The emotional conflict associated with availing of respite care and their frustration with certain aspects of service delivery were also explored throughout the interviews. Taking each if these into consideration, it seems that having a tailored, personalised service would help to ease many of these concerns. Parents are likely to feel more confident in the service they receive and more involved in their child’s care and in planning for their future.

5.4 Strengths and Limitations

The following section will address the strengths and limitations of the present study. The findings reported are based on a small sample of parents who agreed to participate in the
research and be interviewed. As such, the findings represent the perspectives and experiences of this particular group of individuals and should not be considered to be generalisable or representative of the experiences of other parents accessing respite services for their child with ASD who did not participate in the research.

One particular strength of this research is that is the first study to explore the experiences of parents availing of respite care for their child with ASD in Ireland. It provides a unique view into the lived experience of Irish parents of children with ASD, their perspectives of respite services, and an insight into how these services are experienced by children and families. Another related strength is that the researcher was not known to any of the participants prior to the research and was not affiliated with the services providing respite care for their child with ASD. It was hoped this would allow parents to openly speak about their experiences and perspectives without fear of any consequence or judgement. By assuring parents of their anonymity and confidentiality, they could share their honest opinions and discuss any concerns or issues that had impacted their experience of respite care.

The use of IPA as a methodology in this study can also be considered a strength. It allowed the researcher to explore the lived experiences of participants and the meanings they have attributed to these experiences, offering an insight in their ‘life world’. The commitment of IPA to the idiographic approach ensured the researcher considered each individual’s account of their own personal experiences and the identified themes and associated interpretations remained true to the individual narratives of participants. IPA allowed the voice of the participants to be heard, which was felt to be particularly important in this study. The IPA framework also allowed the researcher flexibility in their approach to exploring the research question, and to identify novel areas for future research, not previously addressed in the literature.

The interpretive component of IPA can be viewed as a strength, particularly in relation to the original contribution of this study to the existing literature. It is recognised that these interpretations are the product of the interaction between the researcher and the participant, and that alternative interpretations are possible. Another strength of IPA is that it recognises and openly acknowledges the limitations associated with this methodological approach. It identifies the potential influence of the researcher’s own opinions, biases and preconceptions on the interpretation of the phenomena under study. To minimise the potential impact of these, and to ensure the methodological coherence and rigour was maintained throughout, the researcher
recorded a clear audit trail, and utilised a reflective journal to document personal thoughts and reflections.

There are several potential limitations within the current study. To date, there has been relatively little research carried out exploring the experiences of parents of children with ASD who are availing of respite care. In the absence of literature related to ASD specifically, research from other related areas, particularly intellectual and developmental disabilities, has been considered. When looking to the main findings of the current study, it is important to be aware that the majority of comparisons made to the existing literature relate to children with intellectual or developmental disabilities, not specifically ASD.

Potential participants in this research were identified and contacted by gatekeepers working in the service, based on their ability to meet the inclusion criteria, provide informed consent, and participant fully in the study. Parents themselves could then decide whether to take part in the research and were advised to contact the researcher to discuss this participation. It is possible that the experiences and needs of parents who were not considered eligible to take part by gatekeepers, or who chose not to take part, differ from the findings presented in this study.

The inclusion and exclusion criteria for the current study meant that parents with learning disabilities, verbal comprehension/receptive language difficulties, literacy difficulties, or were non-English speakers were not eligible to take part in the research. As a result, the experience of parents of children with ASD who fall within these categories is not captured in the present study. It is possible that these parents may have different experiences of services, particularly in relation to the availability of additional supports that they may require, cultural differences, the ability of the service to adapt to fit with their needs, and the potential isolation they could experience, which may differ from that of the parents included in this study.

Given that parents were contacted by gatekeepers from the children’s disability service in order to provide information about the study, it is possible that some may have felt uncomfortable about participating. They may have felt reluctant to open up about their experiences or feared their participation could impact on the service they received. Parents may have been more motivated to take part if they had negative views or experiences of respite services, as this would allow them an opportunity to give feedback and discuss their concerns. As parents were required to contact the researcher in order to discuss their participation, it is possible that some may have decided not to participate to avoid adding to the existing demands associated with their caring role.
While participants were spread across a number of geographical areas and accessed different respite services, all of these belonged to the same children’s disability service, which provides support and services to children with complex disabilities and/or developmental delays in the Mid-West. As a result, their accounts and perspectives reflect their experiences with one particular service, which may differ from that of parents of children with ASD who belong to other services. Additionally, all of the participants in the current study were mothers of children with ASD, which appears to be a common finding across the literature. It is possible that fathers, siblings, or other family caregivers of children with ASD may have different views of respite services and it may mean something different to them, compared to mothers of children with ASD.

Additionally, it is important to note that two of the participants in the study had children with ASD who were over the age of eighteen years. While the focus of the research was the experience of parents of children with ASD and the research context was a children’s disability service, it was felt by the researcher that their contribution to the study would be valuable. Both of their children had accessed respite services until they reached adulthood and the researcher ensured participants understood that the focus of the interview was about their experience with the children’s service. The child of one of the participants had recently turned nineteen so had not been out of the service for very long while the other parent had a second child who was still accessing the children’s service which was the main focus of her interview. It is possible that these parents may have a different perspective to that of the other participants as they were providing a retrospective account of their experience and their child had moved on from children’s services. Some of their views expressed during the interviews may have also been influenced by their reflections and experiences of adult services, which was outside the scope of this study. In spite of this, it was felt that it was important to include these parents’ interviews in the analysis as they provided an insight into the world of parents with older children with ASD and could discuss their experience with respite care across different developmental stages. Due to the age of these participants’ children, the researcher also reflected on the process for obtaining consent. As the focus of this research was on the parents’ experience of services, not the child’s, and all data was to be anonymised, it was felt that it was appropriate to only seek consent to participate from parents.

In spite of these limitations, the current study presents a rich, detailed insight into the lived experience of parents accessing respite care for their child with ASD in Ireland, which is a
meaningful contribution to the existing literature and serves as a foundation which future research can build on.

5.5 Critical Reflection

Throughout the course of this project, I have endeavoured to remain conscious of my centrality as the primary researcher in the current study. While my personal interests and past experiences were mentioned in previous chapters, I feel it is important to reflect on how the associated perspectives and expectations, as well as my personal values, may have influenced the research process and the interpretation of participants’ narratives.

My interest in exploring the experiences of parents of children with ASD arose due to my previous employment, working as a teacher for children with ASD in a preschool service and in family homes. By working closely with families of children with ASD to implement educational programmes and design interventions, I developed a passion for this particular area. Having witnessed the significant challenges associated with caring for a child with ASD, I became interested in the additional supports that were available to parents, and how they experience these services.

Due to my past experiences, I had a number of preconceptions at the initial outset of this research. As I was familiar with the demands involved in caring for children with ASD, I initially would have had an assumption that the main purpose of respite care was to provide parents with a break from caring. Having seen so many parents over-stretched to the point of exhaustion, I had assumed parents chose to access respite care purely in order to get a break from the child and to have some time to themselves. Through this research, I now see that this a relatively simplistic view of parents and their experiences of caring for their child. As well as getting a break for themselves, many parents also view respite as an opportunity for their child to develop new skills and build their independence. It was striking how frequently parents compared their child’s experiences to that of typically developing children, and how they wanted respite to play a role in supporting their child to have similar life experiences to children without an ASD diagnosis.

From my conversations with numerous parents of children with ASD and my work in a children’s disability service as part of clinical training, I was aware that respite services were very limited and that many families had no access to respite at all. Based on this, I would have had a preconception that parents would all have been happy to receive respite care and were eager to be deemed eligible and placed on the waiting list. In my experience as a teacher of
children with ASD, parents had always appeared willing and happy to hand their child over to staff for the school day. Working as a trainee clinical psychologist, I had frequently heard parents speak about their need for respite and their frustration with the lack of availability. I am slightly embarrassed to admit that I had not given any consideration to the emotional conflict that parents can feel in relation to availing of respite care for their child. Having carried out this research, I am now aware of the complexity involved in the decision to access respite care and how, many parents, seem to continually struggle with the idea of handing over the care of their child to someone else. Parents’ role as the primary carer for their child seems to make it quite difficult for them to hand over the responsibility to someone else and they struggle to get true respite from this role.

Before commencing with this research, I also had a preconception about how parents adjusted and accepted their child’s diagnosis of ASD. While I had experienced the sense of devastation and grief that some parents felt in relation to their child’s diagnosis, I had assumed that many parents would adjust to their child’s diagnosis, when given time, the right information and support. Carrying out this research has allowed me to see that this is a continuous process for some parents that extends throughout their child’s life and is accompanied by a certain level of doubt, which should be recognised by services. It appears that this can be quite an individualised experience, with some parents finding a proactive approach helpful, and others requiring more time to reflect and accept their child’s diagnosis. I had also not fully considered the impact of the diagnosis on the parent themselves, and how they can struggle with the changes that the diagnosis brings to their own perspectives and view of themselves and their child.

I think being external to the service made the recruitment process slightly more challenging for me as I was quite reliant on staff to identify potential participants and send out the recruitment material, so had very little control over the timing and efficiency of the recruitment process. Reflecting on the interviews, it is apparent during the transcripts that there is a shift in the tone of the interviews as the research progressed. In the initial stages, I feel that nerves and apprehension led me to rely on the interview schedule to guide the conversation too much at times, rather than following the natural flow of the conversation. As I became familiar with the schedule and my confidence grew, I was comfortable adopting a more conversational style, allowing the participant to be more directive in relation to content of the interview, and exploring areas of interest that arose during the discussion in more depth.
I found the data analysis stage the most difficult and daunting aspect of this project. I found the volume of data that was collected during the interviews slightly overwhelming and I continually questioned whether I was accurately interpreting and inhabiting the life worlds of each of the participants. I struggled to condense the data into a meaningful, coherent account of the participants narratives. I also felt grateful that I had the opportunity to meet with such a strong, resilient group of parents who had very openly discussed their experiences, the challenges they face, and shared their thoughts and feeling so honestly. In producing this final report, I really wanted to stay true to their words and do justice to the stories they had shared.

5.6 Implications for Clinical Practice

The current study presents a unique insight into the lived experience of Irish parents accessing respite services for their child with ASD. It is hoped that the findings of this research will add to the existing literature in the area of respite care and individuals with ASD. There are a number of clinical implications from the findings of this study.

Firstly, many participants in this study spoke about their experience of the diagnostic process for their child, the shock they felt, and their subsequent struggle to adjust. Some referred to the sense of isolation and abandonment they felt following their child's diagnosis, feeling as if there was nobody to support them or provide them with information. It is essential that clinical staff working as part of an assessment/diagnostic team recognise the struggle that many parents face when trying to come to terms with an initial diagnosis of ASD. It appears that there should be follow-up appointments for parents after their child has been diagnosed, to discuss how they are coping, offer additional information or talk through anything that was unclear, and to offer support in terms of applications for respite and other additional supports or allowances.

Secondly, several parents spoke about the emotional conflict they experienced when choosing to access respite care for their child. Parents seemed to feel a sense of fear or intimidation when it came to accessing services, as they were often afraid to complain or highlight any concerns they had about respite, in case this would jeopardise their service. Many also highlighted their feelings of guilt about accessing respite care and taking a break from the responsibility of caring for their child. Services should acknowledge the potential for respite to act as a stressor for parents and should offer support in preparing the child and family for respite care. It appears that parents would benefit from a collaborative approach to respite provision, with the opportunity to discuss their concerns with clinical staff, in order to feel more comfortable with the service.
An additional clinical implication relates to the impact of caring on parents' own physical and mental wellbeing. While respite services acknowledge the importance of parents getting a break from the constant demands of caring, they do not seem to offer emotional support to parents or caregivers. Many of the parents in the current study referred to the constant stress, exhaustion and frustration they can experience caring for their child, and the toll this can take on their health. It appears that it would be very beneficial to offer parents psychological support in order to explore their thoughts and feelings, discuss stress management, and to promote their psychological and emotional wellbeing. It seems it would be helpful if this was offered to parents as part of the children’s disability service, in order to recognise the importance of their role as carer of the child, ensure the clinicians offering support are aware of the complexities of ASD, and to minimise the complications associated with referrals to external agencies.

5.7 Implications for Policy

Throughout this research, parents consistently spoke about the need for services to adopt a more family-centred, tailored approach, in order to fit the needs of each individual child and their family. Parents want services that offer choice, that are appropriate for the child’s developmental stage, that have dedicated staff, that are flexible and well-coordinated. Instead of allocating respite hours to parents once they become available, it seems that it would be more helpful to collaborate with parents in order to design a service plan that is meaningful. Parents and families are an extremely valuable source of information and service providers should consult with them where possible and consider their perspectives when designing and allocating services and supports.

Parents also expressed their concerns and frustration with the model of service provision for individuals with ASD and other disabilities. Rather than promoting inclusion in the mainstream community, a lot of the services seemed to support the segregation of children with ASD and/or intellectual disabilities away from their typically developing peers. Many of the parents expressed their disappointment that respite care could not include the child’s siblings or friends, as they felt this would be a more enjoyable, natural environment for the child, and would be beneficial for the child’s social-emotional development and enhance the quality of their relationships. Instead of grouping children with special needs together, it appears that parents would prefer services to remove the ‘red tape’ and to support their children to access and participate in their own community.
Another implication for policy that has arisen out of the current findings is the need for change to the system regarding the eligibility and allocation of services. Many participants spoke about the battle to access services, the struggle to get information, the lack of clarity about service options and allocation, and the lack of opportunity to give feedback and review progress, with similar findings reported in a recent report by the HSE (HSE, 2018). There should be greater communication and inter-agency collaboration between the professionals and services involved in supporting a family. Services should welcome the contribution of parents and should strive to remove the barriers that seem to be placed in their path to accessing necessary supports.

There also appears to be a need for ASD specific legislation and a national autism strategy to work towards the inclusion and empowerment of individuals with ASD in the wider community. While an Autism Spectrum Disorder Bill was passed by the Seanad in 2017, this has not yet been put forward to the Dáil to be signed into legislation. In 2018, the publication of a national autism strategy was announced, which was to be included in the HSE Service Plan for 2019. While it is hoped this will address the complex and varying needs of children and adults with ASD and their families throughout their lifetime, it has yet to be released (O’Brien, 2019).

5.8 Implications for Education

There are also a number of educational implications from the findings of the current study. It is important for any clinicians or professionals working in the area of disability to receive specific training about ASD, the challenges associated with caring for a child with ASD, and the potential impact that a diagnosis can have on parents and the wider family. This should include input about the potential benefits and challenges associated with respite care so staff are informed and can offer support to parents. It also appears that it would be helpful to offer parents who have recently gone through the diagnostic process some educational and training opportunities about ASD, approaches to challenging behaviour, and self-care strategies. This is in line with recommendations put forward by the HSE in their report on the provision of services for individuals with ASD in this country (HSE, 2018).

Some of the participants in this study identified a lack of understanding and awareness of ASD in some schools, and in the wider community. While teachers often receive some form of training in relation to ASD and special needs in the classroom, it would be helpful for them to receive additional input about ASD and the associated behaviours and sensory sensitivities if
they are teaching a child with ASD. While there is a growing awareness of ASD in the community, and numerous ongoing initiatives by various organisations to promote knowledge of ASD, it appears that parents feel that ASD is still misunderstood in the wider community.

Many parents also expressed their concerns about the lack of awareness and understanding of ASD among respite workers and queried the level of training that was offered to staff. It appears that respite services should place a greater focus on training their workers specifically in ASD, how to manage challenging behaviours, and alternative communication skills. Additionally, as some parents mentioned the importance of their relationship with the respite worker and how this offered them support as well as their child, it could be helpful for the respite workers to receive some training in relation to their interpersonal skills and relational style.

5.9 Implications for Service Delivery

The results of the present study also have a number of implications for the delivery of supports and services and provision of respite care within the children’s disability service where the research was carried out, and in the wider community of disability organisations and agencies. As mentioned in preceding paragraphs, many of the parents spoke about the lack of information about the services that were available and about the battle they faced trying to access respite care. It would be helpful for parents who were new to the service to get an introductory session to all the different areas of service provision, including information about different respite services, eligibility criteria, and allocation of hours. This would hopefully ensure that parents were aware of all of the options available to them, would allow them access to essential information, and could also help to ease some of the uncertainty and fear that several parents felt about their respite being taken away.

Across the literature, parents have consistently called for respite services to be more tailored and personalised to each individual child and their family, which is in line with the findings of this research. Before deciding on a respite service and allocating respite hours, it would be helpful for the service to meet with the child and family and with other professionals involved in their care, to design an individualised plan for respite care. This would allow families to discuss their needs, their goals for their child attending respite care, and to outline their schedule in order to identify the most suitable and beneficial time for respite care. It would be helpful to build in review periods or follow up meetings as the child grows develops, to allow parents the opportunity to discuss whether the service is still meeting their needs and those of their child, and to identify whether there is a need to change to a different model of respite care.
in order to continue to support the child and the family in the most helpful way. This could also allow the parents to discuss their own wellbeing and highlight whether any additional supports would be beneficial.

Many parents spoke about the importance of developing a close, trusting relationship with their respite worker and felt that this was not always recognised by the service in their approach to assigning a respite worker to a family. It would be helpful for the service to build in an introductory period before commencing with respite care, during which the new respite worker and family have a chance to meet, to get to know each other and to start to develop their relationship. This would allow the respite worker to become familiar with the child and their needs, and would allow parents the opportunity to observe the respite worker engaging with their child, which may help to ease their concerns. During this introductory period, the respite worker could gradually become more involved in interacting and caring for the child while the parent could begin to step back, before the respite worker is left alone with the child. This approach would also allow the respite worker to learn what the child enjoys and to identify whether there are any areas where they would benefit from some additional training or support, for example learning to use alternative forms of communication. Should there be a change of respite worker, the service should prepare for this and attempt to match the new respite worker with the child and family.

An additional area that the service could explore is actively seeking feedback from parents about their personal experience with respite care and their opinions on future developments within the service. Throughout the interviews, parents noted that the organisation did not look for any feedback about the quality of the service they were receiving or any concerns they may have had. By encouraging and requesting feedback from parents, the service can identify areas that are working areas, areas that may need improvement, and can reassure parents that their views and opinions are being heard and considered.

5.10 Implications for Future Research

As there is relatively little existing literature exploring parents’ experiences of accessing respite care for children with ASD, there a number of opportunities for future research in this area. It would be interesting to replicate the current study with parents of children with ASD accessing respite care from different services and in other geographical areas to get a broader view of parents’ perspectives of service provision around the country. It could also be helpful to carry out research exploring parents’ experiences of different types of respite care, such as
residential, in-home or group respite, and consider how each of these options fit for families of children with ASD.

Research involving parents of children with ASD who do not avail of respite services could provide an insight into their experiences and perspectives of factors that hinder their engagement with services. This could be beneficial in that it could help to identify specific barriers or obstacles that parents of children with ASD encounter when trying to access respite services. It could also highlight areas of service delivery that need improvement or adaptation in order to meet the needs of parents and children with autism.

It would be interesting to carry out longitudinal research, following parents and families from the initial period following their child’s diagnosis through to accessing respite services. This could provide interesting insights into how the needs of the child and family change over time, and how the role if respite shifts in order to meet those needs. It would also be interesting to carry out longitudinal research, looking at the short and long-term impact of respite care on the wellbeing of parents and caregivers of children with ASD.

There is a dearth of literature exploring the specific experiences of fathers caring for children with intellectual or developmental disabilities, as the majority of participants in these studies are mothers, similar to the current study. More research is needed to explore the views and perspectives of fathers, as well as other family caregivers, as these could differ to those expressed and experienced by mothers. Additionally, research exploring the perspectives of siblings of children with ASD, would also be helpful. There is also a noticeable lack of research investigating the experiences of children with ASD themselves, which would be useful in terms of planning for service provision and ensuring that the support options available are appropriate and meaningful for children with ASD.

At a service level, research involving respite workers could prove helpful, in order to explore their experiences of providing care, their perspectives on the role of the respite, and identify the need for any improvements or adaptations that could benefit the worker and the families they support. Services could also carry out their own research evaluating parents’ experiences of respite care, looking at outcomes related to the wellbeing of the families they support, and the impact of providing ASD specific training to its staff.
5.11 Study Conclusion

The principle aim of this study was to explore parents’ experiences of accessing respite care for their child with ASD. A comprehensive review of the literature found that respite care can be an invaluable support for parents and families of children with disabilities, and is associated with lower levels of stress, reduced levels of depression and anxiety, and improved carer well-being. The literature review identified a lack of research involving parents of children with ASD so it was hoped that this study would provide a unique insight into the lived experience of Irish parents availing of respite services for their child with ASD.

By engaging with parents through semi-structured interviews it was possible to capture their lived experiences, explore their perspectives of service delivery and the meaning of respite care for themselves, their child, and their family. It became clear throughout the study that it was not possible to explore parents’ experiences of respite care without first acknowledging the impact that receiving a diagnosis of ASD has had on the parent’s life and that of their child. Many parents spoke about the initial shock of receiving a diagnosis of ASD for their child and highlighted a need for continued support from services with the process of adjustment.

The study provides an insight into the demands and challenges associated with caring for individuals with ASD and highlights the important role of respite, in offering parents a sense of relief from these demands and offering the child opportunities to develop skills and build their independence. The importance of the respite worker is also identified, particularly in relation to their skills and understanding of ASD, their capacity to care, and their relationship with the parent and the child. Although the value of having a respite service is consistently noted, there is a need for improvement in many aspects of service delivery and acknowledgement of the emotional conflict many parents experience with respect to accessing respite care.

The findings of this research have been outlined and discussed in relation to the existing literature. Strengths and limitations of the current study have been addressed, and a critical reflection of the research process has also been provided. Implications for clinical and educational practice, policy and areas for future research have been identified and discussed.
References


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South Asia – Views from Pakistan and India. *International Review of Psychiatry*, 27(3), 247–256.


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Appendices

Appendix A: Information Letter for Service Coordinators

An exploration of parents’ experience of accessing respite care for their child/children with Autism Spectrum Disorder (ASD)

Dear ____________,

I am a Trainee Clinical Psychologist in University of Limerick and as part of my studies I am carrying out a PhD research project. I would be like to invite the parents and families attending your service to take part. This research will explore parents’ experiences of accessing respite care for their child/children with ASD. I would be grateful if you would consider allowing me to seek consent from the parents/guardians availing of your service to participate in this study.

The participating parents would be asked to attend an interview with the researcher. The parents will be asked to complete a short demographic questionnaire and will also be invited to take part in a 60-90 minute interview with the researcher. The parents/guardians will be asked to answer some questions about their experience of accessing respite care, their views and opinions of respite care, concerns and challenges they have in relation to accessing respite care, and the impact of respite care on their family and child. Parents will be assured that participating in the study will not affect them accessing respite in the future.

While some of the questions asked may be sensitive, the participating parents/guardians will not be required to answer any question they do not wish to. The information they give will be kept confidential and stored on the researcher’s computer which is protected by a password. The information will be anonymised and kept for a period of five years, after which it will be deleted and/or disposed of sensitively.

Participation in this study would be entirely voluntary and the parents/guardians may choose not to consent or to withdraw consent and discontinue participation in this study at any time. If you have any concerns or questions about the study, please contact me or my project supervisors (Dr. Barry Coughlan and Dr. Anne O’Connor). Please find enclosed information sheets for parents which explains the exact details of the study.

Thank you for your time and consideration.
Yours sincerely,

______________________________

Aisling McGrath

**Principal Investigator Contact Details:**
Aisling McGrath  
Trainee Clinical Psychologist  
Department of Psychology  
Tel: 087 7600763  
Email: 16030974@studentmail.ul.ie

**Supervisors:**
Dr. Barry Coughlan  
Acting Head of Clinical Psychology  
University of Limerick  
Department of Psychology  
Tel 061-234345  
Email: barry.coughlan@ul.ie

Dr. Anne O’Connor  
Clinical Co-ordinator  
Department of Psychology  
Email: anne.b.oconnor@ul.ie
Appendix B: Invitation Letter for Participants

Invitation to Participate in Research Project

Dear Parent,

I would like to invite you to participate in a research project that I am carrying out as part of my Ph.D. in Clinical Psychology in the University of Limerick. The title of the project is: *An exploration of parents’ experience of accessing respite care for their child with autism spectrum disorder.*

I am looking for parents of children who:
1. have a diagnosis of autism spectrum disorder
2. have accessed and availed of respite care over the course of at least one year

to take part in this study.

The aim of this project is to learn more about parents’ experiences and perceptions of accessing respite services for their child with ASD, to hear about your views and opinions of respite care, learn about any concerns or challenges you may have faced when trying to avail of respite services, and to hear about the impact respite care has had on you, your family and your child. I would like to hear from as many parents as possible so your participation in this research project would be very much appreciated.

If you agree to participate in this study, you will be invited to attend an interview with me. You will be asked to some questions about you and your child, the type of respite services you have accessed, and how long you have availed of respite services. The interview will last 60-90 minutes, and you will be asked questions about your experiences of respite care. The interview will be audio-recorded and then transcribed. Your name and your child/children’s names will not appear on any information. You will be assigned a fictitious name when the information is being written in a report by the researcher.

Participation in this study is completely voluntary. You may choose not to take part in the study or you may choose to withdraw your participation from the study up to one month after your interview by contacting the researchers. Participating in this study will have no impact on your access to respite services now, or in the future. Your participation will be kept confidential at all times.
I have attached an information sheet that may offer you some more information and answer some of your questions. If you have any more questions, please don’t hesitate to contact any of the researchers mentioned below.

**Once you have read all of the information, if you would like to participate in the study please contact me by phone at 087 7600763 or by email at 16030974@studentmail.ul.ie**

Thank you for taking the time to read this. I would be grateful if you would consider participating in this study.

Yours sincerely,

Aisling McGrath

**Contact name and number of Project Investigators.**

**Principal Investigator Contact Details:**
Aisling McGrath  
Trainee Clinical Psychologist  
Department of Psychology  
Tel: 087 7600763  
Email: 16030974@studentmail.ul.ie

**Supervisors:**
Dr. Barry Coughlan  
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Tel 061-234345  
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Dr. Anne O’Connor  
Clinical Co-ordinator  
Department of Psychology  
Email: anne.b.oconnor@ul.ie
Appendix C: Participant Information Sheet

PARENT/GUARDIAN INFORMATION SHEET

An exploration of parents’ experience of accessing respite care for their child/children with Autism Spectrum Disorder (ASD)

As part of my Doctorate in Clinical Psychology in the University of Limerick, I am carrying out a study on parents’ experience of accessing respite care for their child/children with ASD. This information sheet will tell you what the study is about.

What will I have to do?
Should you choose to participate in this study, you will be asked to attend an interview with the researcher. You will be asked some questions about you and your child; and will be invited to take part in a 60-90 minute interview with the researcher. You will be asked to answer some questions about your experience of accessing respite care, your views and opinion of respite care, any concerns and challenges you had in relation to accessing respite care, and the impact of respite care on your family and your child.

What are the benefits?
Research has shown the benefits that accessing respite care can have on parents, families and the child themselves. To date there has been very little research carried out with parents of children with ASD who access respite care, so the aim of this study is to improve our knowledge by learning about parents’ own experiences of respite care. We are interested in hearing about parents’ views and opinions of respite, exploring the impact respite can have on families, and also highlighting challenges or worries that parents may have had. In the future, this information could prove to be very useful in the planning and development of new respite services.

What are the risks?
It is possible that you may become upset/distressed when discussing the challenges you may have faced while availing of respite services. You will be provided with the details of a designated contact person from the service who you can contact should you experience discomfort during the interview. There may be questions that you would prefer not to answer during the interview. If this happens, and you do not want to answer any question, you do not have to.
What if I do not want to take part?
Participation in this study is voluntary and you can choose not to take part or to stop your involvement in this study at any time. Should you feel at any stage that you want to stop taking part in the study, then this is dealt with in a sensitive and confidential manner.

What happens to the information?
The information that is collected will be kept private and stored securely and safely on the researchers’ computer. The computer is protected with a password. Your name and your child/children’s names will not appear on any information. You will be assigned a fictitious name when the information is being written in a report by the researcher. The information that is gathered in the study will be kept for five years. After this time, it will be destroyed.

Who else is taking part?
Other parents and guardians of children with ASD who are accessing respite care will be invited to take part in this study.

What if something goes wrong?
In the unlikely event that something goes wrong, the interview session will immediately stop until the researcher and the parent are ready to restart the session, or the session will be stopped completely.

What happens at the end of the study?
At the end of the study the information will be used to present results. The information will be completely anonymous. No individual’s name appears in any of the results. All data gathered from the research will be stored securely and safely by the researcher in their office for 5 years. Information that is stored on computer will be stored by the researcher on a computer that is password-protected.

What if I have more questions?
If you have any questions about the study you may contact any of the researchers. It is important that you feel that all your questions have been answered.

What happens if I change my mind during the study?
At any stage should you feel that you want to stop taking part in the study, you are free to stop and take no further part. There are no consequences for you if you change your mind about being in the study.

What do I need to do if I want to take part in this project?
If you would like to take part in this study, please contact the principal investigator Aisling McGrath by phone on 0877600763 or by email at 16030974@studentmail.ul.ie.

Thank you for taking the time to read this. I would be grateful if you would consider participating in this study.
Contact name and number of Project Investigators.

Principal Investigator Contact Details:
Aisling McGrath
Trainee Clinical Psychologist
Department of Psychology
Tel: 087 7600763
Email: 16030974@studentmail.ul.ie

Supervisors:
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Dr. Anne O’Connor
Clinical Co-ordinator
Department of Psychology
Email: anne.b.oconnor@ul.ie
Appendix D: Participant Consent Form

PARENTAL/GUARDIAN INFORMED CONSENT

Title of Study: An exploration of parents’ experience of accessing respite care for their child with autism spectrum disorder (ASD)

Principal Investigator: Aisling McGrath

Agreement to Consent

- The research project and procedures associated with it have been fully explained to me.
- I have read and understood the parent/guardian information sheet and have had time to consider whether to take part in this study.
- I have had the opportunity to ask questions concerning any aspects of the project.
- I understand what the study is about, and what my results will be used for.
- I understand where the research will be carried out.
- I understand that my name or my child’s name will not appear on any research data from this study.
- I give permission that my data can be used anonymously in the publication of higher degrees, presentations and academic publications.
- I am fully aware of all of the procedures involving my participation, and of any risks and benefits associated with the study.
- I know that my participation is voluntary and that I can withdraw my participation in the study without giving any reason.
- I am aware that my decision not to participate or to withdraw will not restrict my access to services normally available to me.

This study involves audio recording. Please tick the appropriate box

- I am aware that my participation in this study will be audio recorded and I agree to this. However, should I feel uncomfortable at any time I can ask that
the recording equipment be switched off. I am fully informed as to what will happen to these recordings once the study is finished.

- I do not agree to being audio recorded in this study.

After considering the above statements, I consent to my ___________________ (name) involvement in this research project.

Parent Signature: _______________________________    Date: ____________

Witness Signature _______________________________    Date: ____________
Appendix E: Interview Schedule

Interview Schedule

Interview with Parent/Guardian who accesses respite care for their child/children with ASD

The purpose of the interview is to ask the parent about their experience of accessing respite care, their views and opinion of respite care, concerns and challenges they had in relation to accessing respite care, and the impact of respite care on their family and child.

1. What has your experience of accessing respite care for your child been like?
2. How did you come to the decision to apply for respite care? What was that process like?
3. What are your views and opinions of respite care for children with ASD/disabilities and their families?
4. What are your views and opinions of respite care for your child and your family in particular?
5. What concerns do/did you have about availing of respite?
6. Have these concerns changed over time?
7. Have you faced any challenges in relation to accessing and availing of respite care for your child?
8. What impact does respite care have on you, your child and the family?
9. Have you anything else to add?
Appendix F: Extracts from Reflective Journal

10/05/2018

Phone call with service manager to discuss research idea and recruitment of potential participants. She was very interested in project and felt that it would be helpful for the service to hear parents’ perspectives on respite services. Discussed the various respite services that are provided and how to approach recruitment of participants. Information given about ethics committee and contact details, and for gatekeeper from the service who can assist with recruitment. I am feeling quite positive about the research as the service seem to be interested in the project and are happy to facilitate the research.

8/06/2018

Phone call with gatekeeper to finalise details for the ethics application. Discussed changes to the inclusion and exclusion criteria. Service felt it would be important to mention in the criteria that parents will not be included if they had learning disabilities, verbal comprehension/receptive language difficulties, literacy difficulties, or were non-English speakers, so this was added. Also discussed options for support within the service for parents following the interview should they experience distress. It was agreed that I would advise parents to contact their local service coordinator if they had any concerns.

11/11/2018

Interview with parent today. She was very emotional throughout the whole interview which was slightly challenging as I feel I am still getting used to the interview schedule. Tried to be as supportive as possible throughout and really listen to her as she spoke about her experience. She commented how she never usually cries about things but having to think about the journey she has been on with her daughter and talk about it brought out the tears. It seemed that the diagnostic process was very difficult for her and she is still trying to come to terms with her daughter’s diagnosis and what this means for her and their family. At the end of the interview I enquired about any additional supports she could avail of. Parent assured me that she has support from family members and that she is aware of contact details for service should she continue to feel upset.
21/12/2018

Another interview, will probably be coming to the end of the interviews soon as I am conscious of the deadline for submission. I was struck by how practical and matter of fact this parent seemed in her approach to the assessment and diagnosis process. She discussed some of the negative experiences she has had with respite. Was quite shocking to hear about some of her interactions with one respite worker who did not seem particularly dedicated to her job and complained to parent about pay and conditions, which seemed unprofessional. It appeared she was using respite to get her shopping done instead of doing meaningful activities for the child. Could sense the parent’s disappointment and frustration with this, which I also felt myself to some extent. I was left wondering what it must be like for parents to feel like the person taking over the care of their child does not seem to truly care about them or recognise the importance of this responsibility.

12/03/2019

Working my way through the analysis stage of the project. Feeling slightly overwhelmed by the sheer amount of data collected. Have been following the process suggested in the Smith book and in IPA workshop which has been helpful, making the data more manageable. Hope I will be able to produce a cohesive account of all of the results. Really want to make sure I don’t overlook any important points that were shared by parents. Feel very strongly that I want to do justice to each of the parents and the stories they shared.

05/04/2019

Received feedback from supervisor on draft chapters. I am happy with the comments and I plan to make the suggested changes over the next couple of days in order to finalise these sections. I need to continue to work on my results and discussion chapters.
## Appendix G: Examples of IPA Analytic Process

<table>
<thead>
<tr>
<th>Emergent Themes</th>
<th>Original Transcript</th>
<th>Exploratory Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Diagnostic Process</td>
<td>I: So can you just tell me a little bit about what it’s been like, accessing respite for Molly? R: Em, so when we came back from Temple Street, she....obviously I was up there and (husband) was up there and then she was diagnosed so she came up there. I: Right R: And then she came back in and we didn’t have anyone that would step in to the breach, that would come to our house, and mind her.</td>
<td>Hospital at time of diagnosis <em>Up there repeated</em> Whole family away from home, away from the familiar</td>
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<td></td>
<td></td>
<td>Need for help <em>Step into the breach – sounds like military term. Signify battle? Lack of support at time</em></td>
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<td></td>
<td>Justifying why needed support possibly? Explanation as to why couldn’t manage</td>
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<tr>
<td>2 Impact on parents</td>
<td>R: Coz she kinda needed to stay here and she wasn’t allowed to go to school, em, until (brother) was cleared with E coli, she wasn’t allowed to go to the preschool at all. I: Okay, right.</td>
<td>Respite in crisis situation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Struggle with diagnosis <em>Impact of diagnosis on mother – where did that come from?</em></td>
</tr>
<tr>
<td>3 Impact on parents</td>
<td>R: So she had to be minded and (husband) had to go back to work and, em, the Early Intervention Services got us an agency staff from (name of agency) and then when (brother) came back it was just, I suppose, I mean for me, I was just in a complete bad place..... I: Yeah.</td>
<td></td>
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<tr>
<td>4 Change in parent</td>
<td>R: Because of it, and, eh, Molly was just completely all over the shop and then I was very protective over her because, I just, I just, I changed....and eh, I rang (Children’s Service) because I didn’t actually know they had a service at all.... I: Okay</td>
<td>Turmoil. Protective of child – change in parent <em>’I’ repeated – emphasise impact on her Change in parent due to ASD – need to protect child</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited knowledge of service</td>
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<td>Emergent Themes</td>
<td>Original Transcript</td>
<td>Exploratory Comments</td>
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<tr>
<td>R: I would never had know they had a service but I have a friend who has a son with ASD and...</td>
<td><strong>Uncertainty about diagnosis.</strong> Trying to convey child’s profile, not typically ASD?</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I: Okay R: I had helped her through the process of her son being diagnosed... I: Right R: And I thought she was completely bonkers doing it because Molly does all the same things I: Yeah</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Managing behaviours R: And I would never have put Molly in the same box as, or (child’s name)...I...and I don’t know how she found out about it but she said why don’t you just ring them and ask and, em, so the lady came out to assess us and the only way I could keep both my children from crying was to let them sit in the car and play in the car I: Right R: So they were outside sitting in the car while we were in the living room having a conversation.</td>
<td>‘Box’ for ASD – stigmatising Reluctant to accept child’s diagnosis and reluctant to be judged just by ASD box Challenge of managing behaviours Unconventional/not like other families</td>
</tr>
<tr>
<td>7</td>
<td>Stress in house R: She was like, how long are they in the car and I said for most of the day because they’re just not... they were so de-regulated, the two of them. (Brother) was very upset after being in hospital I: Yeah R: And Molly was very upset because we were all upset and em, so when she came, our house was very stressed</td>
<td>Impact of situation on children Family upset following situation – impact on stress levels</td>
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<td></td>
<td></td>
<td>Stress in house</td>
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<tr>
<td>Emergent Themes</td>
<td>Original Transcript</td>
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<tr>
<td>I: Yeah R: Very, very stressed</td>
<td>Repetition ‘very’ – emphasis What was stress about? Grief/concern about diagnosis? Managing behaviours?</td>
<td></td>
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<tr>
<td>R: So she said that she would give us hours and that it would take time to set into place so that was kind of October….and then we went in and we met some….I suppose like for us it was, taking Molly away isn’t, it’s not a solution because we need a break from both of our children I: Absolutely</td>
<td>Break from both children For this family, acknowledgement that need break from both children to get true rest</td>
<td></td>
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<td>R: And she was like, well you can’t do that and I was like, well why not? What’s the point? I: Yeah R: Like, that’s excluding one of our children and that’s not fair. That doesn’t give…that makes her feel like she’s a burden, in my eyes…and sometimes she is a burden but I don’t want her to feel like that.</td>
<td>Purpose of service if not meeting needs Excluding child with ASD Burden of caring Efforts to ensure child feels loved, cherished – contrast with sense of burden</td>
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<td>I: Sounds like you’re very sensitive to her as well R: Yeah…it is…it’s like….I know that they have a respite club on a Saturday but….the other part of me says that, while a child has special needs, just because they have special needs doesn’t mean that they have to be surrounded by other people that have special needs I: Yeah</td>
<td>Segregation of children with disabilities Repetition of ‘special needs’ – labelling Reluctance to have child labelled, grouped with others purely due to diagnosis. Not fit her image of her child?</td>
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<tr>
<td>Emergent Themes</td>
<td>Original Transcript</td>
<td>Exploratory Comments</td>
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<tr>
<td>11 Respite ‘dumping ground’</td>
<td>R: And that is what I think that respite club is about, and it just, to me, is a dumping ground. It doesn’t, it’s not, it doesn’t rest easy with me. I: It doesn’t fit with what you want for Molly</td>
<td>Unease about leaving child in club  ‘Dumping ground’ – sense of disrespect  Wants child to feel valued and appreciated</td>
</tr>
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Appendix H: Ethical Approval Letter

Enable Ireland Research, Ethics and Quality Committee
Research Proposal Approval Form

Date: 26 September 2018
Reference Number: RA53 AMcGrath June 2018
Applicant Name: Aisling McGrath
Proposal Title: An exploration of Parents experience of accessing respite care for their child with autism spectrum disorder

REQC Feedback

Approved:
You may proceed with the research as outlined in the research proposal submitted to the REQC. The REQC Co-ordinator will contact you for an Interim Progress Report which you must complete at a later date. A final copy of the study must be submitted to the REQC Co-ordinator after completion to the following address:
Kate McMahon
HR & Corporate Affairs
Enable Ireland
8 Rsusset Court
Chuchyard Lane
Baillntemple
Cork

Kate McMahon – Research, Training & Quality Officer

Enable Ireland Research, Ethics and Quality Committee