



**To explore access to respite care services
through the acute care services from the
perspectives of parents of autistic children.**

PhD Thesis

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Emma Cooke

16343471

Supervisors: Professor Maria Brenner and Professor Valerie Smith

Thesis submitted in fulfilment of the requirement for the Degree of Doctor in Philosophy
at Trinity College Dublin.

Declaration

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A handwritten signature in dark ink, reading "Emma Cooke". The signature is written in a cursive style with a large initial 'E' and a long horizontal stroke.

Emma Cooke

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Dissemination of research

The following research outputs published, submitted for publication and/or presented as oral and/or poster presentations form the beginnings of a continuous dissemination plan.

Published papers relating to thesis

- A systematic review protocol was designed in May 2018 to support the systematic review on the research topic and was also registered with Prospero (CRD42018106629).
- A systematic review titled 'Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface' was completed and published in *BMC Paediatrics* in 2020.
<https://pubmed.ncbi.nlm.nih.gov/32443974/>
- This systematic review was translated into Norwegian and published at the request of the Autism Society in Norway.
<https://online.flippingbook.com/view/706011/24/>

Other papers submitted for publication

- A review titled "The impact of COVID-19 on parents of autistic children with a particular focus on access to respite care." was submitted to *Advances in Autism Journal* in July 2022 and has been accepted for publication.
- A review, titled 'A Review of EU and UK Autism Strategies; Where and how does respite care feature?' was submitted to *Advances in Autism Journal* in July 2022 and is under peer review pending decision.

Conference presentations

- December 2019: Children's Research Network- Oral and poster presentation provided on findings from systematic review titled 'Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface'
- March 2020: Trinity College Dublin School of Nursing and Midwifery The Conf2020-poster presentation on 'Parents' experiences of accessing respite

care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface'

Awarded Bursary from EIT Health to participate in the School of Nursing and Midwifery Trinity Health and Education Conference 2020 in response to abstract submitted on conference theme.

Planned research dissemination

- Trinity College Dublin School of Nursing and Midwifery The Conf2023-Two abstracts submitted for poster and oral presentation in Nov 2022 based on completed reviews of 'The impact of COVID-19 on parents of autistic children with a particular focus on access to respite care' and A Review of EU and UK Autism Strategies; Where and how does respite care feature?'. Awaiting outcome of submission.
- Draft paper in progress based on findings from this PhD 'To explore access to respite care services through the acute care services from the perspectives of parents of autistic children'. Plan to submit for journal publication end of January 2023.
- Plan to meet with autism support groups, charities and health and social care professionals that supported this study and disseminate findings from March 2023 onwards.

Summary

Background: Research has consistently shown that parenting an autistic child can be challenging and stressful. Respite care offers a break for parents who experience such stress and also provides positive opportunities for the child to interact with their peers. In the absence of defined pathways to respite care in Ireland, parents of autistic children are accessing the acute services as a means to accessing respite care. To date, little is known about parental experiences of accessing respite care services, especially with respect to the complex decision-making involved and navigation of pathways. This study provides a comprehensive understanding of parent's lived experience of accessing respite care for their autistic child through the acute care services.

Method: A hermeneutic phenomenological approach underpinned the collection and analysis of data. Semi-structured interviews of 15 parents who had experience of accessing respite care through the acute care services for their autistic child took place during 2020 and 2021.

Results: Analysis of the interview data, using Van Manen's framework (2007, 2014) revealed five themes and 11 corresponding subthemes that reflected parents' lived experiences. The five overarching themes are as follows: Parents' experience of caring for an autistic child; Complex system of multiple interactions with services and health and social care professionals; Accessing acute care services for respite care: A last resort; Accessing respite care: An ongoing process across the lifespan; Acquired knowledge and information: Requirements for effective respite provision. Findings identified an overwhelming need for respite care but parents were faced with many barriers when accessing respite across their autistic's child's lifespan.

Conclusion: This study provides a unique insight into the lived experience of accessing respite care through the acute care services from the perspective of parents of autistic children. Findings identified a number of implications for practice, policy, service delivery, education as well as social and cultural implications. In summary, this study highlights a critical need for effective implementation of integrated healthcare services for autistic children and adolescents whose numbers are rapidly growing.

About this study Infographic



i Introduction

Parenting an autistic child can be challenging and stressful.

Respite care offers a break for parents who experience such stress and also provides positive opportunities for the child to interact with their peers.

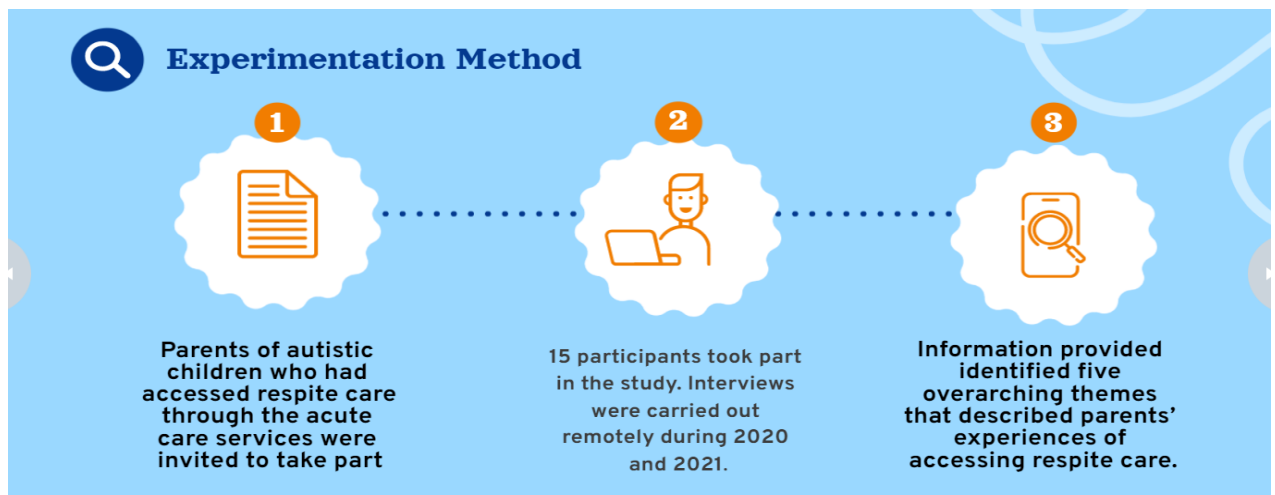
In the absence of defined pathways to respite care in Ireland, parents of autistic children are accessing the acute services as a means to accessing respite care.

💡 Hypothesis

Little is known about parental experiences of accessing respite care services, especially with respect to the complex decision-making involved and navigation of pathways.

This study explores parent's lived experience of accessing respite care for their autistic child through the acute care services.

About this study infographic

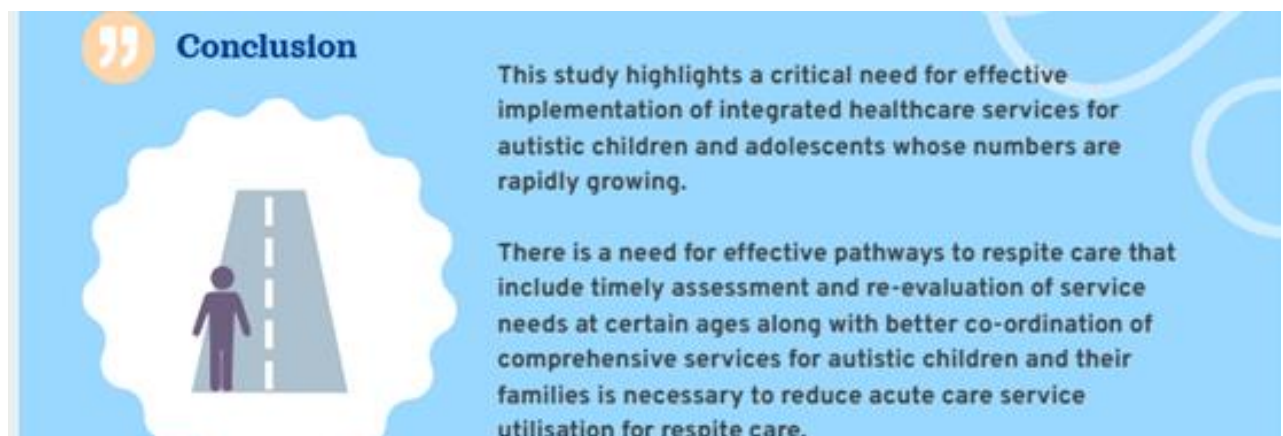


Result

Parents identified that there was no defined pathway to respite care for autistic children

Findings identified an overwhelming need for respite care but parents were faced with many barriers when accessing respite across their autistic child's lifespan.

- The average age of a child when respite services were initially sought was 8.7 years
- Parents faced many challenges when accessing respite care. Issues such as a persistent lack of or refusal of respite care, difficulties with scheduling due to respite being offered at very short notice, gaps in service provision, and insufficient levels of support and funding.
- Parents described inflexible supports, delays in provision or long waiting lists, restricted or unreliable services, inequality of respite distribution and lack of emergency respite in a crisis situation.
- Parents called for increased respite services particularly crisis respite and effective transition planning from children to adult services to ensure the needs of their child are being met across the lifespan.



List of Abbreviations

Abbreviation	Meaning
APA	American Psychiatric Association
ASDEU	Autism Spectrum Disorders in the European Union
CASP	Critical Appraisal Skills Programme
CDC	Centres for Disease Control and Prevention
CHO	Community Healthcare Organisations
DSM	Diagnostic Statistical Manual
ED	Emergency Department
HSCPs	Health and Social Care Professionals
HSE	Health Service Executive
NICE	National Institute for Health and Care Excellence
PIL	Participant Information Leaflet
PSI	Psychology Society of Ireland
WHO	World Health Organisation

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Glossary

The following definitions of terms can be used to assist with understanding some of the key terms related to the area under study.

Autism: A lifelong neurodevelopmental condition that is characterised by differences in social communication and social interaction, restricted and repetitive patterns of behaviours and interests, and sensory processing differences (Psychology Society of Ireland (PSI) 2022).

Behaviours that challenge: A term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour (Murphy *et al.* 2015). Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety.

Care pathway: A system designed to improve the overall quality of healthcare by standardising the care process and promoting organised efficient service user care based on best evidence to optimise service user outcomes (Schrijvers *et al.* 2012).

Child: A child is defined as a person under the age of 18 years (Child Care Act 1991).

Case management: Aims to provide support to sustain family self-care and resilience and be an interface between family support and multi-agency collaborative care (Green 2019).

Crisis situation: An experience arising from an imbalance between the cumulative impact of numerous types of demands in one's life (e.g. child behaviour, family problems, and health problems) and the availability of external resources available to meet these demands (support, emergency services, and finances) (Weiss *et al.* 2014).

Developmental disabilities: A group of conditions involving impairment in physical, learning, language, or behaviour areas of growth and development (Centres for Disease Control and Prevention (CDC) 2022).

Integrated care: Integrated health services are managed and delivered so that people receive a continuum of health promotion coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course (World Health Organisation (WHO) 2016).

Intellectual disabilities: Neurodevelopmental disorders that begin in childhood and are characterised by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living (American Psychiatric Association (APA) 2013).

Interdisciplinary team: a group of health and social care professionals with various areas of expertise who work together toward the goals of their clients (Oliver 2019).

Respite care: The provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to main carers and their family (Brenner *et al.* 2016).

Support services/systems: A term used to describe a set of health, education, social care, employment, financial, and safety net services, including informal networks or relationships, that families and autistic people may require access to in the community.

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Chapter 1: Introduction

1.1 Chapter overview

The aim of this study is to explore access to respite care through the acute care services from the perspectives of parents¹ of autistic children within an Irish healthcare context. In the introductory chapter, the study's aim and objectives are presented along with a background and rationale for the study. This is followed by a statement of the problem that the study proposes to explore. The use of autistic language and how it will be applied throughout this thesis is also outlined. The chapter concludes with an outline of the overall structure of the thesis.

1.2 Research objectives

1. To systematically review the global evidence on access to respite care for autistic children.
2. To develop an understanding of how parents access respite services through the acute hospitals in Ireland.
3. To identify any issues parents experience with accessing respite care.
4. To determine, if possible, the preferred pathway to respite care and model of respite care by exploring parents' motivation for accessing respite care for their child through a particular pathway.
5. To identify implications/recommendations for policy, practice and future research arising from objectives 1-4.

1.3 Definition of autism

Autism is a lifelong neurodevelopmental condition that is characterised by differences in social communication and social interaction, restricted and repetitive patterns of behaviours and interests, and sensory processing differences (PSI 2022). Worldwide

¹ Although parents usually are the primary caregivers for their autistic child, it is also recognised that others (e.g., siblings, grandparents, friends, etc.) may often take on a primary carer or parental role. In this thesis, the word parent(s) is used throughout, referring mainly to the biological parents of the child, while acknowledging that it may also represent others who are assuming a primary carer/parental role for an autistic child.

estimates suggest that about one in 100 children are autistic (Zeidan *et al.* 2022b). However, establishing the exact prevalence of autism is challenging due to the modifications to diagnostic criteria over time and because of the heterogeneity of autism (section 2.3.5). Medical comorbidities are more common in autistic children than in the general population (Aishworiya & Kang 2021, Al-Beltagi 2021) with autistic children often displaying a range of co-morbidities including attention problems, oppositional behaviours, emotional difficulties, language impairment, epilepsy, and intellectual disability (Posserud *et al.* 2018). Therefore, severity of autism varies greatly, not only between individuals but also within the same individual over time resulting in different clinical profiles at different times (Waizbard-Bartov *et al.* 2021)

1.4 Background and significance of study

Raising an autistic child can often be demanding and complex (van Tongerloo *et al.* 2014, Zeidan *et al.* 2022b) involving management of problematic behaviours and balancing associated stress while overseeing the well-being of the child and the rest of their family (Aishworiya & Kang 2021, Tathgur & Kang 2021). Parents of autistic children often report high levels of stress and mental health problems associated with the challenges of caring for their child. This can be compounded by having to navigate multiple service sectors in seeking support across their child's life course. As parents take on complex care tasks associated with autism such as dealing with behaviours that challenge, while balancing all other aspects of family life and work commitments, the complexity of the parental role and well-being of these parents is increasingly becoming a public health issue of concern (Case-Smith *et al.* 2015) as services struggle to keep up with demand.

At the outset of this study, it is important to clarify that not all autistic children will require respite care, although many will. Respite care, however, has been cited as one of the greatest unmet needs of families caring for autistic individuals (Dyches *et al.* 2016, Whitmore & Snethen 2018a, Cooke *et al.* 2020). Respite care can be defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to the main carers and their family (Brenner *et al.* 2016). The benefits of respite care for the parent and child have been well documented throughout the literature such as significant improvement in psychological adjustment, fatigue, mental health, lower levels of stress, reduced levels of depression and anxiety, and more time for rest and rejuvenation (Welsh *et al.* 2014, Remedios *et*

al. 2015, Mc Grath 2019). Without respite care, those caring for autistic children are at risk of burnout within a short period of time (Woodgate *et al.* 2015).

Respite care is not without its own challenges with research often citing issues around lack of choice around the type and frequency of respite received, difficulty accessing respite, long waiting lists and strict criteria to be deemed eligible for such services (Hodgetts *et al.* 2014). Additional challenges include inadequate capacity and funding, and inappropriate respite care placements to support autistic individuals with complex care needs (Gadd 2019). Furthermore, the literature highlights difficulties associated with transitioning from child to adult respite care services which has been described as service-driven rather than person-centred (Ryan *et al.* 2020). Autistic children can display behaviours that challenge such as aggressive or self-injurious behaviours which often necessitate the need for respite care for the child and family yet it is these types of behaviours that can often disqualify children from receiving respite care (Lavelle *et al.* 2014) as services may not be able to meet their particular needs or may not have suitably trained or qualified staff. Consequently, parents may be forced to access acute care services to access respite care as a last resort.

Autism has been significantly associated with a number of co-occurring medical and mental health conditions that contribute to high rates of emergency department (ED) utilisation and repeated contact with healthcare systems (Cummings *et al.* 2016, Tint *et al.* 2017, Weiss *et al.* 2018). Autistic children and adolescents are hospitalised in mental health facilities at significantly higher rates than children with other developmental or psychiatric disorders and have longer lengths of stay than non-autistic patients (Kalb *et al.* 2012). Research has found that autistic children are nine times more likely to visit an ED, compared with non-autistic children, as a result of psychiatric problems such as physical aggression, disruptive behaviour, running away and hurting themselves (Kalb *et al.* 2012). The acute clinical hospital setting and environment can often be inappropriate for some autistic children who can display significant communication, behavioural and social challenges (McGuire *et al.* 2016) as well as sensory sensitivity (Salvatore *et al.* 2021) and routine rigidity (American Psychiatric Association & Association 2013).

The literature continues to report an overall lack of access to appropriate support services for autistic children including respite care. In Ireland, there is both a historical and current lack of appropriate autism services. In 2017 the Health Service Executive (HSE) carried out a review of the Irish Health Services for autistic individuals and found

that pathways to health services were unclear, confusing and difficult to navigate (HSE 2018). Parents of autistic children identified the need for increased support such as 24-hour support and respite care. The review also found a lack of communication from the HSE to parents about important information relating to autism including access to respite services. The review concluded with a number of recommendations aimed at improving services for autistic individuals including the need to develop clearer pathways to services and to adopt a more collaborative and integrated approach to service delivery.

Key determinants to the development of effective care pathways to services such as respite care for autistic children include integrated care systems supported by interdisciplinary working. Integrated health services are managed and delivered so that people receive a continuum of health promotion, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course (WHO 2016). However, the integration of health services which necessitates care from multiple systems is often costly and insufficiently coordinated (Lavelle *et al.* 2014, Lord *et al.* 2022). In the context of specific autism service provision, integrated care is particularly challenging due to a number of factors such as: scarcity of healthcare providers qualified to treat autistic children (Stadnick *et al.* 2020, Colvert *et al.* 2022); lack of autism specific policies within primary care to facilitate co-management or care integration (Van Cleave *et al.* 2018); and inadequate capacity and resources within the primary care sector to implement specific care pathways and provide greater access to primary care interventions. In addition, when caring for autistic children, healthcare providers often experience complexity beyond their usual role, limited knowledge and resources, lack of training and prior experience, barriers related to communication and collaboration, need for information, and need for care coordination and systemic changes (Morris *et al.* 2019).

In Ireland, integration of health services can be insufficient with no structured access to, or assessment of, respite services. The *Sláintecare Report* (2017) outlines a significant geographic difference in access to respite care services (Houses of the Oireachtas Committee 2017). The challenges that can plague the Irish healthcare system are shared internationally, with recommendations for a seamless service to avoid over burden on parents and more effective communication processes to enhance continuity of care (Ventura 2014). Where pathways do exist, ineffective communication at the acute and primary care interface often acts as a barrier to achieving desired outcomes (Holmes & Himle 2014, Esegbe *et al.* 2015, Fenikilé *et al.*

2015, Shawahna *et al.* 2017). Specific barriers to effective communication include navigating parent perspectives that differ from provider perspectives, perceived resistance from parents to understand diagnosis or engage in discussions related to treatment (Zuckerman *et al.* 2013, Holmes & Himle 2014, Eseigbe *et al.* 2015) and awareness of how to help families navigate service options (Shawahna *et al.* 2017).

Confusion over points of accessing care and having no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team across acute and primary care services also exists (Brenner *et al.* 2015). In the absence of a standardised pathway to respite services for autistic children, accessing respite care services can be a daunting and an exhaustive process, with parents sometimes forced to access the acute services as an initial point of contact or in a crisis situation. Although hospitalisation is sometimes warranted, it often is an undesired outcome that may represent an inability to appropriately care for children rather than the needs of the child *per se* (Mandell 2021). Despite evidence supporting the efficacy of integrated care for autistic children, the required services such as respite care are in short supply. A key recommendation arising from the HSE review on services for autistic individuals was the need to have clear and functioning pathways to services (HSE 2018). Research, however, suggests that this is not in place, for example, an Irish survey found that 63% of autistic individuals believe that healthcare services in Ireland are not inclusive of autistic people and that they have been let down by the HSE regarding the lack of services and support provision as a result of excessively long waiting lists for diagnostic and therapeutic support, inadequate mental health supports and public health services (As I Am 2022).

My personal and professional background have also been a significant influence for undertaking this study. I have worked as a children's nurse in an acute children's paediatric hospital for ten years and have been actively involved in the care and management of autistic children. I have witnessed and experienced on many occasions autistic children being admitted for what are considered 'social admissions' (where the child is medically well but admitted to hospital) as parents do not have access to supports to help them manage the day-to-day behavioral challenges that can often be associated with caring for an autistic child. These children were effectively being admitted to the acute care setting in the absence of alternative and suitable support services for them and their parents. From my encounters with these parents, it was clear that this decision was not taken lightly and was a very difficult decision to make. Interestingly parents had explored many avenues and pathways prior to

presenting to the acute care services. Equally, it was apparent that the acute care setting was not an appropriate environment and for some triggered certain behaviors. However, this enabled the parent to demonstrate the type of behaviors they were finding difficult to manage and health and social care professionals could observe the behavior and difficulties parents experienced. Over a period of time I continued to observe the numbers of these types of admissions occurring and on some occasions, parents had represented to the acute care services as respite care plans put in place on discharge. Therefore, these scenarios left me questioning why this was happening, what challenges parents were experiencing when trying to access respite care and essentially what could be done to prevent the increasing numbers of autistic children presenting to the acute care services in the absence of defined pathways to respite care. In addition, I have a young autistic family member and continue to observe the challenges his parents face navigating a complex health and social care system when trying to access supports. Overall, I feel my personal and professional experience was a great driver in undertaking this study with the need for the study further substantiated by the gap in literature which was identified.

Overall, there is a critical need for effective implementation of integrated healthcare services for autistic children and adolescents whose numbers are rapidly growing with 1 in 100 children estimated to be diagnosed with autism worldwide (Zeidan *et al.* 2022b). Autistic children often have complex physical, intellectual and mental healthcare needs that necessitate both paediatric primary care and specialty care services (Stadnick *et al.* 2020). In many health systems, integrated care is seen as a possible solution to the growing demand for improved patient experience and system efficiency for people by cutting across multiple services, providers and settings.

1.5 Problem statement

Research has consistently shown that parenting an autistic child can be challenging and stressful. Respite care offers a break for parents who experience such stress and also provides positive opportunities for the child to interact with their peers. The increasing prevalence of autistic children has implications for future respite service provision as the demand for respite care services grows. Despite the strong focus on the need for respite care for parents caring for an autistic child, there is a paucity of research and limited evidence on parental experiences of accessing these services, especially with respect to the complex decision-making involved and navigation of pathways. Furthermore, little is known about the profile and numbers of autistic

children accessing respite care through acute care services in Ireland. Motivating factors for parents attending acute care services as a means of seeking respite care for their children is multi-factorial and needs to be explored. Despite evidence supporting the efficacy of integrated care for autistic children (Stadnick *et al.* 2020), the required services such as respite care are in short supply. In order to improve integrated care services it is necessary to explore what is currently happening by examining the literature, exploring the pathways to and model of respite services and exploring the experiences and perspectives of parents accessing respite care for their autistic children through the acute care services.

The aim of this study was to provide a comprehensive understanding of parent's lived experience of accessing respite care for their autistic child through the acute care services in Ireland. The study also aimed to explore what constitutes effective respite care for autistic children and what factors may contribute to designing and developing an optimum model of respite care for autistic children, one that is united (or linked) across all settings (acute and primary) and which is based around the specific respite needs of autistic children, from the perspectives of their parents.

1.6 Terminology: Autism and language

There is greater visibility and awareness of autism nationally and internationally (PSI 2022). For this reason, language within the autism community is evolving, although the terminology used when referring to autism remains considerably varied. Whilst Autism Spectrum Disorder (ASD) is the term used in current diagnostic manuals, there is some ambiguity within society and in the literature over what language is appropriate to use when talking about autistic individuals and autism itself.

At the forefront, it is important to use terms that are respectful, positive and acceptable to the autism community. The use of person-first versus identity-first language has been subject to much debate, with autistic people, researchers, professionals, and parents often differing on the language they use to describe autism. Many published and unpublished surveys show that autistic people prefer identity first language ("autistic person") to person-first language ("person with autism") (Kenny *et al.* 2015, Bury *et al.* 2020). While there is no definitive consensus on the preferred language of autistic people (Vivanti 2020), there is clear consensus that the least preferred language is use of "person with autism" or "person with autism spectrum disorder/condition" (Kenny *et al.* 2015, Bury *et al.* 2020, Lei *et al.* 2021).

Participants in this study, during data collection, used a variety of terms and language when talking about their autistic child, and were supported and encouraged to do so. For the purpose of this thesis, however, with the exception of the Findings Chapter (Chapter 6) which comprises direct quotes from participants, a consistent approach to the autism language was applied based on the evidence available from the literature, best practice guidelines and the autistic community at the time of writing this thesis. Therefore, the use of 'identity first language' has been applied throughout this thesis and the term 'autism' has been used throughout the document, instead of 'autism spectrum disorder'.

To assist with either defining or clarifying the key terms related to the area under study, please refer to the glossary of terms (page xii).

1.7 Thesis structure

This thesis is sub-divided and presented across eight chapters. The current chapter is presented as the introductory chapter, inclusive of the study aim, objectives, and rationale. Chapter 2 presents a review of the literature. A description of autism is provided and prevalence rates, sociodemographic factors and associated co-morbidities are discussed. The current literature related to accessing respite care services for autistic children is also addressed. This chapter also reviews the national and international policy context relating to autism and respite care. Chapter 3 reports the conduct and findings of a systematic review of qualitative studies (qualitative evidence synthesis) on the experiences and perspectives of parents of autistic children who have accessed respite care. The findings from this chapter were used to inform the research methodology of the study.

Chapter 4 considers the epistemological, ontological, and philosophical assumptions that shaped and guided the study. The rationale for the research design and the adoption of the methodological framework are also presented. Chapter 5 focuses on the research methods and includes details on the research aim and objectives, sampling and recruitment, participant characteristics, data collection and data analysis. Ethical considerations, trustworthiness and credibility of the research, and researcher reflexivity are also discussed. Chapter 6 presents the study findings from the qualitative interviews with participants. The five overarching themes and associated sub-themes that emerged from the data are discussed. Chapter 7 discusses the study findings and places the findings from the systematic review in context with the current

study's findings. The strengths and limitations of the research are addressed, and a critical reflection of the research process is also provided. Chapter 8 concludes the thesis. Implications for policy, practice and future research are presented in this chapter.

Chapter 2: Literature review

2.1 Chapter overview

This chapter provides a review of current literature in the area of accessing respite care for autistic children. The aim of this chapter is to provide context and rationale for choosing to explore access to respite care for autistic children through the acute care services. The chapter commences with an explanation of the process undertaken in sourcing the literature for the review. An overview of autism is provided, followed by a review of the literature, best practice guidelines and national and international policy on autism and respite care. Findings in relation to respite care models and pathways for autistic children are then discussed. The final section of this chapter examined the current provision of and access to respite care services for autistic children in Ireland.

2.2 Sourcing literature

To inform this chapter, and to ensure extensive reading on the topic of respite care, an extensive search of computer databases and a search of the grey literature was performed. The following electronic databases were searched, initially in 2018, and periodically since up to Sept 2022, with a 10-year search limiter, to ensure the review remained contemporary: Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE (PubMed), EMBASE, PsycINFO and Wiley Science. The following search terms were used and combined with the AND OR Boolean operands: 'children' or 'p(a)ediatric' or 'adolescents' or 'parent(s)' or 'father' or 'mother' AND 'autism' or 'autism spectrum disorder' AND 'respite' or 'shortbreak' or 'crisis' or 'emergency respite' or 'emergency department' or 'hospital'. Secondary references were identified from the reference lists of selected records and read in full to determine their relevance to the literature review. Textbooks were also sourced and included. Articles were not limited to geographical location as it was intended to gain a global perspective of respite care for children. Articles pertaining to respite care in other contexts such as palliative care related to children were also included. Best practice guidelines in relation to diagnosis, interventions and care and management of autism were also reviewed. National and international reports, government publications, policy documents and newspaper articles pertaining to autism were reviewed and also incorporated into the literature review, if relevant, to provide political, social and legislative context. The inclusion of records was limited to English publications due to

an inability to translate from other languages. Figure 1 shows the outcome of this search.

	Pubmed	CINAHL	EMBASE	PsychINFO	Emerald
	4221	4221	16	161	68
Screening of Title and Abstract	476	476	8	64	9
After Duplicates Removed	46	46	8	32	9
Full Paper Assessment	43	46	8	32	9
Best Practice Guidelines		18			
Policy Documents		25			
Grey Literature		10			
Included in Literature Review		168			

Figure 1 Outcome of preliminary literature search.

2.3 Autism

2.3.1 The evolution of autism

The concept of autism has evolved over the last four decades from one that defined autism as a disorder by virtue of deficits within the person affected to one in which autism can result in fluctuating levels of disability depending on the individual and their environment (Happé & Frith 2020).

Autism was first described as Infantile Autism in 1943 by Dr. Leo Kanner who identified a unique group of children who failed to develop normal social relationships, were upset by changes in their environments and showed abnormalities in speech and language (Harris 2018). Although Kanner did not develop diagnostic criteria, he offered descriptive case histories highlighting common characteristic features. Following from this, in 1944, Dr. Hans Asperger, a Viennese paediatrician, presented a distinct syndrome which shares many of the characteristics noted by Kanner but generally includes average intellectual and structural language abilities. Autism continued to be a feature of child psychiatry in both research and clinical practice for decades with

autistic adults remaining largely invisible in research into the 1980s (Happé & Frith 2020). However, changes in diagnostic criteria over the past 30 years has resulted in significant increases of autism prevalence rates

2.3.2 Diagnoses

Over the past 10 years, there has been a surge in autism diagnoses, due to a combination of increased awareness, changes in the perception of autism, and revisions to the diagnostic criteria (Posserud *et al.* 2018). Definitions have been amended to reflect the research that has been undertaken in the area of autism. The most commonly used manuals, by health professionals around the world to diagnose autism, are the International Classification of Diseases (ICD), published by the WHO in 2020 and the Diagnostic and Statistical Manual of Mental Disorders (DSM), edited by the American Psychiatric Association (APA 2013). These manuals are updated regularly as new research findings lead to revisions of diagnostic criteria. The Diagnostic and Statistical Manual of Mental Disorders (DSM) fifth edition, DSM-5, took effect in May 2013. The goals for updating the criteria for diagnosing autism included a more accurate diagnosis, identification of symptoms that may warrant treatment or support services, and assessment of severity level. The update to the manual in 2013 included six major changes to the way autism is diagnosed. An example of some of these changes is outlined in Table 1. A significant change involved the consolidation of four previously separate categories of autism (Autistic Disorder, Asperger Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder) into one umbrella diagnosis of “autism spectrum disorder.”

Table 1 Example of some of the changes in autism diagnosis criteria from the DSM-IV to DSM-V

DSM-IV	DSM-V
3 sub-criteria Qualitative impairment in social interaction Qualitative impairments in communication Restricted repetitive and stereotyped patterns of behaviour, interests, and activities	2 sub-criteria Persistent deficits in social communication and social interaction across multiple contexts Restricted, repetitive patterns of behaviour, interests, or activities
Age of development Onset prior to age 3 years	Age of development Symptoms must be present in early developmental period but may not manifest until social demands exceed limited capacities or may be masked by learned strategies
Sensory symptoms Not addressed	Sensory symptoms A new criterion introduced in DSM-5 under the

	sub-criteria of restricted, repetitive patterns of behaviour, interests, or activities

A major feature of autism is the heterogeneity of its clinical features (section 2.3.5), however the main clinical features are impairments in speech, social interaction, and the presence of repetitive or restricted behaviours (Sauer *et al.* 2021). Children as young as two years old can be diagnosed with autism, but some children and adults may not be diagnosed until later in life, partly because signs and symptoms might not be clear, and partly because of insufficient recognition and understanding of autism and poor access to appropriate services (Lord *et al.* 2022). Autism is also associated with many co-morbidities, which can be psychological and physiological. Secondary symptoms of autism include aggression, hyperactivity, impulsivity, and the occurrence of co-morbidity such as anxiety and depression (Sauer *et al.* 2021).

The historical definition of autism as a “disorder” necessitated evidence of significant impairments in daily life. However, concepts of autism have shifted from a purely medical model to a more social model of disability (Woods 2017). Considering the broad diagnostic classification of autism, there is emerging recognition of the heterogeneity and neurodiversity of autism (PSI 2022) which has subsequently influenced autism prevalence rates.

2.3.3 Prevalence of autism

The reported prevalence of autism has increased both nationally and internationally in recent decades (Chiarotti & Venerosi 2020). Affecting about 78 million people worldwide, autism is a condition of global importance because of its prevalence and the degree to which it can affect individuals and families (Lord *et al.* 2022). Previous research found that the median prevalence of autism in children globally was 62/10,000 (Elsabbagh *et al.* 2012), however, recent prevalence studies estimate that 1 in 100 children are diagnosed with autism around the world (Zeidan *et al.* 2022b). Autism prevalence rates across Europe, Asia, and North America are estimated at 1% and 2 % of their respective populations (CDC 2019). In the UK, around 1 in 57 (1.76%) children are autistic (Roman-Urrestarazu *et al.* 2021). The estimated prevalence of autism within the school aged population in Northern Ireland is 4.5% in 2020/21 (Rodgers & McCluney 2020).

In Ireland, there is currently no reliable method of estimating prevalence of autism. Consequently, this can be a challenge for policy makers and for future service planning. Nonetheless, there are multiple sources of data that are used to estimate the prevalence rate including the Irish census, National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database. However, these databases are often voluntary and do not collect diagnosis. For example, individuals with intellectual disability and a secondary diagnosis of autism can be recorded on the NIDD but autism specific data cannot be extracted. Therefore, not all autistic individuals are captured. Notwithstanding this, several epidemiological studies have aimed to measure the prevalence of autism in Ireland (Fitzgerald *et al.* 1997, VanDenHeuvel *et al.* 2014, Boilson *et al.* 2016). The most recent study conducted by Boilson *et al.* (2016) reported a prevalence rate of 1% (of children aged between 6-11 years) and when further analysis was conducted to weight for a low response, the figure was estimated at 1.5%. This study used a protocol developed in Europe called the European Protocol for Autism Prevalence which was designed to facilitate a standardised approach to estimating autism rates across Europe. The Irish study was the first to operationalise the screening phase of the protocol and validate the use of a screening instrument - the Social Communication Questionnaire (SCQ) - as a primary screener for autism among national school children. The study demonstrated the feasibility of screening children for autism using the EPAP protocol and a validated questionnaire in a non-clinical setting and included over forty Irish primary and special schools. Another strength of this study is that the prevalence of autism reported ($63/5457 = 1\%$) was consistent with rates quoted by the Centre for Disease Control (2014). Overall, autism affects at least 1% of the Irish population, similar to rates in the UK and the US (Boilson *et al.* 2016).

At large, studies have shown a rapid increase in the prevalence of autism worldwide (Christensen *et al.* 2016, Posar & Visconti 2017, Baio *et al.* 2018, Chiarotti & Venerosi 2020, Delobel-Ayoub *et al.* 2020, Maenner *et al.* 2020). A review of autism prevalence estimates published since 2014 found a high variability in prevalence estimates across the world (i.e., from 0.8/1000 to 93/1000 (Chiarotti & Venerosi 2020)). In addition, some researchers believe that autism may be over-diagnosed (Rogers *et al.* 2016, Arvidsson *et al.* 2018b, Mottron & Bzdok 2022) or that professionals may not be practicing in a way that is consistent with international best practice guidelines for autism diagnosis (Taylor *et al.* 2016). For example, Arvidsson *et al.* (2018) reported that the observed increase in autism diagnosis is due to fewer autism symptoms being required for clinical diagnosis and overall suggest that the bar for diagnosing autism is perhaps too

low. According to Rogers *et al.* (2016), increased prevalence rates can also be explained by diagnostic upgrading, i.e. the assignment of an autism diagnosis in the face of uncertainty. For example, Taylor *et al.* (2016) reported that 17% of clinicians in Australia had diagnosed autism in individuals with autistic traits not meeting full diagnostic criteria, for purposes such as enabling access to school supports and disability services. Applying a consistent and standardised approach and working in agreement with best practice guidelines as outlined by Arvidsson *et al.* (2018) can support a more standardised and consistent approach to autism diagnosis which can contribute to more consistent prevalence rates.

Overall, there remains high levels of inconsistency in the prevalence rate of autism globally as a result of methodological differences in case detection, variances with prevalence estimates across geographical area as well as socio-demographic factors (Delobel-Ayoub *et al.* 2015, Delobel-Ayoub *et al.* 2020).

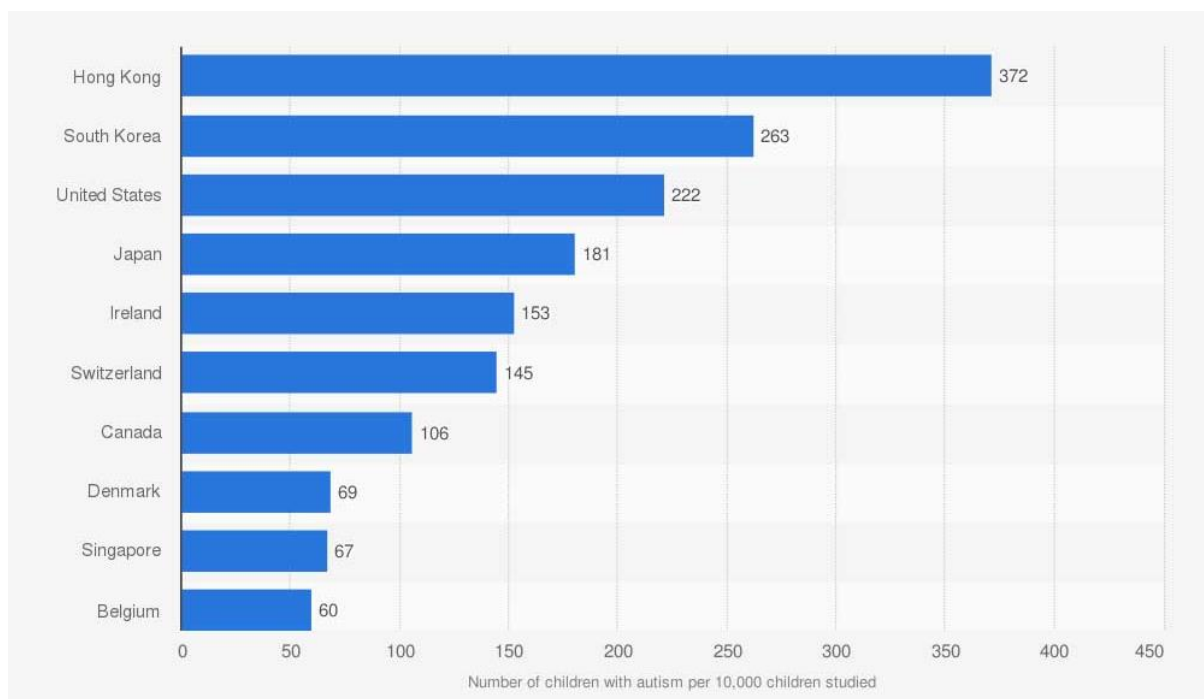


Figure 3 Prevalence of autism among children in select countries worldwide as of 2020 (per 10,000 children) (World Population Review © Statista 2020).

Sociodemographic factors and geographical variables

To date, studies of the impact of socioeconomic status on autism has yielded conflicting results (Delobel-Ayoub *et al.* 2015, Hrdlicka *et al.* 2016, Dickerson *et al.* 2017, Kelly *et al.* 2017a). There is some evidence to suggest that socio-economic

status can influence autism prevalence rates. For example, studies in the United States have found lower rates of autism diagnosis associated with lower socioeconomic status (Thomas *et al.* 2012) and that autism rates are higher for children whose parents have higher levels of education (Dickerson *et al.* 2017).

Similar studies have found higher autism prevalence rates among households with higher socioeconomic status as measured by parental educational level or household income (King & Bearman 2011, Hrdlicka *et al.* 2016, Dickerson *et al.* 2017). A UK study, comprising 13,857 children born between 2007 and 2011, found that 1.5% of children of mothers educated to A-level or above had twice the rate of autism diagnosis, compared to children of mothers with lower levels of education status 0.7% (Kelly *et al.* 2017). However, only 128 children in this study were autistic which despite the large cohort is a possible limitation of the study. A systematic review on autism prevalence with respect to gender and socioeconomic status, involving 26 studies, from 18 countries, concluded that higher prevalence rates of autism were found in developed or more affluent countries as well as urban areas (Adak & Halder 2017). Consistent with previous research, the systematic review found that studies from USA and UK (involving urban and rural populations) continue to report high estimations. On the other hand in European countries like Portugal and Spain had lower prevalence rate in comparison to other countries. Notably, studies in Sweden and France, which have universal health care and fewer barriers to access medical care, found no association between socioeconomic status and rates of autism diagnoses. However findings must be interpreted with caution noting reported autism prevalence rates varied substantially by country, use of methodology, assessment tools, gender, geographic region and socioeconomic status and therefore have the potential to influence these findings.

Possible explanations for increased prevalence rates of autism among households with higher economic status could be attributed to individuals with high resources being better placed to receive an early diagnosis. In addition, King *et al.* (2011) suggests that parents with higher socioeconomic status may have children at a later stage in life in which there is some research to support that delaying childbirth can increase the chances of having an autistic child (Lyll *et al.* 2020, Wu *et al.* 2017).

In contrast, other studies suggest that, low socioeconomic status is associated with an increased risk of autism (Rai *et al.* 2012, Delobel-Ayoub *et al.* 2015). Studies have shown an increase in prevalence associated with a lower occupational class of parents

(Rai *et al.* 2012), lower level of maternal education (Lung *et al.* 2018) or lower household income (Rai *et al.* 2012, Lung *et al.* 2018). This can often have implications for the child as research suggests that these lower socioeconomic families may not be well positioned to meet the needs of the child due to several barriers such as transportation, finances, long wait lists and insurance (Pickard & Ingersoll 2016).

In the context of accessing respite care services for autistic children, Pickard and Ingersoll (2016) examined the role of socioeconomic status on parent reported service knowledge, service use, unmet service needs, and barriers to service use. The study, conducted in the United States found that parents of lower socioeconomic status were more likely to report needing respite care compared to higher socioeconomic status parents. The authors suggest that this may be because lower socioeconomic status parents may be less knowledgeable about navigating through available service options and can be attributed to their use of fewer services for their child (Pickard & Ingersoll 2016).

Overall there is inconclusive conflicting evidence on the relationship between autism and socioeconomic status. Notwithstanding this, the evidence demonstrates the potential for socioeconomic inequalities for autism diagnosis in children as a result of various levels of knowledge about autism, resources available and ability to navigate healthcare systems.

In summary, the marked increase in prevalence rates can be attributed to multiple factors as reported in the literature such as better analytic tools, better identification and screening methods, changes in diagnostic criteria, earlier identification and diagnoses variability of prevalence study methodologies, increased awareness among parents and clinicians, and changes in the availability of services (Sun *et al.* 2015, Zablotsky *et al.* 2015, Arvidsson *et al.* 2018a, Chiarotti & Venerosi 2020).

Epidemiologic studies continue to report mixed findings on the association of autism with socioeconomic status. Further population-based research using more consistent methodology is needed to determine a more accurate autism prevalence rate (Delobel-Ayoub *et al.* 2020) and to provide further understanding of the socioeconomic factors associated with autism.

2.3.4 Aetiology of autism

Genetic and environmental factors

The cause of autism is unknown; however, evidence suggests that autism can occur due to a combination of genetic and environmental factors (Bölte *et al.* 2019). Although it is generally unclear which genetics and which environmental factors are important (Ng *et al.* 2017), research suggests that genetic factors consistently play a stronger role than environmental factors (Taylor *et al.* 2020). To date, numerous studies investigating the association between genetic variants and autism risk have been published (Peñagarikano *et al.* 2011, Bai *et al.* 2019, Grove *et al.* 2019, Qiu *et al.* 2019). Findings from a large population-based multinational cohort study including more than two million individuals with a diagnosis of autism found that 80% of autism risk can be traced to inherited genes rather than environmental factors and random mutations (Bai *et al.* 2019). Notably, advanced parental age (particularly paternal age) has been identified as one of the most important risk factors for autism (Karimi *et al.* 2017, Manzouri *et al.* 2019, Lyall *et al.* 2020).

A myriad of environmental factors across social, physical and psychological domains have been examined but were not consistently found to be associated with autism (Karimi *et al.* 2017). A few of the suspected environmental causes for which there is some scientific evidence for includes: prenatal infection allergies (Fox *et al.* 2012); pesticides, heavy metal toxicity (Rossi-George *et al.* 2011); exposure to certain drugs during pregnancy such as antiemetic drugs e.g. Thalidomide (Kumar & Chhibber 2011) and psychiatric drugs (Gidaya *et al.* 2014, Harrington *et al.* 2014); deficiencies in essential nutrients (Bölte *et al.* 2019). Other prenatal risk factors such as maternal physical health (Karimi *et al.* 2017), bleeding during pregnancy and foetal complications have also been found to increase the risk of autism (Gardener *et al.* 2011). In addition to prenatal maternal infection during pregnancy, postnatal infections such as meningitis have also been correlated with a high risk of autism (Karimi *et al.* 2017). As research continues to evolve in this area having an understanding of the genetic and environmental factors that can influence autism is vital.

2.3.5 Heterogeneity of autism

Given the broad diagnostic classification of autism, there is an emerging recognition of the heterogeneity of autism (PSI 2022). Heterogeneity refers to the longstanding observation that individual differences in the aetiology, clinical presentation, and care needs of autism vary over time (Lord *et al.* 2022). Failure to recognise heterogeneity in

autism can adversely affect public awareness, assessment and diagnosis, clinical management, access to services, public policy and equity (Lord *et al.* 2022).

Autism can affect both male and females, however, research has found that autism is more prevalent in boys than girls (Elsabbagh *et al.* 2012, Werling & Geschwind 2013) and that males are diagnosed at a rate four times than that of females (Thomas *et al.* 2012). This has remained consistent since the first published descriptions of autism as a male-typical condition in which eight of the eleven cases described by Kanner were male (Kanner 1943).

Studies exploring phenotypic differences in autistic males and females show that females present with fewer restricted interests and repetitive behaviour symptoms and greater social motivation. However, it has yet to be determined whether differences in male and female presentations are as a result of sex-differential neural activity (Werling 2016). Evidence suggests that sex chromosomal gene dosage and sex hormone levels may modulate presentations of autism, however further research is required to conclusively identify key contributory factors and to elucidate the precise mechanisms by which these sex-specific factors can influence presentations of autism.

An autistic individual's functioning can vary widely across the spectrum of autism and profiles of strengths and weaknesses can change with age and interventions. Hence, there is significant variability in the presentation and severity of autism (Bessette Gorlin *et al.* 2016). All neurodevelopmental conditions, including autism often occur with a range of co-morbidities. Autistic children can display a range of medical, neurological and psychiatric co-morbidities including attention problems, sleep disruption, self-injurious behaviours, oppositional behaviours, emotional difficulties, language impairment and intellectual disability (Posserud *et al.* 2018). The prevalence of autism and co-occurring psychiatric conditions (e.g., disruptive behaviours, attention and hyperactivity problems) is estimated at greater than 70% (Farmer *et al.* 2014). In addition, approximately 30% of individuals on the autism spectrum have a co-occurring intellectual disability (Baio *et al.* 2018). Autism also co-occurs with other mental health conditions (e.g., anxiety, depression, obsessive compulsive disorder) and are known as dual diagnosis. Research suggests that 70% of the autistic population receive at least one co-occurring psychiatric disorder diagnosis with 41% receiving two or more diagnoses (Mosner *et al.* 2019). Common non-psychiatric problems for autistic children include epilepsy, seizures, and/or neurological symptoms, gastrointestinal disturbances

such as nausea, vomiting, diarrhoea, abdominal pain and constipation (Cohen-Silver *et al.* 2014, Deavenport-Saman *et al.* 2016, Vohra *et al.* 2016).

In summary, the presence of co-occurring conditions with autism adds to the heterogeneity in individual presentation resulting in different needs for supports and services for autistic individuals across the lifespan.

2.4. Concept of respite care

To explore access to respite care services through the acute care services for autistic children, it is necessary first to explore the current definitions and concepts of respite care. Not only will this assist with the understanding of the term respite care, but it also helped in providing an operational term for the purpose of the study.

Respite care can be defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to main carers and their family (Brenner *et al.* 2016). Definitions of respite care have encompassed meanings such as short-term, intermittent, long-term, on-going, or emergency intervention (Whitmore & Snethen 2018c). Respite care has also been defined as planned or emergency care provided to a child with special needs in order to provide temporary relief to family caregivers who are caring for that child (Kirk & Kagan 2015). Respite services can also be viewed as a means to limit the need for out-of-home placement and to keep families together (Nankervis *et al.* 2011). Respite care is considered to be an important intervention to avoid or reduce parental stress and burnout (Soohoo 2019) as well as to increase the social/peer interaction for the child with disabilities or chronic illnesses (Whitmore 2018).

Respite care as a process, outcome or service

The terms respite and respite care have been used interchangeably throughout the literature with both terms described as a process, outcome or service. An important aspect to consider when trying to define respite and respite care are the recipients of this care. As respite care offers parents a temporary break from their daily routine and the stress from caregiving (Shi *et al.* 2018, Min *et al.* 2020), it could be argued that the parents are the main recipients of respite. That is, parents may get respite when their child attends a day programme or a home care worker provides services that free up the parent. Thus, respite may be viewed as an outcome and not explicitly a service with parents themselves acknowledging that they are recipients of respite (as both a

service and an outcome) because they also benefit from the service (Whitmore & Snethen 2018c, Murphy *et al.* 2021). Respite as an outcome is further espoused in parental descriptions of the activities that they are able to engage with as a result of respite such as going to the supermarket, spending time with other family members, or simply participating in activities they are otherwise unable to do. Such activities may not require overnight care but rather a shorter period of respite such as daytime care may be sufficient to satisfy these needs (Willet *et al.* 2014). Respite has also been referred to as a process whereby family members describe what they want their child or relative to experience in respite (Mc Conkey 2011). By simply examining the literature, it can be difficult to delineate respite explicitly as an outcome, process or service, however, in the context of children's respite care, more often than not, it is not the child who requests respite but rather the parent in order for the family to have a break. In this regard the benefit of respite becomes the outcome however it is still based on the benefits described which are underpinned by a service provision process. Considering the above it would be reasonable to suggest that respite is neither explicitly a process, outcome or service but rather recognising these interwoven aspects is what makes respite effective.

The literature outlines both advantages and disadvantages of respite care in a general sense. Respite care can be beneficial to the individual receiving care as well as parents, carers and families (Pilkington *et al.* 2019). Respite provides opportunities for the child to enjoy social interaction with their peers (Whitmore 2018). Respite has been shown to increase family carer resilience (Whiting 2014) and improve psychological well-being of parents (Remedios *et al.* 2015) and is associated with lower levels of stress, reduced levels of depression and anxiety, reduced risk of breakdown (Mitchell 2016), and avoids costly unplanned hospital admissions, length of stay or social care (Pilkington 2019). Having access to respite care shifts the focus from the child's needs to the family members' needs, so parents have time to do more typical activities (e.g., go grocery shopping, eat out at a restaurant, clean the house) and to spend time with their family resulting in more time for rest and rejuvenation (Mc Grath 2019).

The varied ways in which respite is described and defined in the literature, and the inconsistent applications of the term respite and respite care, renders conceptually defining respite care difficult. Multiple services have been classified as respite, but are very different in form and do not provide the same kinds of care (McConkey *et al.* 2011). Furthermore, characteristics and attributes are not usually included in the definitions of the term, which can prevent parents from understanding and knowing the

opportunities and benefits of respite. While the literature shares a common definition of 'respite' as giving a break to parents and caregivers, very few studies addressed what the caring aspect of the concept of 'respite care' involved. Research suggests that definitions of respite care should be guided by what caregivers want. Therefore, a shift away from attempting to define respite care to more of a focus on the concept of respite care can perhaps accurately capture the purpose, attributes and outcomes of respite care. Whitmore's (2017) concept analysis of respite care formulates a definition of respite care that is based on providing caregivers temporary relief from their responsibilities of caregiving. However, this definition is supported by a concept analysis that provides a more comprehensive understanding of respite by outlining desired criteria, defining attributes (e.g., location, safety, trust in provider) and outcomes of quality and effective respite care (Whitmore 2017b) (Whitmore 2017b).

In general, there appears to be a lack of explicit definitions of respite care and there remains a general disagreement as to what can be considered respite and respite care as both terms are used interchangeably throughout the literature. It was found that while most research discusses the benefits, characteristics and usage of respite, there is no uniformly accepted definition of the word. Consequently, multiple services could be included in the category of respite. Current definitions of respite care also lack detail in relation to how and when to assess for respite.

Having a broader understanding of the concept of respite care rather than a single definition may help families to become aware of different forms of respite that may be appropriate to their needs and the needs of the child and can support informed decision making. Nonetheless, a review of these definitions in respite literature indicates that 'break/breaks' and 'short' are two of the most commonly used terms (Willet *et al.* 2014) and research suggests that the term 'short breaks' should be used as it encompasses a wider variety of services (Robertson *et al.* 2011). For the purpose of this study, respite care will be defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to main carers and their family (Brenner *et al.* 2016). Choosing this definition for the purpose of this study is based on research exploring the experiences of users of disability respite services in Ireland which found that the majority of families of young children with disabilities favour a combination of short break respite care options and in-home respite care (Gadd 2019).

2.4.1 Models of respite care

Models of respite care can vary across different dimensions that reflect the purpose, duration, location and provider of the respite service (Shea 2017). However, a full understanding of the particular models of respite care is limited given that the focus of most research is on conceptual aspects of respite as a whole, rather than specific models of service delivery (Robertson *et al.* 2013).

The location from which respite care is provided has changed significantly over the years as the provision of respite shifts away from the medical model to a more social model. Historically, respite care was provided in institutional settings in a residential basis. However, there has been a shift towards the provision of services for people with disabilities within their own community which has led to the development of alternative models of respite care.

The literature describes various models of respite care that can be categorised as both formal and informal, planned and emergency (Table 2). These include short in-home breaks, overnight in-home breaks, respite facility placement, hospital respite, emergency respite, family-based respite, hospital-based overnight care and overnight stays in a residential home (Shea *et al.* 2017, Pilkington *et al.* 2019).

Table 2 Models of respite care described in the literature

Type of respite	Purpose	Location	Duration
Residential Respite	Respite is provided in a residential home for a defined period of time either short term or long term. Planned/unplanned	Specialist facility/Residential centre	Short-term and long-term
Centre-based day respite	Individual will attend a designated place for the day and engage in activities Planned	Specialist facility/day centre	Provided during the day
Community respite	Individual is linked with community organisations that provides social experience through group activities or outings Planned	Community group/Organisation	Provided during the day or overnight
In-home respite	Provision of respite care in an	Individual's home	Allocated hours

	individual's home. Planned		during the day/overnight
Crisis/Emergency respite	Respite provided in response to an emergency or crisis situation Unplanned	Residential care, Specialist Facility, Hospital	Short term
Host family	Host family respite links the person to another local family or individual carer who is specifically recruited and prepared to provide respite. Planned	In host family's home	Short-term, overnight or weekends
Holiday respite camps	The provision of respite in designated holiday/camps providing opportunity to engage with activities and socially interact with peers. Planned	Designated holiday/camp locations	Short-term School holiday times
Family/Relatives	Respite care provided by family members.	In persons home or family members home	Short-term

2.5 Autism and respite care: Emerging themes from the literature.

2.5.1 Caring for an autistic child.

As previously discussed the needs of autistic individuals and their families differ depending on their age, autism severity, general mental health needs, cognitive, communication ability and adaptive skills, and interventions should address the multiple components of needs and consider personal preferences (Lai *et al.* 2018)

The literature on the lived experiences of families caring for an autistic child has focused largely on stress experienced by these families. Many parents, siblings and carers of autistic children experience significant challenges over extended periods as well as regular and often severe stress. This stress can often be attributed to autism related behaviours such as: crying; lack of sleep; tantrums; agitation and self-injurious behavior which has been identified in several studies (Lutz *et al.* 2012, Bultas & Pohlman 2014). Other common behaviours associated with autism that can be challenging for parents include sensory sensitivities (Jones 2018), feeding difficulties

(Nadon 2013) rigidity or restricted interests (Poljac *et al.* 2017, Tei *et al.* 2018). Families spend a substantial amount of time dealing with the child's "meltdowns" or behaviours leaving little break time for family members (Larson 2010). Parents caring for autistic children have been shown to have significantly higher levels of stress, anxiety and depression than parents of typically developing children, and children with other disabilities (Al-Farsi *et al.* 2016, Scherer *et al.* 2019). Often, as the child grows these behaviours become more challenging with research suggesting that mothers of autistic children experience chronic stress comparable to combat soldiers (Smith *et al.* 2010). Other sources of stress associated with caring for an autistic child includes challenges of coordinating their child's health care and educational needs, social isolation and altered family dynamics (Mulligan *et al.* 2012, Bultas & Pohlman 2014).

A key feature for some autistic children and adults, across their lifespan, is engagement with multiple health and social care systems. Care is sought from multiple sectors and providers, with integration, coordination, and transition of care a lifelong challenge for both families and providers (Lord *et al.* 2022). Notably, some autistic children and families have intense involvement with services at one time and much less, or none at other times. At the same time, others have never interacted with services, or have done so minimally. One of the many services parents of autistic children have repeatedly highlighted the need for, however, is respite care. Parents raising autistic children have been reported to experience high degrees of stress and severe inadequacies in support and respite care (Dillenburger & McKerr 2011).

2.5.2 Respite care: An unmet need of parents caring for autistic children

Over the past decade respite care has been studied in relation to parental mental health and the impact of respite care use on stress among parents of autistic children (Harper *et al.* 2013, Welch *et al.* 2014, Minhas *et al.* 2015b, Dyches *et al.* 2016, Whitmore & Snethen 2018c). Qualitative research by Minhas *et al.* (2015) found that mothers of autistic children frequently reported high levels of stress due to the constant demands of their child's needs and lack of respite. Research indicates that respite care can be beneficial to parents of autistic children (Harper *et al.* 2013) and is associated with lower psychological distress of parents of autistic children (Ekas 2010). A study by 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. However, a limitation of this study is that participants were volunteers and responded to invitations and therefore may represent

a high level of family functioning. Dyches *et al.* (2016) asked 122 single mothers of autistic children to complete questionnaires concerning respite care, daily uplifts, depression, and caregiver burden. More than half (59.8%) accessed respite care which was provided for one hour per day from multiple sources such as grandparents, community agencies, extended family, babysitters. Of the mothers receiving care, 71% were satisfied or highly satisfied with the respite care they received, and 29% were neutral or dissatisfied with the respite care. Overall, the study found that respite care was positively related to daily uplifts, and uplifts mediated the relationship between respite care and depression. Conversely, these findings may be somewhat limited given the cross-sectional design of this study which does not enable conclusions to be drawn about the directions of effects between variables.

In contrast, some research has reported that respite care can be associated with higher levels of stress (Gadd 2019, Keilty 2017, Whitmore 2016), due to, for example, issues surrounding transitioning of care, which has been described as service-driven rather than person-centred (Ryan 2020), lack of choice around the type and frequency of respite received and inadequate capacity to support individuals with complex care needs (Gadd 2019). Respite care, specifically when not meeting the individual needs of the child and family, can ultimately be counter-productive and lead to an increase in parental stress. For example, parental hesitation in trusting a respite service in being able to provide safe and quality care for their child's complex medical needs (Whitmore 2018). Parents experienced fear, guilt, worry, frustration, lack of control and anxiety (Keilty 2017), with non-trusting relationships diminishing opportunities for respite, thereby placing parents at further risk for isolation and burnout (Keilty 2017).

In summary, respite care has been identified as an unmet need of parents that can potentially reduce stress and assist parents to cope with the hidden burden associated with the, often unrelenting, demands inherent in raising an autistic child. However, accessing respite can often be difficult and contribute to this stress (Hodgetts *et al.* 2014). Furthermore, respite services available for autistic children may be inappropriate or inadequate (Gadd 2019). Of the limited research that has examined the use of respite care for autistic individuals and their families, findings have suggested its positive impact on parent stress, self-efficacy and marital quality.

2.5.3 Predictive factors in accessing acute care services for autistic children.

Autistic children tend to have more complex health care needs which necessitates higher utilisation of primary, specialty, and acute care services. Several studies have

shown that autistic children and adolescents are more likely to visit an emergency department (ED) and exhibit higher rates of ED encounters and repeat ED visits compared to their counterparts without autism (Deavenport-Saman *et al.* 2016, Vohra *et al.* 2016, Liu *et al.* 2017, Lytle *et al.* 2018, Badgett *et al.* 2022)

Using a large private insurance claims database, Liu *et al.* (2017) compared ED visits for adolescents with and without autism aged 12 to 21 years for the years 2005–2013. The percentage of autistic adolescents who had an ED visit increased from 3.1% in 2005 to 15.8% in 2013 while the percentage of adolescents without autism with ED visits remained around 3% for the same time period. Concerns about the increasing trend in ED utilisation among autistic children and adolescents has resulted in research focusing on identifying predictive factors for ED utilisation among this population. Older autistic children (i.e. school-age compared to preschool-age) appear to utilise the ED more (Deavenport-Saman *et al.* (2016), with psychiatric illnesses or symptoms being one of the most common presentations (Wu *et al.* 2015, Lytle *et al.* 2018). Research has found that autistic children and adolescents are psychiatrically hospitalised at significantly higher rates than children with other developmental or psychiatric conditions, are more likely to present to the ED with psychiatric concerns, more likely to be psychiatrically admitted following ED visits, and have longer hospital stays compared to non-autistic children (Cohen-Silver *et al.* 2014, Liu *et al.* 2017, Righi *et al.* 2018).

One possible explanation for these findings is that autistic adolescents, who often have co-occurring psychiatric and medical comorbidities, can have poor continuity of care (Rast *et al.* 2018) as a consequence of navigating complex healthcare systems (Vogan *et al.* 2017). Furthermore, a lack of providers with specialised training in meeting the specific needs of autistic children and adolescents may, in part, explain the increased frequency of ED utilisation among this population (Warfield *et al.* 2015). In the context of the current study it is necessary to explore the reasons for increased ED presentations and hospitalisations for autistic children and to gain an understanding as to why parents access the acute services for their autistic child and identify factors that may be contributing towards this trend.

A review of the literature suggests that the overall increase in ED presentations for autistic children can be attributed to several factors which in general may reflect a deficit of services. At the outset, it could be argued that the increase in ED utilisation and hospitalisation is directly associated with the increased prevalence rates of autistic

children. However, further exploration indicates that there are several predictors of or motivators for ED utilisation in autistic children and adolescents (Figure 3).

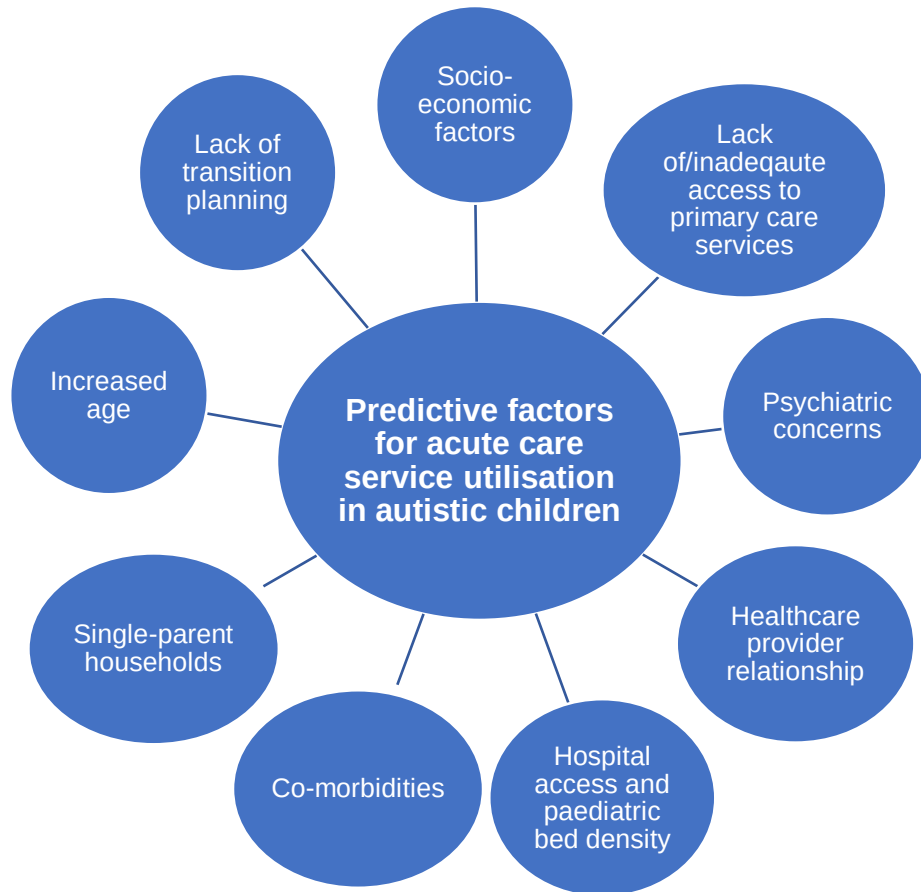


Figure 3 Predictive factors for acute care service utilisation in autistic children.

Psychiatric and behavioural concerns

Cohen-silver *et al.* (2014) found that 10% of autism presentations to the ED were primarily related to behavioural concerns. Similarly autistic children and adolescents have been found to use ED services if they have unmet mental health care needs (Liu *et al.* 2017) (Badgett *et al.* 2022). At particular risk for psychiatric hospitalisation are autistic children who; exhibit self-injurious and aggressive behaviours; have depression or obsessive–compulsive disorder; are prescribed psychotropic medications; received an autism diagnosis late in life, have sleep problems; have poor adaptive skills or severe social impairment or come from single parent households (Righi *et al.* 2018). Kalb *et al.* (2012) found that ED visits for autistic children and adolescents were more likely to be related to psychiatric concerns than non-psychiatric concerns. Autistic

youth have also been found to have repeat ED visits and are more likely to be admitted to a psychiatric unit or medical floor than non-autistic youth (Lytle *et al.* 2018).

Higher ED attendances and hospitalisations associated with psychiatric concerns has been linked to inadequate access to mental health services for autistic children (Soto *et al.* 2009, Wharf *et al.* 2011). Soto *et al.* (2009) argues that a lack of psychiatric evaluations available in outpatient mental health clinics and educational settings was also a contributing factor to increased ED visits by autistic children and adolescents. This is further substantiated by Wharff *et al.* (2011) who found that children with developmental disabilities, including autism, were 2.5 times more likely to utilise the ED while waiting for an opening on a psychiatric inpatient facility and those presenting for emergent psychiatric care appear to have difficulty accessing community based mental health services. A US study carried out by Baggett *et al.* (2022) using data from a National Survey of Children's Health (2016-2018) also found that autistic children with current behaviour problems were 17% more likely to visit the ED in the previous year and having unmet mental health care needs increased the odds by 1.58 times of visiting ED. However, it is noted that these results are based on claims data from a sample of private insurers and does not include data from the uninsured. Therefore findings may not be representative of the wider population. Notwithstanding this, Beverly *et al.* (2021) found that the odds of frequent ED use were significantly higher for those with Medicaid coverage compared to private insurance plan beneficiaries. Noting the differences in socioeconomic status as discussed in section 2.3.3, it would be reasonable to suggest that this could be more or less.

Considering all of this evidence, psychiatric presentations are evidently one of the leading causes for ED presentation and acute service utilisation for autistic children. Specifically, autistic children with moderate to severe autism and behavioural and psychiatric concerns appear at higher risk for acute service utilisation and subsequent hospitalisation. However, other motivating factors must also be considered. These studies clearly indicate an unmet health care need relating to a lack of access to mental health services for autistic children and their families.

Co-morbidities

Frequent ED use (defined as greater than or equal to 4 ED visits per year (Wu *et al.* 2015) in children and adolescents has commonly been associated with complex and special healthcare needs and multiple comorbidities (Beverly *et al.* 2021). Therefore it is plausible that autistic children and adolescents might be more likely to exhibit

frequent ED use compared to those without autism due to the high rate of co-morbidities associated with autism (Straus *et al.* 2019). Common comorbidities associated with an autism diagnosis include gastrointestinal issues, eczema, allergies, asthma, ear and respiratory infections, seizures, and migraines (Kohane 2012). Epilepsy, seizures, and/or neurological symptoms and gastrointestinal disturbances such as nausea, vomiting, diarrhoea, abdominal pain, and constipation have been reported as some of the most common non-psychiatric presenting problems for autistic children utilising the ED (Cohen-Silver *et al.* 2014, Deavenport-Saman *et al.* 2016, Vohra *et al.* 2016).

Increased age

There is consensus amongst the evidence that autistic children appear more likely to frequently present to the ED as they age (Nayfack *et al.* 2014, Liu *et al.* 2017, Beverly *et al.* 2021). Liu *et al.* (2017) found that autistic adolescents above the age of 14 accessed the ED at significantly higher rates than those aged 12 to 14 years old. Similarly Beverly found that the odds of frequent ED use were significantly higher for patients who were aged 18–22 years compared to those who were aged 2–5 years.

Nayfack *et al.* (2014) carried out a retrospective study of paediatric hospitalisations for children aged 1 to 18 years in California during the period 1999 to 2009 and found that hospitalisations for autistic children increased nearly threefold over 10 years. Moreover, the largest increase was in the two oldest age groups, age 10-14 and 15-18. Interestingly, Nayfack *et al.* (2014) identified that the increase in hospitalisation for this particular group was primarily attributed to mental health conditions.

Hospital access and paediatric bed density

Hospital and paediatric bed density can also influence decisions to access the ED and acute care services. Liu *et al.* (2017) found a tendency of community providers to avail of hospitals knowing that bed capacity was not an issue. Higher rates of hospitalisation were seen in children of older age and those living in rural areas with high paediatric bed supply. Interestingly, Nayfack *et al.* (2014) found that patients living forty or more miles from a paediatric specialty centre were less likely to be hospitalised.

Limited research is available on the amount of ED presentations for autistic children and adolescents that result in admission. Liu *et al.*'s (2017) study notes that the majority (88.2%) of autistic children had one or two ED visits per year and that 8.2% had at least one ED visit that resulted in admission.

Of the research studies explored, little information was provided on whether autistic children are most likely to present during the day or night . One study carried out by Cohen-silver *et al.* (2014) found that the majority of children and adolescents present to the ED during weekday, daytime hours however further research is warranted to substantiate this.

Overall, there seems to be some evidence to suggest that access to acute care services and paediatric bed density can influence decisions to attend the ED. However, further research exploring time of day at which autistic children are most likely to present is required as well as admission rates following ED presentations.

Socioeconomic factors

Acknowledging the evidence outlined in section 2.3.3 exploring the relationship between autism and socioeconomic status, there is also conflicting evidence in relation to socioeconomic factors as predictors of ED utilisation amongst autistic children. Research suggests there could be a relatively low risk of hospitalisation for the higher income families as they have the financial resources to access community supports that avoids hospitalisation (Nayfack *et al.* 2014). However, cautious interpretation is warranted the noting that a large proportion of studies exploring predictive ED factors have used private insurance databases which has demonstrated a steady rise in ED utilisation amongst those with access to private health insurance.

Overall, the relationship between socioeconomic status and hospitalisation risk is inconclusive. However the research does highlight that some families may not be adequately resourced to cope with the demands of caring for an autistic child as families with lower socioeconomic status may not have equal access to additional support services (Mandell 2012).

Single-parent households

The stressors associated with raising an autistic children can cause tremendous stress for parents that may lead to marital conflict and relationship dissatisfaction (He *et al.* 2022).

Limited evidence suggests that autistic children from single-parent households are more likely to be hospitalised related to psychiatric conditions (Righi *et al.* 2018). This could be due the lack of additional support from another adult and therefore may not be able to keep a child with challenging behaviour from hurting himself or siblings.

However, further research is warranted to explore the relationship between single-parent households of autistic children and rates of hospitalisations.

Lack of/inadequate access to primary care services

Parents of autistic children and adolescents have reported that they have significant trouble accessing their primary care physician and experienced decreased satisfaction with their children's general health care (Nageswaran *et al.* 2011). Furthermore, evidence suggests that autistic children do not receive the appropriate care from their primary care providers (Cummings *et al.* 2016). Inadequate access to primary care physicians acts as a barrier to parents and therefore can be considered as a contributing factor to increased ED and acute service utilisation for autistic children (Bebbington 2013).

In contrast, where parents may have adequate access to primary care physicians, they may not trust or have confidence in this service. For example, parents' experiences of medical professionals having limited information about autism and a lack of understanding about the condition has been reported (Hodgetts *et al.* 2013, Minhas *et al.* 2015). It could be argued that parents may not access primary care services, even if available, as their child is more likely to be admitted (and hence they get some respite) if they attend the ED. Furthermore, Soto *et al.* (2009) found that approximately two-thirds of autistic children and adolescents who present to the ED were in receipt of ongoing outpatient care but utilised this infrequently. A possible explanation for this relates to findings from a study carried out by Lin *et al.* (2014) in which parents of autistic children and adolescents reported that they are more likely to access acute services for healthcare when they perceived their healthcare providers do not listen to their concerns, display cultural insensitivity, do not supply needed information, and do not involve caregivers in decision making. These findings are important as they identify trust issues or lack of confidence in primary care providers which is further discussed in section 3.6.2 and section 7.3.2.

Overall, the evidence for increased acute care service attendance points towards deficits in first line, community-based, outpatient care for autistic children. Consequently, parents and community mental health services may not be in a position to meet the complex needs of some autistic children and may, therefore, be contributing to a direct increase in hospitalisations. Furthermore, differences in healthcare policies and pathways of care may impact on hospitalisation rates and service use for autistic children over time.

In summary, the rising prevalence of autism, and identified predictive factors, contribute collectively to an increase in ED utilisation and hospitalisation of autistic children. The evidence presented has demonstrated that autistic children and adolescents have increased healthcare needs with disproportionately higher ED utilisation compared to their non-autistic peers. In the context of the current study, identifying the predictive factors for ED and acute care service utilisation for parents of autistic children has informative relevance. Not only are autistic children accessing the ED at a disproportionate rate in comparison to their non-autistic peers, the most prominent reason for accessing the ED appears to be for psychiatric concerns such as aggressive and self-injurious behaviours. ED services should be considered a “last resort” within the continuum of care for autistic children. The predictive factors discussed can be helpful in identifying autistic children that could be in need of respite care and subsequently be most at risk of attending the acute care services in the absence of access to respite care.

Despite an increasing prevalence of autism, a lack of funding and investment in primary care resources including respite care is apparent. Better access to services designed for autistic children, such as specialised care coordination and respite care is needed to reduce the burden on acute services and prevent parents from seeing acute services as their only source of meaningful help and access to support services.

Further qualitative research involving parents is needed to help to understand these relationships and identify specific factors that may affect or modify the risk of hospitalisation in autistic children and improve outcomes. In addition, research of service utilisation before and after ED attendances for autistic children is needed to develop a more effective intervention for children and parents in need of access to support services such as respite care.

2.6 National and International policy context

Historically there has been a view that the optimal way to support individuals with disabilities like autism was to care for them in residential institutions that are separate from local communities. Over time, there has been a major shift in this thinking, driven by the values of equality, the right of people to be integrated into their community to plan for their own lives by making their own choices and to be enabled to access the personal supports they require to optimise their independence (HSE 2011).

Deinstitutionalisation is one of the most significant policy developments for people with disabilities in the late 20th century (Tatlow-Golden *et al.* 2014) and can be defined as the gradual abandonment of large residential institutions and their replacement by small services to enable people to live in the community (Mansell *et al.* 2007). Towards the end of the 1990s both international and Irish policy began to place more attention on the development of respite services.

2.6.1 International policy context

Several developments at an international level have supported the move away from a medical model of understanding disability towards a social model of disability. The most notable of these developments are, at a European level the European Union Charter of Rights for Persons with Autism (European Parliament 1996), and internationally, the recently ratified United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations 2006). The UNCRPD is an international treaty that aims to promote, protect and ensure the rights of persons with disabilities so that they can fully participate in society and enjoy the same freedoms and opportunities as others. These policies also place further pressure on Irish policy and legislation to promote the rights of people with disabilities which include family support services.

2.6.2 Autism strategies

In May 2014, the Sixty-seventh World Health Assembly adopted a resolution entitled '*Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders*' (WHO 2013) which was supported by over 60 countries. The resolution urged the WHO to collaborate with Member States and partner agencies to strengthen national capacities to address autism and other developmental conditions. The WHO and partners' agencies recognised the need to strengthen countries' abilities to promote the optimal health and well-being of autistic children and adults. One of the many actions outlined in the resolution includes the need for member states to systematically shift the focus of care away from long-stay health facilities towards community-based, non-residential services (Lavelle *et al.* 2014). Other priority areas included enhancing the commitment of governments and international advocacy on autism, providing guidance on creating policies that address the care of autistic people and contributing to the development of evidence on effective strategies for the assessment and management of autism.

To evaluate progress made in response to recommendations issued by WHO, a review of countries with autism strategies was conducted, initially in 2021 and updated in July of 2022 ² (Appendix 1). The purpose of my undertaking this review was to determine what autism strategies existed across the United Kingdom (UK) and the European Union (EU) and if, and how, the concept of respite care was portrayed within these strategies. In total, 31 countries were included (27 EU countries and the four divisional countries of the UK; England, Scotland, Wales and Northern Ireland).

A strategy can be described as a high-level plan to achieve one or more goals (Barad 2018). Specifically, an autism strategy aims to achieve meaningful inclusion and empowerment of autistic people within wider society (As I Am 2020). Countries with strategies in place are internationally recognised as leaders in implementing best practices for people with disabilities (Autism Spectrum Disorders in the European Union (ASDEU) 2020). The review found an increasing number of countries have developed autism specific strategies to respond to the specific needs of autistic individuals (Figure 4), however, some countries were at a more advanced stage than others.

² The review, titled 'A Review of EU and UK Autism Strategies; Where and how does respite care feature?' was submitted to *Advances in Autism Journal* in July 2022 and under peer review pending decision.

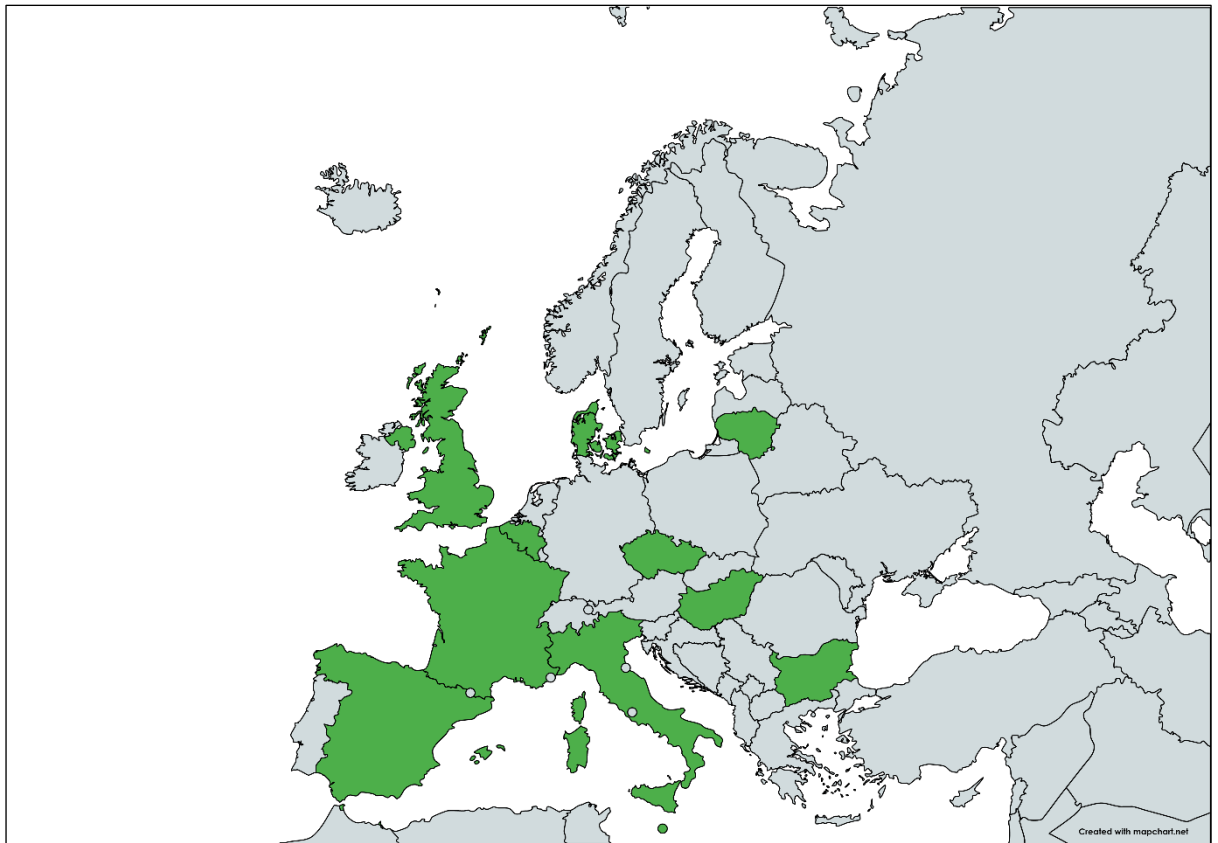


Figure 4 Countries with autism specific strategies in place at time of review (2022).

Ten countries were found to have autism strategies in place. Of the ten countries, seven explicitly referenced the concept of respite and three referenced the need for ‘specific or specialised supports’ but these did not refer explicitly to respite. Of the seven autism strategies that referenced the concept of respite, this was mentioned in the context of ‘respite care’, ‘family respite’ ‘short break’, ‘residential services/homes’ and ‘residential and semi-residential assistance’. An important finding of this review is that while some countries may not have an autism specific strategy, they have opted to include autism explicitly in the definition of disability at national level. Many countries have enacted legislation, which may not make direct reference to autism, but include autism under the umbrella of disability and have amended the definition of disability in their relevant legislations to include explicit reference to autism. In Ireland, for example, the Disability Act 2005 places legal obligations regarding assessment of need and services for all individuals with a disability, including individuals with autism (The Government of Ireland 2005).

In summary, the review concluded that an increasing number of countries are passing specific legislation for autistic people and developing strategies with the intent of

improving the quality of life for autistic people. The extent to which respite was referenced throughout the countries which had autism strategies varied. The need for respite care for some autistic people was identified as a significant unmet need. Findings highlight that autism service development needs to be informed by national and local strategies and plans and service providers need guidance and direction for future respite service planning and provision.

2.6.3 National policy context

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 (Commission on the Status of People with Disabilities 1995). The Report also acknowledged that respite care is a crucial element of community support services for people with disabilities and put forward that respite services should be flexible, including a range of options including home support, organised holidays and residential care. Following this report, The National Disability Authority was established in 1998 with the primary function of being policy advisors on disability to the government. Subsequently the government published the first National Disability Strategy in 2004 which put in place a plan of policy and service development for people with disabilities in Ireland. Respite care is listed among a range of specialised services for people with disabilities in the strategy. The 2004 Strategy also led to the enactment of The Disability Act in 2005 which while not addressing respite services, does establish that every person with an intellectual disability is entitled to an independent assessment of needs, an official statement of these needs along with a time-scale for the delivery of services to meet these needs. It has been argued that respite can be included as part of this assessment of need, however, a major criticism of the Act is that while the assessment of needs can describe the ideal level of resources that a person might need, the statement of needs is bound by the availability of services and so is limited in its scope.

An Autism Spectrum Bill is currently (2021) before the house of parliament in the Republic of Ireland. A similar Bill was introduced in 2012, however it lapsed at the time. There has since been a renewed focus on autism policy from a national perspective with plans progressing for the development of an Autism Innovation Strategy with the appointment of an oversight and advisory group and the completion of public consultations in 2022.

Currently, in Ireland there is no national policy on respite services and children with disabilities have no right to respite. Furthermore, there is paucity of accurate data on the location and number of autistic children who require or who are in receipt of respite services. This lack of information is part due to a lack of a national database or register containing information on the number of children diagnosed with autism. In addition, there is a marked overlap between the needs of children with neurodevelopmental conditions such as autism and those with disabilities, palliative care conditions and other complex care needs and therefore it is not possible to clearly separate and identify the funding and level of respite care services required or provided to autistic children. Consequently, estimating and projecting the need for respite care services for autistic children is challenging. Notwithstanding this, several policy documents (Table 3) aimed at improving the lives of individuals with disabilities in Ireland have continued to focus on and recommend the provision of care within the community through residential settings and day services

Table 3 A sample of Irish policy documents aimed at improving the lives of individuals with disabilities and their reference to respite care.

Year	Policy	Reference to respite
2019	National Policy on Access to Services for Children & Young People with Disability & Developmental Delay (HSE)	Nil
2017-2021	National Disability Inclusion Strategy (Justice & Equality 2017)	'residential and day services'
2014-2020	Better Outcomes Brighter Futures the Policy Framework for Improved Outcomes for Children and Young People (Department of Children, Equality, Disability, Integration and Youth 2019)	'residential settings'
2015	HSE Integrated Care Programme for Children. A National Model of Care for Paediatric Healthcare Services in Ireland. Chapter 33: Neurodisability (HSE & RCPI 2015).	'access to respite services'

The Health Information and Quality Authority (Health Information and Quality Authority (HIQA)) has responsibility for developing and monitoring standards, as well as monitoring compliance with regulations by disability residential services. HIQA's *National Standards for Residential Services for Adults and Children with Disabilities* impacts on respite services (Health Information and Quality Authority (HIQA) 2013). The standards set out the requirements for service providers to ensure compliance is achieved and that quality and safe care is provided to people living in, or using, residential and residential respite services.

2.7 Autism Guidelines: How does respite care feature?

Evidence based guidelines play an important role in ensuring access to high-quality autism assessment, diagnosis and management. In ascertaining if respite care is identified as an important support service, 13 international autism-specific guidelines, published in English, were identified. Respite care, described by terms such as 'residential care', 'short breaks', 'specialist residential services', 'respite-in-home supports', and 'respite homes' was mentioned in eight of the 13 guidelines only (Table 4).

Table 4 Autism guidelines reviewed for reference to respite care				
Country/Or ganisation	Year	Title	Purpose of Document	Reference to respite
UK: NICE Quality Standard (NICE 2021)	2021	Quality statement 4: Coordination of care and support	Covers health and social care services for adults, young people and children with autism. It includes assessment and diagnosis of autism , and care and support for people diagnosed with autism. It describes high-quality care in priority areas for improvement	Nil
(NICE 2017)	2019 (UK)	Autism spectrum disorder in under 19s: recognition, referral and diagnosis	Covers recognising, referral and diagnosing autism in children and young people from birth up to 19 years.	Nil
(NICE 2012)	2021 (UK)	Autism spectrum disorder in adults: diagnosis and management	Covers diagnosing and managing suspected or confirmed autism in people aged 18 and over. It aims to improve access and engagement with interventions and services, and the experience of care, for people with autism.	During a comprehensive assessment, assess the following risks: breakdown of family or residential support If residential care is needed for autistic adults it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation).
(NICE 2013)	2021 (UK)	Autism spectrum disorder in under 19s: support and management	Covers the different ways that HSCPs can provide supportand help for children and young people with autism, and their families and carers, from the early years through to their transition into young adult life.	Offer all families (including siblings) and carers verbal and written information about their right to: short breaks and other respite care If the sleep problems continue to impact on the child or young person or their parents or carers, consider: short breaks and other respite care for one night or more. Short

				breaks may need to be repeated regularly to ensure that parents or carers are adequately supported. Agree the frequency of breaks with them and record this in the care plan.
Ireland (PSI 2022)	2022	Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents, 2nd Edition	Focus on the assessment, formulation, and diagnosis of autism in children and adolescents and were developed to promote proficiency and to help facilitate a high level of professional practice by psychologists.	Nil specific
Scotland (Healthcare <i>et al.</i>)	2016	SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders. A National Clinical Guideline	Provides recommendations for best practice in the screening, surveillance, diagnosis, assessment and clinical interventions for children and young people with autism. It also incorporates evidence and recommendations on assessment, diagnosis and interventions for adults with ASD	Supportive intervention following diagnosis of autism Multiagency multi-professionals (integrated and collaborative and in partnership with the family) should discuss wider family/sibling support, provision of respite, and the role of social work assistance' Services take a wide range of formats and include outreach services, support in the local community and 24-hour housing support and care at home. Some general service providers are now providing specialist residential services, which has enabled people who were previously placed out of area to return to their home communities.

Belgium (Veereman <i>et al.</i>)	2014	Management of Autism in Children and young people: A good clinical practice guideline.	Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents were developed to promote proficiency and to help facilitate a high level of professional practice by psychologists	Short breaks should be repeated early to ensure parents are supported.
Spain (Ministry of Health and Social Policy 2019)	2019	Clinical Practice Guideline for the Management of Patients with Autism Spectrum Disorders in Primary Care	Purpose of this guide is to help health professionals in Primary Care to be able to perform an early detection and monitoring of autistic children according to recommendations based on scientific evidence	Nil specific
France (Haute Autorité de santé 2018)	2018	Autism spectrum disorder Warning signs, detection, diagnosis and assessment in children and adolescents Clinical practice guidelines method	This guideline is for all professionals involved in the detection and diagnosis of autism in children and adolescents.	-Consideration should be given to the parents' usual needs for information as well as their needs for support with the administrative processes in terms of the resources available in the territory (childcare, personal care service, respite home, documentation services available in the territory including those of the autism resource centre, associations for families and people with autism).
New Zealand (Ministries of Health and Education 2016)	2016	New Zealand Autism Spectrum Disorder Guideline.	Provides guidance on autism in both children and adults in New Zealand. The guideline is an evidence- based summary that covers the identification and diagnosis of autism, and ongoing assessment and access to interventions and services for autistic individuals. It seeks to provide the best evidence currently available to assist informed decision-making	Respite care: The use of alternative strategies for behavioural difficulties, including behavioural and psychological approaches, environmental modification to ensure safety of the child and others, and adequate provision of respite care, should always be considered before using pharmacotherapy Services should include flexible and intensive support,

			to improve the health, educational and social outcomes for autistic individuals.	planned respite (if required), a range of planned short-term breaks, parent education and empowerment, home-based support, financial support, behavioural intervention, substitute care and transition services to adulthood Systems which need to be in place to support a crisis response include: short break respite (with specific ASD knowledge) and other respite in-home supports for families Where a child or young person is provided with a respite service or is outside the normal home environment, the environment needs to be structured and predictable, and it needs to support the function of the child in communication, personal independence and safe leisure skills. Information packages in relevant and appropriate language about ASD in health, education and disability services should be developed. In plain and simple language, the packages could include the following: · respite care information Culturally appropriate day services and respite and residential placements were also called for.
Australia (Trembath 2022)	2022	National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia	Focuses on supports provided to autistic children aged 12 years or younger and their family members. It is concerned with guiding the use of supports delivered in clinical and community settings that seek to promote learning, participation, and wellbeing of autistic children, including through addressing environmental and contextual barriers.	Connecting with appropriately qualified disability-specific and mainstream (e.g.)health, education) service providers to access appropriate supports, including respite services

Australia (Whitehouse <i>et al.</i> 2018)	2018	A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia	Defines clinical best practice and a new diagnostic standard. It aims to make the practice of assessing and diagnosing autism clearer and more consistent throughout the country so that individuals and their families receive the best possible care.	Nil
Canada (Ip <i>et al.</i> 2019)	2019	A. Canadian Paediatric Society clinical practice recommendations for Post-diagnostic management and follow-up care for autism spectrum disorder	Focuses on post-diagnostic management and follow-up care for autism.	Provide information about in-home supports and interventions and help with securing respite care and social assistance

Guidelines related to respite care identify the importance of respite care as a supportive intervention following an autism diagnosis and can outline the range of available respite services, such as housing support, care at home and specialist residential support. Guidelines from New Zealand provided the most information, including advocating the use of respite care as an alternative strategy for behavioural difficulties, before using pharmaceutical interventions, the need for respite services to be flexible and having available planned respite care as well as systems in place to support a crisis response such as short break respite and in-home supports for families. Guidelines from the UK and New Zealand offered guidance on the type of respite care environment that should be provided, ranging from in-home respite services to community-based respite services. Further guidance is also provided in relation to respite care environments. The provision of information packages on respite care to parents strongly featured across guidelines from Canada, New Zealand, France and UK.

While many guidance documents for autism diagnostic assessments do exist, Penner *et al.* (2018), in their review of 11 documents noted considerable variation in guidance, including in the recommended tools and personnel used for the assessments. This variation can be attributed to insufficient evidence supporting the various assessment practices. A general finding from this review is that guidelines published in recent years are not just focusing on autism diagnosis but are also focusing on the care and management of autistic individuals compared with earlier guidelines that have primarily focused on diagnosis and assessment. This can be attributed to the influence of autism strategies and action plans that have been developed in countries with the intent of improving the quality and life of individuals with autism. In summary, in order for health and social care professionals to assist parents of autistic children to access the necessary support services such as respite care, it is vital that respite care is highlighted in these guidelines with further guidance as to how to assess and plan for respite as well as respite care options.

2.8 Respite care models and pathways for autistic children

The optimum service model for the provision of respite for autistic children is currently uncertain. 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. In reviewing the evidence on what constitutes effective respite care for autistic children, it became

apparent, however, that there is no one size fits all approach. Consequently, no single system of care delivers services across the lifespan, rather various models and pathways exist that either describe what respite care for autistic children should comprise of, or describe care pathways in which respite care is an essential service within an overall care pathway.

2.8.1 Essential elements for the provision of respite care for autistic children

Drawing on the aforementioned best practice guidelines and relevant literature, what constitutes effective respite care for autistic children, was explored (Mesibov & Shea 2010, McCubbin & Patterson 2014, Wolpert *et al.* 2019, Wainer *et al.* 2021a).

Overarching principles and operational elements as essential elements for the delivery of effective respite care services for autistic children were identified. These include:

- being person centered/needs led
- being responsive to the needs of service users, careers and families
- providing the least restrictive care/intervention options with likely clinical benefit
- provision of evidence-based care and guidance over the lifespan
- collaboration with other professionals and autistic individuals and their families
- adapting a holistic approach by looking at person, family and community
- training of professionals
- integrated care (liaison between primary and secondary care)
- consideration of family adaption to stressors/ability to cope
- create groupings based on levels of need to create an overall pathway
- single point of access
- linking in early to help prevent escalation
- focus on building resilience.

In summary, these findings are informative in terms of the requirements necessary to provide effective respite care for autistic children and provide a basis on which respite care services for autistic children can be delivered. However, further research is required to determine whether particular models of service delivery are more effective than others in improving outcomes for autistic children.

2.8.2 Integrated care pathways and models: A requirement in the provision of effective respite care for autistic children

Integration, coordination, and transition of care are repeatedly highlighted as lifelong challenges for autistic individuals, families and providers (Lord *et al.* 2022). Autistic children are particularly at risk as many paediatric services usually end at 18 years of age. Current patterns of care provision for autism internationally are described as patchy, reactive, usually received too late and short-term focused, and commonly not evidence-based (French & Kennedy 2018, Green & Garg 2018, Sandbank *et al.* 2020, Whitehouse *et al.* 2021). Identifying models of care which have demonstrated effectiveness is thus timely and critical. One such model described in guidelines and in the literature is the 'stepped care model' (Lord *et al.* 2022 Green and Garg 2018, Ramirez *et al.* 2020, Naithani 2022, Webb 2014, Wainer *et al.* 2021)

Stepped-care model

Stepped-care is an adaptive model of care in which less intensive interventionist care as a first-line treatment is offered, followed by more intensive care only when clinically indicated (Wainer *et al.* 2021b). The underlying principle of a stepped-care model is offering the least restrictive care/intervention options with likely clinical benefit over more resource intensive service options (Bower & Gilbody 2005). 'Least restrictive' also refers to the intrusiveness of the intervention on the client, and in the context of limited healthcare resources (Bower & Gilbody, 2005).

Benefits of a stepped-care model, include accessible, cost-efficient, acceptable and effective individualised management particularly for brief interventions (O'Donohue & Draper 2011). However, much of the efficacy evidence of this model has come from its application across other health conditions such as anxiety, depression and childhood trauma (Wainer *et al.* 2021a). Nonetheless, international best-practice autism guidelines have provided support and evidence for the efficacy of such a stepped-care model for targeted interventions for autism (O'Donohue & Draper 2011). Most recently, The Lancet commission on the Future of Care and Clinical Research for Autism recommended a 'stepped-care personalised approach' to care, acknowledging that profile of strengths and needs of each autistic individual and their family should determine the intervention and support priorities, but also that these can change over time and in a stepped manner (Lord *et al.* 2022)

Stepped-care services typically involve processing referrals in a tiered manner whereby autistic children are first screened for complexity by primary care services, with cases progressing through to secondary care services such as disability services, or alternatively with specialised care being incorporated into primary care as required based on needs (HSE and Tusla Joint Protocol, 2017). Key determinants for an effective stepped-care approach include individual and family participatory decision making in each step, the requirement to consider the needs, abilities, and personal costs (not just financial) of autistic individuals and their family (Pellicano 2020, Lord *et al.* 2022). Other requirements that have been advocated for within a stepped-care model include: systems to support self-care and resilience; sustained case management; and the need for timely access to more intensive step-up care if needed to support the family as needed through predictable transitions and unpredictable life events (Green & Garg 2018, Lord *et al.* 2022).

Notwithstanding the evidence which highlights the benefits and effectiveness of the stepped-care approach, there are a number of challenges. A potential concern with this model is that individuals and families can get stuck in an early step of care, without consideration of needs that should be addressed in later, more costly steps (Lord *et al.* 2022). Consequently, progress monitoring while ensuring appropriate allocation of needed services is also an integral part of this model. In addition, for such a 'stepped-care' model of service delivery to function, liaison between primary and secondary care services is imperative (Appleton 2020) along with effective interdisciplinary and interagency working. Furthermore, although case management is a key requirement to the effectiveness of this model and has been recommended in other guidance documents (NICE 2013) in order to sustain family self-care and resilience and be the interface between many agencies and health and social care professionals, its application can be challenging in the context of service demand and availability.

A repetitive theme that consistently emerges from review of autism services and policy reports is that such services would be improved if they worked in a more collaborative manner (Cameron *et al.* 2012; HSE 2012, 2017, NICE 2011). Research has provided evidence for the efficacy of interdisciplinary team assessment and intervention delivery for autism (PSI 2010, Wright *et al.* 2016). Interdisciplinary working refers to a model of working whereby multidisciplinary team members such as Occupational Therapists, Paediatricians, Psychiatrists, Psychologists, and Speech and Language Therapists work together in assessing and delivering interventions. Despite evidence supporting the efficacy of integrated care for autistic children, the required services such as

respite care are in short supply with limited functioning pathways to services (HSE 2017).

In summary, the stepped-care model goes beyond short-term reactive care to a more pro-active, developmentally phased, and scalable programme of support for autistic children and their families from the earliest opportunity, with timely access to later step-up care when needed. While further empirical evidence is needed to critically evaluate the application of the stepped-care model as a care model for autistic individuals and associated outcomes, it does appear to be a suitable model that has potential to respond to the diverse and evolving complex needs of autistic children and their families. Respite care can easily be placed within the concept and process of this model. However, barriers to effective implementation such as sustained case management and enhanced service capacity need to be addressed in order for this to be an effective pathway for accessing respite care services for autistic children.

2.9 Current provision of and access to respite care services for autistic children in Ireland

In Ireland, health-related support services (including respite care) to autistic children are primarily provided by voluntary agencies, funded by the HSE and others, or provided directly by the HSE. Currently access to respite care for autistic children is either sought through a child's social worker, public health nurse or local disability manager if the child is linked to a HSE service. Notably there is no centrally maintained waiting list for respite services and access is heavily influenced by a child's location, meeting specific criteria for respite, resources available and allocated funding. Despite expansion of the services over the last number of years, respite remains a largely unmet need for many families with autistic children in Ireland. There is also significant variability in the provision of respite services across different areas in the country (Hourigan *et al.* 2018). Policies around respite have developed at organisational level and are limited by the scale and scope of that organisation's activities and capacities. This contributes to regional variations throughout the country and raises questions of inequality of respite distribution.

Reconfiguration of existing health and social care services for children with disabilities are currently underway through a number of policies. Ireland's current '*National Policy on Access to Services for Children and Young People with Disability and Development Delay*' states that health and social care services in Ireland must be delivered in an

integrated manner, as close to the person's home as possible (HSE 2019). This is also in line with the vision of the *2017 Sláintecare Report* and implementation plan (Department of Health Government of Ireland 2021) and the *HSE's National Model of Care for Paediatric Healthcare* (Health Service Executive. Royal College of Physicians in Ireland 2016). A national programme called '*Progressing Disability Services for Children & Young People*' is changing the way services are currently provided in Ireland. The programme aims to ensure that disability services are easily accessible and equitable to all and that there is collaboration between families and health and social care providers. The programme will see the implementation of Children's Disability Network Teams (CDNTs) across the country for all children with complex needs to access. CDNTs are being established within defined geographic areas with co-existing Primary Care Networks in each of the nine Community Healthcare Organisations (CHO). CDNTs will address the needs of children with a wide range of disabilities including, but not limited to, intellectual disability, physical disability, sensory disability and autism. This will be regardless of the child's disability, diagnosis or where he or she goes to school. It is anticipated that parents and health professionals will no longer have to navigate a complex maze of services and will easily be able to find out where a child should be referred. The team members will work within an interdisciplinary team model, contributing to a joint integrated plan for each child, young person & family and will have joint working protocols with other services such as mental health services. The pathway for referral and access to services for children with disability (inclusive of autism) is outlined in Figure 4.

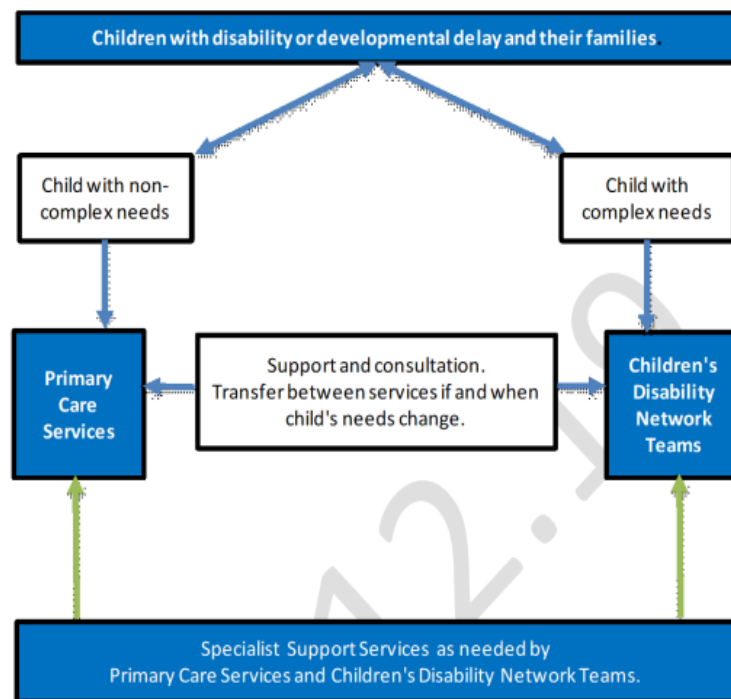


Figure 4: Access and referral pathway to service for children and young people in Ireland as per National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (HSE 2019).

2.9.1 Gaps in autism and respite care services

In Ireland, there is currently an underdeveloped service response for autistic children as highlighted through various HSE reviews, surveys and reports from advocacy groups (As I Am 2021, Gadd 2019, HSE 2018, HSE 2012). However, Ireland is not unique with other countries experiencing similar situations (Green *et al.* 2022). Although significant advancements and progress has been made in Ireland in recent years in relation to autism and associated services, service users, parents and professionals continue to highlight numerous gaps in service provision. Research also continues to highlight gaps in service provision across all areas of health and social care . In the context of the current study, gaps in service provision for autistic children primarily relate to;

- a lack of defined pathways for autism services (HSE 2012)
- inadequate distribution of respite services which can often be based on geographical location (Hourigan *et al.* 2018) (HSE 2012)

- insufficient supply of an appropriate range of respite options (day services, residential to meet the diverse needs of children (Doherty *et al.* 2012)
- a lack of capacity within respite services/unmet need for respite (Casey *et al.* 2020)
- lack of crisis respite (Whitmore *et al.* 2018, Gadd 2019, Cooke *et al.* 2020,)
- insufficient access to mental health services (HSE 2012, 2018, Cooke *et al.* 2020)
- inadequate access to health and social care professionals (As I Am 2021)
- a lack of education/training and support for professionals and service providers
- inadequate family support services and in particular support for parents who are involved in caring for their autistic child (Doherty *et al.* 2012)
- insufficient provision of quality information relating to autism services (O'Brien 2021)
- inadequate post diagnosis support (O'Brien 2021)
- a lack of comprehensive information on the number of autistic children to support service planning (Gadd 2019, HSE 2018)
- inadequate structures to support transition process from child to adult services (HSE 2012).

In summary, the rising prevalence of autism is straining health, education, and community service systems, making service access increasingly problematic (Brown *et al.* 2011). Consequently, there is a heightened economic, social and political need to address the issue of integrated care and access to respite care for a growing population of autistic children.

In Ireland, there is no comprehensive mapping of autism services and little evaluation of existing services, particularly respite. Research continues to highlight that pathways to support services are fragmented and difficult to navigate. The absence of an autism register, results in an absence of vital data which makes planning for service needs challenging and also makes cost effectiveness studies of certain interventions more difficult. Although some organisations and representative bodies of autistic individuals are gathering data, having a nationally mandated autism database would enable the development of a stronger evidence base to be used by policy makers in deciding how to plan for and allocate resources and bridge the gaps across many services. However, it is equally important to obtain the views of those navigating these complex pathways so that gaps in service provision continue to be identified and addressed.

2.10 Chapter summary

This chapter has provided an overview of autism and presented the key findings from the literature review relating to accessing respite care services for autistic children.

Potential predictive factors for autistic children attending acute care services has been identified. This chapter also presented a review of national and international policies and guidelines pertaining to the provision of care for autistic individuals and explored how respite care featured within these documents. Respite care models for autistic children were reviewed and current respite service provision for autistic children in Ireland was outlined. Overall, this chapter has provided background and context to support the research aims and objectives.

Chapter 3: Parents' experiences of accessing respite care: A systematic review

3.1 Chapter overview

Chapter 2 highlighted an array of physical (e.g., behaviours that challenge, complexities of service navigation), emotional (e.g., burn-out, stress) and social (e.g., isolation) experiences for parents of autistic children. A review of the literature demonstrated that there is limited evidence of the actual experience of families seeking access to respite services for autistic children. Furthermore, little is known about the profile and numbers of autistic children accessing respite care. Gaining further insight and understanding of parental experiences explicit to accessing respite care was deemed important to my study in elucidating (potentially) further unknowns on the topic as well as helping inform the interview guide used during the data collection/field work phase of the study (section 5.6.1). For this reason, I conducted a systematic review of qualitative studies (now commonly referred to as qualitative evidence synthesis) on parents' perspectives/experiences of access to respite care for their autistic children at the acute and primary care interface. The protocol for this systematic review was registered with PROSPERO CRD42018106629 and the review is now published (Cooke *et al.* 2020).³

3.2 Review aim

The aim of this systematic review was to synthesize the available evidence on access to respite care from the perspectives of parents of autistic children and report on the quality of the findings. In addition to informing my study interview guide, understanding the motivating factors for parents accessing respite care for their autistic child could support the development of a model of respite care for autistic children.

3.2.1 Definitions and terminology

To avoid ambiguity, respite care, for the purposes of the review, was defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to the main carers and their family (Brenner 2016). Autism was defined as a lifelong neurological condition characterised by unusual behaviours and impairments in communication skills and social (APA 2013).

³ Cooke, E., Smith, V. & Brenner, M. Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: a systematic review. *BMC Pediatr* **20**, 244 (2020).

Other conditions on the autistic spectrum which are included under the heading of autism, and were considered for inclusion in the review, were Asperger's Syndrome, Retts Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder and Atypical Autism (APA 2013).

3.3 Methods

3.3.1 Inclusion and exclusion criteria

As this review question focuses on individuals experiencing a phenomenon, the PEOS mnemonic (**P**opulation, **E**xposure, **O**utcome, **S**tudy type) was used to describe the review's inclusion criteria. The review included parents of autistic children (P) who have accessed respite care (E) and offered their views and experiences of the process (O) through qualitative inquiry (S). The age of the child had to be below 18 years. While the literature can often describe parents of autistic children and adults together, research suggests that parental adaptation might vary across different age groups (Mugno *et al.* 2007). Studies focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory and narrative approach. Qualitative components of mixed method studies that represented the experiences of parents accessing respite care for autistic children were also eligible for inclusion. Quantitative studies and quantitative components of mixed method studies were excluded.

3.3.2 Search strategy

An initial search of the Prospero Systematic Review database was performed to ensure the absence of similar reviews. A broad approach to the search strategy was applied to maximise the potential for capturing all relevant data and to minimize the potential for non-retrieval of relevant studies. Search terms were developed using a combination of keywords combined with Boolean limiters, and index term searching. Keywords and search terms derived broadly from a combination of the review's population and exposure inclusion criteria were sub-divided into concepts. Identified terms were tagged against the following concepts which reflected the PEOS criteria; autism, respite and children. When developing a key word for a concept, each word was separated with the 'OR' operand. Once the search for each of the concepts was completed, all the concepts were combined together using the 'AND' Boolean operator to narrow the set of results. Figure 5 outlines an example of the search strategy.

☐ Select / deselect all Search with AND Search with OR Delete Searches Refresh Search R			
Search ID#	Search Terms	Search Options	Actions
☐ S10	 S3 AND S6 AND S9	Search modes - Boolean/Phrase	 View Results (60)  View Details  Edit
☐ S9	 S7 OR S8	Search modes - Boolean/Phrase	 View Results (35,439)  View Details  Edit
☐ S8	 autism OR autistic or autistic disorder OR child with autism OR behavioral disorder OR child development disorders OR mental disorders diagnosed in childhood	Search modes - Boolean/Phrase	 View Results (30,112)  View Details  Edit
☐ S7	 "autism" OR (MM "Asperger Syndrome") OR (MM "Developmental Disabilities") OR (MH "Autistic Disorder")	Search modes - Boolean/Phrase	 View Results (28,105)  View Details  Edit
☐ S6	 S4 OR S5	Search modes - Boolean/Phrase	 View Results (662,009)  View Details  Edit
☐ S5	 child OR children OR teen OR teenager OR adolescent OR baby OR young person OR adult child	Search modes - Boolean/Phrase	 View Results (662,009)  View Details  Edit
☐ S4	 (MM "Child")	Search modes - Boolean/Phrase	 Rerun  View Details  Edit
☐ S3	 S1 OR S2	Search modes - Boolean/Phrase	 Rerun  View Details  Edit
☐ S2	 Respite OR respite care OR unscheduled care OR shortbreak OR breakaway	Search modes - Boolean/Phrase	 Rerun  View Details  Edit
☐ S1	 respite care	Search modes - Boolean/Phrase	 Rerun  View Details  Edit
<< Refine Results Search Results: 1 - 10 of 60 Relevance ▾ Page Options ▾  Share			

Figure 5 Example of search strategy applied when searching literature database.

Once the search terms based on free text words and indexing terms were finalised, the main search to identify studies for inclusion in the review was undertaken across selected databases. This was first conducted in May 2018 and updated in August 2018. Databases searched included: Cumulative Index to Nursing and Allied Health Literature (CINAHL+) (via EBSCOhost); PsycINFO (via EBSCOhost); PubMed and Embase, with search strings adapted for controlled vocabulary as appropriate for the different databases. To meet the aims of a broad exploratory systematic review, studies published in English, during any publication period were accepted. Studies identified as relevant based on the PEOS eligibility criteria were selected for inclusion.

Searching other sources

To ensure a comprehensive search for all potentially relevant publications, a manual search of the reference list of all articles included at full text level was conducted to identify additional studies that potentially may not have been captured by searching the databases. The search strategy also targeted unpublished studies and ‘grey literature’ to help minimise the risk of missing unpublished studies. The search for unpublished studies included: Irish Lenus Repository; Governmental sites and reports (e.g. Department of Children and Youth Affairs (DCYA) Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020); Databases for graduate thesis; Doctoral dissertations (ProQuest Dissertations & Theses Global database, EthOS, DART, American Doctoral dissertations), abstracts of

conference proceedings (National Autism Conference, Irish Society for Autism, Autism Europe, Autistic Disorder Congress). Websites of organisations relevant to the review question-WHO, NICE, CDC, Open-Grey, Grey Literature Report were also searched. The search strategy also included relevant reports, position and opinion papers that represented the experience and voice of the parent in the context of the review question. For example, if the information or data provided was directly obtained from parents or guardians of autistic children accessing respite care or if the report was written by a parent outlining their views or experiences in the context of the review question, these were also considered.

3.3.3 Selection process

Study selection was performed using a two-stage process; i) screening of title and abstracts only, excluding those obviously ineligible at this stage, and forwarding those that appeared relevant or where uncertainty existed around their relevance, for review of their full-texts; ii) retrieval and assessment of full-texts for inclusion in the review. Two reviewers (myself and one of my supervisors) independently screened titles and abstracts of all citations retrieved during the search, after removal of duplicate citations, for eligibility. Disagreements that arose between the reviewers were resolved through discussion and consensus.

3.4 Results

Database searching elicited 430 records of which 291 studies remained after removal of duplicates (139). Following title and abstract screening 31 studies remained. Of these 31 studies, 25 were excluded after full text review for the following reasons: wrong study design [15]; wrong exposure [3]; wrong patient population [3]; duplication [2]; not in English [1]; and unable to obtain full text [1]. Communication was made with the author of the one study that could not be obtained, however, there was no response. This resulted in six studies that met the inclusion criteria. At this stage the reference lists of identified papers were searched manually to identify any potentially additional studies. One additional study that met the inclusion criteria was sourced during the manual search. As a result, 7 studies were identified as eligible and included in the review. Figure 6 illustrates the searching and selection process. Interestingly, no single study was found that exclusively explored the views of parents of autistic children accessing respite care, rather this aspect was a component within the studies.

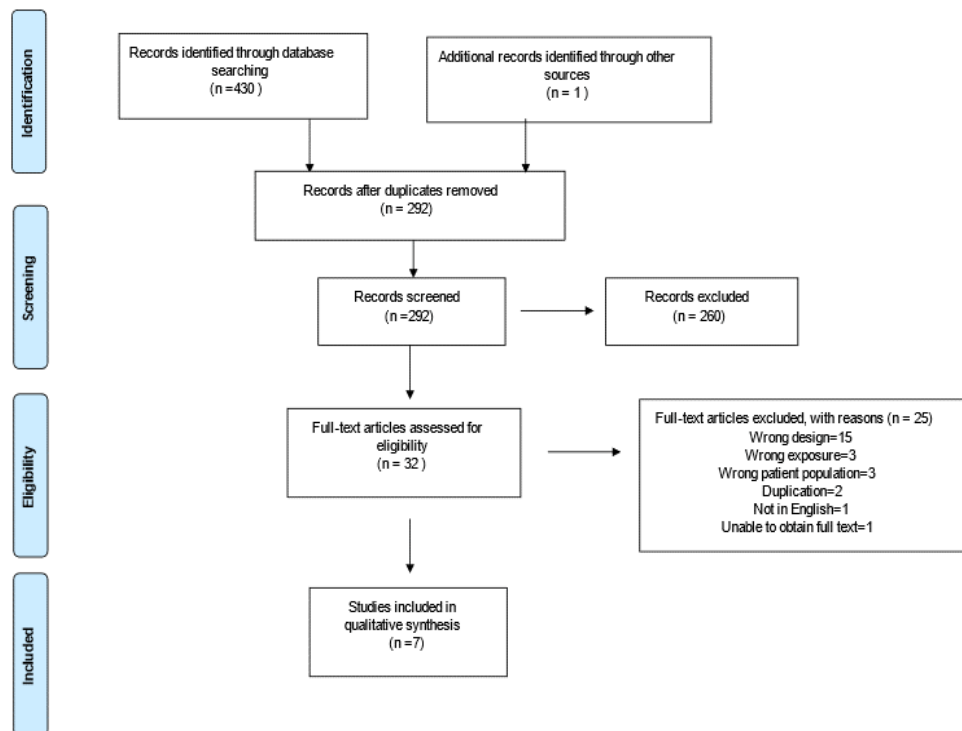


Figure 6 Flow chart of search outcomes and included studies (PRISMA)(Moher *et al.* 2009).

3.4.1 Appraisal of study quality

Assessing credibility and the quality of the studies was about ensuring studies were sufficiently methodologically robust so that the findings, and the evidence emerging from the systematic review, can be deemed reliable and valid. All included studies were formally assessed for methodological rigor by myself, and a second independent reviewer assessed three of the selected studies. A number of quality assessment tools were piloted including the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI Institute 2014) and the Critical Appraisal Skills Programme (Casp) model (Casp 2018). However, I chose a critical appraisal tool from Brunton *et al.* (2011) for use in the review as it provided a more comprehensive approach to appraising the selected studies. Issues considered during the appraisal process included rigor, credibility and relevance of the included studies.

In appraising the papers, they were summarized in table form, showing the study and reference, aim/objectives, sampling and recruitment, characteristics of participants, socio-economic status, validity and reliability of data collection methods and tools and relevance to the systematic review (Table 5).

Table 5 Critical appraisal tool used for systematic review (Brunton et al. 2011)

Quality Assessment Tool Scoring System: Not applicable = 1, Explicitly stated = 1, Implicit = 0.5, Not stated = 0, Unclear = 0 What is this study's weight of evidence in terms of answering this review question? 1. High (8 – 10 points), 2. Medium (5 – 7.5 points), 3. Low (0 – 4.5 points)											
Journal/Article	Section A: Aims 1. What are the broad aims of the study? (please specify) a. Explicitly stated b. Implicit c. Not stated d. Unclear	Section B: Sampling 2. Which methods does the study use to identify people, or groups of people, to sample from and what is the sampling frame? (please specify) a. Not applicable b. Explicitly stated c. Implicit d. Not stated e. Unclear	3. Which methods does the study use to select people, or groups of people (from the sampling frame)? (please specify) a. Not applicable b. Explicitly stated c. Implicit d. Not stated e. Unclear	Section C: Characteristics of participants 4. What was the total number of participants in the study? (please specify) a. Not applicable b. Explicitly stated c. Implicit d. Not stated e. Unclear	5. Age (please specify) a. No evidence of measurement/Not applicable=1 b. Under 12 years c. 12 – 18 years d. 19 – 34 years e. 35+ years f. Not stated g. Unclear (h. could add Not applicable here is appropriate)	6. What is the socio-economic status of participants? (please specify) a. Not applicable b. Explicitly stated c. Implicit d. Not stated e. Unclear	Section D: Data collection tools & methods 7. Do the authors describe any ways they addressed the reliability of their data collection tools/methods? (please specify) a. Yes b. No	8. Do the authors describe any ways they have addressed the validity of their data collection tools/methods? (please specify) a. Yes b. No	Section E: Accessing people's views 9. Does this study use appropriate data collection methods for helping people to express their views? (please specify) a. Yes b. Partially c. No	Section F: Relevant to the review question 10. How useful is this study in helping to answer the review question? (please specify) a. Very useful b. Somewhat useful c. Not useful	QA Outcome High=6 Medium=1 Low=0

(Benderix <i>et al.</i> 2006)	1	Implicit =0.5 (convenience , case study)	Unclear 0.5	1 (10 parents from five families)	1 (10-11yrs)	0 (Not stated)	1 (Research ers outline their experience within the field)	1 (Separate analysis followed by compared assessment t)	Yes=1 (Narrati ve interview w)	1 (Focuses on experien ces in respite home)	8 (High)
(Gona <i>et al.</i> 2016)	1	1 (Purposive- convenience sample)	1 (Recruit ment through neuro assessment clinic)	1 (103 participant s)	1	1 (Detailed paragraph on socio- economic status)	0	0	1 (Interviews and focus groups)	0.5 (Somew hat useful)	7.5 (Medium)
(Hartrey <i>et al.</i> 2003)	1	1 (Convenience)	1 (Two mothers of children with learning disabilities, who used residential respite care)	1 (Two mothers)	1 (11-year-old boy and 8- year-old girl)	0 (Not stated)	0.5 (Account provided about Heideggerian principles of interpretation and why it was chosen in the study)	0.5 (Account provided about Heideggerian principles of interpretation and why it was chosen in the study)	1 (Narrative reflection)	1	8 (High)

(Hodgetts <i>et al.</i> 2013)	1	0.5 (Purposive-convenience)	1 (Email lists accessed through the city's Autism Society)	1 (Parents of 9 individuals with autism)	1 (3–29-year-olds with ASD)	1 (Detailed paragraph on socioeconomic status)	0.5 (Member checking mentioned and detailed coding method described using NVivo)	0.5 (Account provided on how grounded theory approach was most suitable to the study)	Yes=1 (Interview)	0.5 (Somewhat useful)	8 (High)
(Mann 2013)	1	1 (Purposeful sampling, snowballing procedures, and inclusion/exclusion criteria)	1 (Recruited through an autism support association)	1 (13 mothers)	1 (Children aged 4–17years)	0.5 (one mother not working)	1 (Pilot interview/review of transcripts)	1 (Pilot interview/review of transcripts)	Yes=1	0.5 (Somewhat useful)	9.0 (High)
(Minhas 2015)	1	1 (Purposively using a maximum variation sample)	1 (New referrals to the centre)	1 (15 parents)	1	0.5 (Some socioeconomic status-education)	1 (Thematic analysis carried out by two independent researchers, triangulation through literature)	1 (Two researchers independently carried out the first two stages of the analysis)	Yes=1 (In depth interviews)	0.5 (Somewhat useful)	9.0 (High)
(Keenan <i>et al.</i> 2007)	1	0.5 (Purposive-convenience)	1 (Accessed through organisations and charities)	1 (95 parents and carers representing 100 children)	1	1 (Detailed description available)	0.5	0.5	Yes=1 (Focus groups)	1	8.5 High

				with ASD and 67 MDT profession als)							

The overall quality of each included study was reported as high, moderate or low based on the results of the critical appraisal process. However, the author intended to include all studies, irrespective of methodological quality in the review, with studies of high and moderate quality, highlighted appropriately. Justification for this is that it is possible that valuable insights and perspectives of study participants could be lost if papers were excluded on the grounds of quality.

Seven articles were appraised in total. Six studies were reported as high quality and one study was reported as medium. No studies were found to be of low quality. The author and independent reviewer reached a 97% agreement on the independent quality appraisal assessment of three included studies.

3.4.2 Data extraction and synthesis

Details from eligible studies were extracted using a pre-designed data extraction spreadsheet detailing study characteristics such as publication year, study design, country of origin, methods, sample size, data collection and data analysis procedures, point of access to respite care, type of respite care, conclusion, key findings. This also allowed for synthesis of methodologies and methods. A meta-aggregative approach was used during data synthesis. The meta-aggregative method is aligned with the philosophy of Hannes & Lockwood (2011) where the meaning is connected to the idea of practical usefulness and pragmatism and supports the pragmatic approach to this systematic review. Furthermore, the mega-aggregative method has been developed in order to deliver usable synthesised findings to inform decision making at the clinical or policy level. Therefore, this approach was considered helpful when attempting to explore current practice on accessing respite care from the perspectives of parents of autistic children.

3.4.3 Characteristics of included studies

One study was conducted in Pakistan and India. Two studies were conducted in Ireland and the remaining studies were conducted in Sweden, Kenya, Canada, and the United States. The profile of participants included a mixture of mothers, fathers and grandmothers. Six of the studies employed a qualitative design and one study employed a mixed methods design of which the qualitative data were extracted only for the purpose of this review. The majority of autistic children were male; however, two

studies did not specify the gender. Some of the children had been newly diagnosed with autism (Mann 2013) and other children, in addition to their autism, were described as having either a learning disability or an intellectual disability characterized by limitations in intellectual functioning (e.g., learning, reasoning, problem solving skills) and/or adaptive behaviour (conceptual, social and practical skills) which was classified as moderate to profound within some studies. Table 6 outlines the profile of participants from the included studies.

Table 6 Profile of participants from the included studies.

Author and Year	Number of Parents	Profile of Parents mother/father	Number of Children	Gender of child	Age of Children	Disability
Benderix <i>et al.</i> 2007	5 couples	Not specified	5	Not specified	10-11years	Learning disability moderate x1 severe x3 profound x 1
Gona <i>et al.</i> 2016	103 (incl HCP's)	Not specified	Not specified	Not specified	Not specified	Not specified
Hartrey 2003	1	Mother	1	Female	8 years	Intellectual regression
Hodgetts <i>et al.</i> 2013	9	Mothers (8) Father (1)	9	Male (9)	6-10 years (7) 19 years (1) 29 years (1)	All had moderate to severe intellectual disability.
Mann 2013	13	Mothers (13)	13	Male (11) Female (2)	4-17yrs	Not specified. Autism described as moderate, mild and severe.
Minhas <i>et al.</i> 2015	15	Mothers (11) Fathers (4)	15	Male (12) Female 3	7-16 years	Not specified
Keenan 2007	95 parents and carers	Mothers (84) Fathers (8) Foster parents (2) Grandparent (1)	100	Male (80) Female (20)	Mean age 8years 30 (1-6yrs) 56 (7-12yrs) 11(13-15yrs) 3 (16yrs)	Intellectual disability: 56 with learning disability ranging from mild, moderate and severe

3.5 Synthesis of research findings

The results synthesised during meta-aggregation were the qualitative findings related to parents of autistic children and views/experiences of access to respite care. The aim of meta-synthesis by meta-aggregation was to assemble findings from qualitative research, categorize those findings into groups on the basis of similarity in meaning and aggregate these to generate a set of statements that adequately represent that aggregation (Hannes *et al.* 2017). Meta-aggregation was achieved using NVivo software through the following three step approach:

- Extraction of all findings from all included studies related to views/experiences of access to respite care only.
- Developing categories for findings with at least two findings per category.
- Developing one or more synthesized findings from at least two categories.

Categorization involved repeated, detailed examination of the extracted findings. Groups of findings were identified on the basis of similarity in meaning to create categories. A category is the combination of a brief description of a key concept arising from the aggregation of two or more similar findings. This description is accompanied by an explanatory statement that conveys the whole inclusive meaning of a group of similar findings. The results are presented based on the synthesised findings that emerged. Synthesis of the included studies data identified three prominent themes that reflected the perspectives of parents of autistic children on accessing respite care (Table 7). These include [1] The journey to getting and maintaining respite care; [2] The role of healthcare professionals in supporting parents to access services including respite care; and [3] Facilitating factors and barriers to accessing respite services.

Table 7: Synthesised finding from included study

Finding (from study)	Category	Synthesised Finding
Challenges with access to respite care and services	Accessing and maintaining respite care services is an ongoing process	The journey to accessing and maintaining respite care
When behaviour becomes unmanageable is the point at which parents start to access respite care and services		
Types of respite care received		
Maintaining respite care		
Benefits of respite care	Identifying the need for	

Care giver burden associated with caring for an autistic child Increased stress levels as a consequence of not having access to respite services.	/motivating factors for seeking respite care	
The need and reason for respite care/Motivating factors for seeking respite care		
Alternative pathways to support services such as traditional healers in the absence of formalised respite	Alternative options to respite care/supports	
Financial burden associated with caring for an autistic child	Parental concerns	
Parental concerns about using respite care	Parental concerns about respite services	
The attitude of HSCPs towards parents when seeking respite care-made feel inferior. HSCPs placing emphasis on the medical model rather than social model of respite care HSCPs limited information and knowledge about autism. HSCPs not informing parents about statutory services available.	The role of HSCPs in accessing respite care in acute and primary care	The role of HSCPs in accessing respite care in acute and primary care
Lack of information available to help parents access respite and services	Lack of information to assist parents, barriers to accessing respite care, criteria needed to provide adequate respite care	Facilitating factors and barriers to accessing respite services
Barriers to respite care-geographical location, lack of information, services not suited to child's evolving needs		
Requirements for adequate respite care-noting an improvement in the child Child satisfaction expressed Emphasis on education and social model	Facilitating factors for accessing respite care	

3.5.1 The journey to accessing and maintaining respite care

Parents' experience of accessing respite care was described as a relentless journey. A total of four stages emerged from the synthesis as part of the process of accessing and maintaining respite care services for autistic children. Although these stages were not necessarily sequential, each stage featured within the overall journey to accessing respite care. The stages included: identifying the need for/motivating factors for seeking respite care, accessing and maintaining respite care services, parental concerns about respite care services, and alternative options to respite care. One of the motivating factors for seeking respite was associated with an inability to manage

behavioural problems which directly caused increased stress levels amongst parents (Keenan 2007, Mann 2013). Parents reported that as the child grew stronger, they became more difficult to manage (Benderix *et al.* 2006). Parents began to seek help outside the home when the secondary behavioural problems associated with autism became visible and disrupted family life.

'We thought he would grow out of it, but he has become worse. Now if he gets upset he bites himself, bangs his head on the wall and if somebody goes near him he gets even more upset. No one comes near him' (Minhas 2015, p 252).

A number of studies outlined how family members were the main source of respite care for parents (Benderix *et al.* 2006, Minhas *et al.* 2015a, Gona *et al.* 2016). In the absence of any external support, parents described how spouses, siblings, grandparents and extended family members provided the main respite for the mothers and often families moved closer together so that the extended family could provide the support (Keenan M. 2007, Minhas 2015). Two studies reported that state-provided respite care was non-existent (Mann 2013, Minhas *et al.* 2015a). Those availing of respite care services were receiving some respite care via supported housing, residential group home and boarding school (Benderix *et al.* 2006, Hodgetts *et al.* 2013a, Gona *et al.* 2016). One study described the various types of respite services available to participants including out-of-home respite, in-home respite, home-to-home scheme, holiday club and after school club and were in receipt of direct payments to choose from different respite care options for their child (Keenan 2007). In the absence of any formalised support system or state funded respite care, traditional healers were cited in one study as being the first port of call for both rural and urban parents in the context of being a source of guidance for carers (Minhas *et al.* 2015a). These were identified as religious, traditional healers or herbal practitioners and others involved in magic or sorcery.

Accessing respite care services in rural areas was described as a challenge for parents (Mann 2013, Minhas *et al.* 2015a). The most commonly cited reason was that services were located mainly in major cities which were at a distance and parents could not afford the financial or time costs (Mann 2013, Minhas *et al.* 2015a). Overall, parents outlined a significant requirement for respite care but could not access this. Some parents described how they had attempted for many years through the government to obtain adequate home-based respite care services for their children in order to be able to manage the family situation but had not succeeded and resorted to arranging a

specialised group home in a building that the government made available (Benderix *et al.* 2006). Parents also described alternative methods used to find respite care such as online advertisements, newspapers, posting at local universities, grocery stores and word a mouth. For parents that had accessed and were receiving respite care, the outcome or the impact was described in terms of both the child getting respite and the family (Hartrey & Wells 2003).

'Looking forward to the respite knowing it is for 2 or 3 days. Longing to be able to mentally relax for a few days' (Hartrey & Wells 2003, p 338)

Some parents felt that respite services placed too much emphasis on the medical model and valued a more social care model delivered by healthcare professionals (Keenan 2007). For example, parents reported wanting a stronger educational orientation and less nursing and for the children to be given more training (Benderix *et al.* 2006) as parents hoped their child would become more independent and receive lifelong school training or a meaningful daily occupation. Parents also valued non-pharmacological behaviour management strategies recommended by allied health professionals such as psychologists, behaviourists and occupational therapists (Hodgetts 2013).

The benefits of respite care were described and reported in all studies. However, parents in one study described how they were not satisfied with their form of respite care, which was provided through a group home, as they felt that their child did not get enough of the activities they needed. The group home was described as a specialized group home made available by the municipality for autistic children with and learning disabilities in which the parents could leave their child for respite care ranging from weeks to days (Benderix *et al.* 2006). Equally parents acknowledged that no longer having control over their child caused stress and anxiety (Benderix *et al.* 2006). The child refusing to return to respite care also caused stress and anxiety and would prevent the parent from sending their child back (Benderix *et al.* 2006). Despite experiencing positive outcomes as a result of availing of respite care, parents still expressed ambivalent feels towards leaving their child. Strong attachments to their children rooted in their child's dependency made availing of respite care and the associated short-term removal of their child difficult and led to a sense of guilt (Benderix *et al.* 2006).

3.5.2 The role of health and social care professionals (HSCPs) in seeking respite care services and additional supports.

With the exception of one (Hartrey 2003), all studies mentioned the role of health and social care professionals in the context of seeking support services including respite care or the impact of HSCPs on the child and family while in receipt of respite care services (Benderix 2006, Keenan 2007, Hodgetts 2013, Mann 2013, Minhas 2015, Gona 2016). Parents in one study described how they were made to feel inferior by HSCPs when deciding to seek home and family respite support for their children and families:

“Dreadful, made to feel inferior by even seeking it.” (Keenan 2007 p 98).

HSCPs refusing access to respite care was also cited by some parents as their child did not meet predefined criteria (Keenan 2007). Families also reported that health and social professionals they met did not appreciate what they went through on a daily basis (Keenan 2007). Almost half the parents in one study had not been informed by statutory services about home and respite supports available to their family (Keenan 2007). Parents felt not knowing the questions to ask health and social professionals prevented them from accessing the appropriate support services (Keenan 2007).

“If we don’t know the questions to ask, then we don’t get any answers. Social services should be called secret services” (Keenan 2007 p 98).

Parents reported that the medical profession had only limited information or knowledge about autism and a lack of understanding about the condition (Hodgetts 2013, Minhas 2015) which often impacted on their ability to provide appropriate supports such as respite care. Parents spoke about how doctors sometimes focused on providing medication as a primary source of intervention (Minhas 2015) and did not consider alternative options. Parents in receipt of respite services for their child valued continuity with staff (Minhas 2015) but also reported that a lack of experienced staff in respite centres was a concern to them (Hodgetts 2013).

3.5.3 Facilitating factors and barriers to accessing respite care services for autistic children.

Perceived barriers to respite care were described at a systems level such as lack of information to assist parents and a lack of general support services for autistic children

(Keenan 2007, Mann 2013, Gona, 2016). The uncertainty of the autism condition and lack of adequate information from medical professionals was also described as a barrier to accessing respite care. Parents wanted a shift from the medical model to a more social model of care within respite care services (Benderix 2006). Seeing their child pleased was reassuring for parents but knowing that their child is being taken care of properly enabled parents to have confidence in the respite care service. Noticing an improvement in their child indicated that their child was happy in respite care which had a positive impact on the parents.

'He's making more progress both in the group home and at school than he is at home' (Benderix 2006 p 636).

The following section provides a general discussion based on the findings of the systematic review. A full discussion specific to the findings of this systematic review is available in the published paper (Appendix 2). Findings of the systematic review are discussed in greater detail in Chapter 7 (Discussion) where they are integrated with the overall findings from the current study. Implications of the systematic review and present study will also be highlighted in Chapter 8 (Conclusion).

3.6 Discussion

Autistic children primarily live with their families and research has shown that parenting an autistic child can produce stress in the family. All the studies in the systematic review described the stress associated with caring for an autistic child. Stress caused by the child's aggression and an inability to cope with challenging behaviour was found to be one of the greatest motivating factors for parents seeking respite care.

The review identified that respite care is an important support service for parents of autistic children, yet there was a reported lack of respite care for autistic children and their families. Findings highlighted that families were the biggest providers of respite care for parents of autistic children which reflects research findings throughout the literature (Dyches *et al.* 2016). The benefits of respite care were also described and reported throughout the studies in this review with parents identifying the need for respite care to be based on a more social model than a medical model. This is consistent with previous research supporting the need for respite care to be more than just the physical separation of a parent from their child (Wilkie & Barr 2008, Mansell & Wilson 2009).

There are a number of additional key findings arising from this systematic review that are consistent with previous research and also emerged as similar findings from this study. These are:

- An immense need for, but inability to access respite care
- The point and age at which parents began to seek respite care services for their autistic child
- The critical need for both behavioural and crises intervention to reduce the burden on acute services
- The role HSCPs play in supporting parents to access respite care
- Quality of respite care
- A critical need for effective implementation of integrated healthcare systems for autistic children who have many service needs, including the need to access effective mental healthcare.

As these findings emerged as similar findings within the current study, these will be discussed collectively with the study's findings in greater detail in Chapter 7.

A reoccurring feature of the literature and this review is that parents and families have demonstrated great resilience when faced with challenges accessing respite care services for their autistic children. Disparities with accessing respite services in rural areas was also a finding of this review which is shared nationally and internationally. It is clear that the sociocultural, demographic, economic and health systems context is quite different from high income countries, where most interventions for such conditions are researched and developed. Dew *et al.* (2013) reported that caregivers of autistic individuals living outside of metropolitan centres in Australia noted a lack of autism expertise in healthcare providers in rural and remote areas of the country. Similarly, Thomas *et al.* (2012) found that caregivers of autistic children who lived in rural communities in the United States reported significantly less access to special summer camps and respite care. In Ireland, the *Sláintecare Report* (2017) outlined that there remained significant geographic differences in access to respite care services in the general sense. Furthermore, the report suggests that based on the evidence, there are often long wait times to access rationed services without choice of service provider and that they also end up paying out of pocket for such services. The financial burden of caring for an autistic child was also reported by parents in five out of the seven included studies in this systematic review (Keenan 2007, Hodgetts *et al.* 2013a, Mann 2013, Minhas *et al.* 2015a, Gona *et al.* 2016). Parents in receipt of direct payments to

access respite support services or respite care grants found this approach very beneficial (Keenan 2007).

Findings also identified an appetite for respite services within a home setting. This reflects the trend in care delivery for children requiring respite for physical care issues. A lack of home-based respite services along with inflexible supports, delays in provision or long waiting lists, restricted or unreliable services and inequality of respite distribution has been well documented throughout the literature (Chan 2008, Wodehouse & McGill 2009, Caples & Sweeney 2010, Robertson *et al.* 2011, Coll & Scully 2011, McConkey *et al.* 2011, Anderson *et al.* 2013, Spruin *et al.* 2017, Pullin & McKenzie 2017, Southby, 2018).

It is apparent that autistic individuals have a wide range of needs across the lifespan and that meeting these needs requires government coordination between healthcare, education, finance, and social sectors across the life span, and active inclusion and participation of autistic people and their families. Notably, the integrated care agenda did not seem to have influenced care delivery in this area to any great extent. Notwithstanding this, findings from this systematic review have identified particular gaps across the integrated care model particularly within primary care and mental healthcare needs. Paediatric primary care is an ongoing point of healthcare that is well positioned to identify mental health concerns and facilitate linkage to mental health services for autistic children. However, identifying mental health problems in autistic children by primary care providers is complex, subject to being overlooked and may significantly vary based on primary care organizational characteristics. Efforts targeting integrated primary-mental healthcare implementation require a tailored approach for autistic children. Findings relating to the requirement for more effective integrated services that meet all the needs of autistic children, including mental healthcare needs, will be discussed in greater detail in Chapter 7.

Overall, the limitations of respite care identified from the systematic review findings and previously highlighted within the literature are primarily associated with accessing respite care and can be attributed to the level of information about the availability of respite services (Dew 2013), inflexibility in services, a lack of choice of services (Cocks 2000) and geographical location (McGill 2006). These findings, along with findings from the literature review were used to inform the interview guide used during the data collection phase of this study (Chapter 5).

The systematic review identified specific implications for health services and further research. These will be discussed in greater detail alongside the wider implications of the overall study in Chapter 8.

3.7 Strengths and limitations of the review

This review identified and included seven published studies only, of which none exclusively explored the issue of access to respite care, thus the data informing the meta-synthesis and the overall review's findings, while narratively rich, were limited. Respite care has been identified as a challenge for systematic reviewers, particularly regarding how best to identify appropriate evidence for inclusion (Mason 2007). The variety of need, type of breaks and range of impacts leads to difficulties when attempting to evaluate outcomes and effectiveness of services provided. A lack of thorough evaluation around the benefits of respite care has been attributed to concerns around existing research methodologies, ethical issues, sample sizes and the use of inappropriate outcome measures. A significant strength of this review, however, is that included studies were assessed as methodologically robust (high quality), which adds weight to, and increases confidence in the validity and reliability of the findings for informing care, practice and policy. However, it must be noted that not all autistic children require the same needs as respite care. While a number of studies did indicate the severity level of autistic children, others did not. Therefore, not all the results obtained in the reviewed studies are necessarily comparable to all families of autistic children. A possible limitation to the methodology of this review is that inter-reliability checks were not carried out after validation of extracted data and identified themes.

3.8 Chapter summary

This chapter presented the findings of a systematic review aimed at exploring available evidence on access to respite care from the perspectives of parents of autistic children and reported on the quality of the findings. Respite care was viewed by parents as a vital resource to assist in the management of their autistic child, however, access to respite services was a significant challenge for parents. Findings highlighted that the provision of respite care may not be solely sufficient to alleviate parental burden. This review discovered several barriers to respite care, all of which could be addressed in future service provision and research. Knowledge of parental experiences in caring for an autistic child is vital in addressing the need and type of respite care required for autistic children.

Chapter 4: Methodology

4.1 Chapter overview

This chapter discusses the philosophical assumptions and the research design and methodology that underpins this study. The chapter begins by exploring existing research paradigms and discusses the epistemological and ontological assumptions that have shaped and guided this study. This is followed by a discussion on the chosen methodology and associated rationale for this study.

4.2 Research paradigm

A paradigm is a basic belief system and theoretical framework comprising four components; ontology, epistemology, methodology and methods (Abdul Rehman & Alharthi 2016). These various concepts form relationships to each other in that ontological and epistemological positions should have a bearing on the methodology and methods selected for a study. Ontological and epistemological aspects concern what is commonly referred to as a person's worldview. It constitutes the abstract beliefs and principles that shape how a researcher sees the world, and how they interpret and act within that world (Kivunja & Kuyini 2017).

Ontology is the philosophical study of the nature of being, becoming, existence, or reality (Khamparia & kaur 2014). Researchers have assumptions (sometimes implicit) about reality, how it exists and what can be known about it (Abdul Rehman & Alharthi 2016). Within ontology there are two key positions: objectivism that defines social phenomena and their meanings as being independent of the social actors; and constructionism or subjective ontology which is the belief that social phenomena are being accomplished by their social actors therefore social reality is created through the actions of the social actors (Bryman 2012). Epistemology is the theory of knowledge and belief about how we may come to know the world (Ryan 2018). There are several branches within epistemology, however, three key approaches were looked at for the purpose of this study, these include; positivism, interpretivism and critical inquiry.

When choosing an appropriate paradigm to guide this inquiry two important aspects were considered. These were, the aims and objectives of the study and the need to choose a paradigm which closely approximates my worldview as the researcher. There are several possible paradigms aligned with how research can be conducted e.g. positivism, interpretivism, critical inquiry, pragmatism and subjectivism (Creswell &

Poth 2016). Table 8 outlines the research paradigms and their ontological and epistemological stances and their applicability for use in the present study.

Table 8 Research paradigms and their ontological and epistemological stances and their applicability for use in the present study

Paradigm	Principles	Ontology	Epistemology	Methodology	Applicability to current study
Positivism	The application of methods from natural science focuses on explanation and prediction (Park <i>et al.</i> 2020).	There is a single reality or truth Realism (Scotland 2012)	Knowledge must be developed objectively, without researchers' or participants' influence (Park, 2020) -Objectivity/Dualism	Examines the explanatory or causal relationships between variables in the study (Park <i>et al.</i> 2020) -Experimental Research -Survey research	Positivist research is quantitative and looks at high levels of generalisability. This study aims to examine a phenomenon and the meanings attached to it, not to quantitatively measure the experience.
Interpretivism	The social world differs significantly to the world of natural science therefore scientific approaches are not transferable (Bryman 2012). The researcher is part of the research, interprets data and as	There is no single reality of truth -Multiple realities Reality can be explored, and constructed through human interactions and meaningful actions. (Kivunja & Kuyini 2017)	Reality needs to be interpreted. It is used to discover the underlying meaning of events (George 2020). Interpretivists are interested in specific, contextualised environments and acknowledge that reality and knowledge are not objective but influenced by people within that environment.	Naturalist qualitative approach to research inquiry. Ethnography, Grounded Theory, Case Study, Phenomenological Research, Discourse Analysis and others	The objective of this research is to study the phenomenon of accessing respite care through the acute care services from the perspective of the meanings that parents attach to it. -the need to make

	such can never be fully objective and removed from the research.	-Relativism	-Subjectivity		sense of why parents are accessing respite care in this particular way
Critical Inquiry	Seeks to challenge world views and the underlying power structures that create them. The researcher and society are influenced by their own perceptions and experiences, which are manipulated by power structures such as culture, politics, race, gender, class and the mass media (Howell 2013).	Realities are socially constructed entities	Reality and knowledge are socially constructed and influenced by those within society	Critical discourse analysis, Critical ethnography	The gap in existing research on this topic means that critical social theory has an inadequate base from which to challenge, contrast and question to provide a comprehensive critique of the phenomenon under investigation
Pragmatism	A deconstructive paradigm. Focuses on what works as the truth regarding the research	Reality is constantly renegotiated or debated	The best method is one that solves problems.	Mixed methods	The research question under investigation aims to understand the experience therefore

	questions under investigation. (Kelly 2020)				this paradigm would not be appropriate.
Subjectivism	The view that knowledge is subjective and that there is no external or objective test of its veracity. No moral truths are possible, they are relative to the person. (Alexandre <i>et al.</i> 2022)	Reality is what we perceive to be real	All knowledge is purely a matter of perspective	Discourse theory Genealogy	The objective of this research was to study the phenomenon and the meanings attached to it, not to study the interactions and interpersonal dynamics between health and social care services and parents.

Notably, health services research literature tends to focus on two key paradigms: positivism and interpretivism (Bonache & Festing 2020). However, having reviewed the above paradigms and their philosophical underpinnings, and considering that the study's purpose is to gain a deeper understanding of parents' experience of accessing respite care through the acute care services for their autistic child, interpretivism was chosen to guide the study. This approach was considered most appropriate as the researcher is part of the research and as such can never be fully objective and removed from the research (Ryan 2018), further engendered considering my background as a paediatric nurse with experience of caring for autistic children. However, it is also noted that this philosophical outlook is more subjective and subject to biases. Therefore, reliability of data is undermined to a certain extent and cannot be generalised in the way that positivist research can be (Leung 2015). However, as this study aims to explore parents' experiences and noting that the data generated was heavily impacted by personal experiences and values the data, to a certain degree, can be associated with a high level of validity because data generated via interpretivism studies tends to be trustworthy and honest.

The following section outlines the application of the interpretive paradigm as the philosophical underpinning adopted in this study and how this approach aligns to the study's overall aims and objectives.

4.2.1 Alignment of the interpretive paradigm to the study's aims and objectives.

As the focus of this study is on parents' experience of accessing respite care through the acute care services for their autistic child, the application of the interpretive paradigm enabled greater scope to address issues of influence and impact, and to ask questions such as 'why' and 'how'. The purpose of the interpretive approach is to produce an understanding of the context and the process and is influenced by the context (Nickerson 2022).

The ontological and epistemological viewpoints of the interpretivist paradigm also align well with the aim and objectives of this study. Firstly, from an ontological perspective, it is acknowledged that multiple realities exist, and that reality can be explored, and constructed through human interactions and meaningful actions (Al-Saadi 2014). Many social realities also exist due to varying human experiences, including people's knowledge, views, interpretations and experiences (Thomas 2012). From an

epistemological perspective, events are understood through the mental processes of interpretation that is influenced by interaction with social contexts (Brown 2017). Those active in the research process socially construct knowledge by experiencing the real life or natural settings. The inquirer and the inquired-into are interwoven in an interactive process of talking and listening, reading and writing (Chambers & Poidomani 2022).

The research question, aims and objectives outlined in Chapter 1 also align with the principles of the interpretivist paradigm. The overall aim of the study reflects the desire to give meaning to parents' experience of accessing respite care through the acute care services for their autistic child, the factors which influenced the context and the parents' experiences within this context. The study's objectives cannot be measured or answered in isolation as the objectives of the study lend themselves to understanding the whole experience through its parts, that is, before, during and after parents have presented to the acute care services to access respite care. This is in keeping with the interpretivist principle of the "hermeneutic circle" (Creswell 2014). Therefore, the interpretivist paradigm allows for the experience of accessing respite care to be explored and interpreted through multiple parents' perspectives.

Lastly, this study provides analysis and interpretation of the complex healthcare system in which the research participants (parents of autistic children) experience, navigate and give meaning to in the context of the phenomenon under investigation. The study interprets and seeks to understand parents' experiences by looking beyond parents' answers into the essence of meaning they give to their experiences and identifying and describing their beliefs and examining the consequences of these.

4.3 Research design

As the primary aim of this study was to gain an insight into parents' lived experiences and explore the meaning they have given their experiences, a qualitative research design was considered the most appropriate. At the outset of this study, several qualitative research methodologies were reviewed when considering which methodologies would support the study's aims and objectives. These included phenomenology, ethnography, grounded theory, and action research. These were all considered in terms of their potential advantages and limitations to the study's overall aims and objectives.

Participatory action research (PAR) was initially considered for this study noting that individuals and patients are increasingly seeking involvement in policy and research (Anderson 2017). This is particularly relevant to research involving the autism community (Pellicano *et al.* 2014, Fletcher-Watson *et al.* 2018, Botha 2021). One of the core values of PAR is that the research design involves stakeholders at various levels of the research process (Wright *et al.* 2014). However, this was not chosen due to the amount of time required for building relationships as an essential requirement of effective PAR (Huffman , Whitzman 2017). This was also not considered a viable option noting that it would be challenging to develop an intervention for access to respite care in the absence of an existing formalised pathway to respite care for autistic children. Discourse analysis was also deemed unsuitable due to its focus on the linguistic resources utilised by participants (e.g., context of the language/conversation and not just the words) to construct accounts of their experience (Shanthi *et al.* 2015). Therefore, by focusing entirely on the language, there is a potential that the essence of the lived experience might get lost. Furthermore, case study methodology was discounted, as while it provides a depth of information on a single case it does not provide an understanding of a phenomenon as experienced by participants as each case may have a number of unique characteristics (Krusenvik 2016) which was also relevant to this study noting the broad spectrum of autism.

Having reviewed all the possibilities and considered their potential advantages and limitations in the context of the present study's aims and objectives, it was considered that phenomenology would be optimal as it would enable a more detailed and in-depth examination and analysis of the lived experience of parents. While phenomenology and grounded theory share common characteristics and seek to explore individual's experiences in the world in which they live, they do have differing philosophical underpinnings in that phenomenology relies almost exclusively on the collection of interview data to describe the lived experiences of participants whereas grounded theory seeks to develop theory through the collection of interview data from multiple sources (Bainbridge *et al.* 2012). Phenomenology was further chosen as the study is concerned with uncovering the richness and detail of parents' experiences and the interpretation of these. In addition, Streubert and Carpenter (2011) highlight that a phenomenological approach is an appropriate method where limited data is available and where further clarity is required to understand a phenomenon which was highly relevant to the context of this study.

4.4 Phenomenology

Phenomenology seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it (Teherani *et al.* 2015). The goal is to describe the meaning of this experience, in terms of what was experienced and how it was experienced (Teherani *et al.* 2015). By examining an experience as it is subjectively lived, new meanings and appreciations can be developed to inform, or even re-orient, how we understand that experience (Neubauer *et al.* 2019). From an ontological perspective, phenomenologists believe that experience is an essential part of being human and therefore to understand people one must understand their contexts and how they live.

4.4.1 Phenomenology: A philosophy and methodological approach

Phenomenology is a philosophy and methodological approach originated by Edmund Husserl and later developed by Martin Heidegger that seeks to study the lived human experiences and the way things are perceived and appear to the consciousness.

Phenomenology is supported by multiple philosophical views that differ in their approach to research using this method (Neubauer 2019). Husserl believed that the focus should be primarily on providing a pure understanding of the phenomenon known as descriptive phenomenology (Zahavi 2021) while Heidegger believed that phenomenology is interpretive and moved beyond describing human experience to focus on interpreting and understanding them (Sloan & Bowe 2014). While there are some distinctions between both phenomenological approaches, they share common principles in that they try to make explicit what people have lived through in their life world. Choosing the phenomenological approach for this study was influenced by the nature of the research question and both philosophical underpinnings were reviewed to determine which of the approaches were more suitable to the study's aim and objectives.

4.4.2 Descriptive phenomenology

Edmund Husserl (1859-1938), a German philosopher and mathematician, is considered to be the founder of the 20th century philosophical school of phenomenology. According to Husserl, phenomenology is a form of inquiry that holistically describes the research participants' lived experience of meaning-making and points out that phenomenological data are "lived-through data" (Koopman 2015). Husserlian views are strongly epistemological (Berghofer 2017, Neubauer *et al.* 2019)

as he believed that to understand the nature of human knowledge, the objective and scientific measurements are not sufficient and that subjective experiences cannot be reduced completely to a measurable object. Husserl argues that the knowing of the world is through consciousness and proposed that one should focus on the experiences of human beings through the objects of consciousness (Gutland 2018).

Husserl's approach to phenomenology involves four main steps; bracketing, intuiting, analysing and describing (Koopman 2015). Husserl suggested that to explore the life worlds, one should stop taking for granted the things perceived about the phenomenon, or 'bracket out them' and take a look at phenomenon again (van Manen & van Manen 2021). Bracketing or reduction is a key feature of descriptive phenomenology and involves the researcher constantly assessing their impact on the research and setting aside previous understandings, experiences, knowledge and assumptions as well as scientific theories (Sorsa *et al.* 2015). The literature reveals multiple debates on the use of bracketing (Chan *et al.* 2013, Dörfler & Stierand 2021) particularly associated with its reliability and the difficulty experienced by researchers in suspending their presuppositions. Key questions asked about the use of bracketing centres around when, or whether, bracketing should be used within research and who should be bracketed, the participants or researcher (Chan *et al.* 2013, Sorsa *et al.* 2015). For example, Chan (2013) argues that bracketing should occur at the outset of the research proposal and not just in the data collection and analysis process.

4.4.3 Hermeneutics (Interpretive) phenomenology

Hermeneutic phenomenology has been widely used in enabling understanding of the meaning of lived experiences in health research. Hermeneutic phenomenology is a philosophy influenced by many philosophers including Heidegger (1889-1976), Gadamer (1900-2002), Merleau-Ponty (1908-1961), Sartre (1905-1980) and Ricoeur (1913-2005). Hermeneutic phenomenology seeks to understand the deeper layers of human experience that lay obscured beneath surface awareness and how the individual's 'lifeworld' or the world as he or she pre-reflectively experiences it, influences this experience (Bynum & Varpio 2018). Hermeneutic phenomenology studies individuals' narratives to understand what those individuals experience in their daily lives 'lifeworlds' (Neubauer *et al.* 2019). Similar to Husserl, Heidegger was concerned with human experience as each individual lived (Horrigan-Kelly *et al.* 2016).

Heidegger further developed the work of Husserl and also challenged some of Husserl's assumptions (Horrigan-Kelly *et al.* 2016). One of the key distinguishing

features of Heidegger's viewpoints compared to Husserl's is that emphasis is placed on interpretation rather than description. As previously noted, Husserlian phenomenology was based on the epistemological viewpoint, whereas hermeneutic phenomenology was introduced from the ontological view that lived experience is an interpretive process.

Heidegger was concerned with exploration of the lived experience 'Dasein' or the situated meaning in the world rather than concentrating on people or phenomena (Peters 2019). Instead of looking for simple descriptions of core concepts and essences, hermeneutics looks for meaning embedded in day-to-day life practices (Feeley 2019). Heidegger used the term 'lifeworld' to articulate the notion that individual's realities are consistently influenced by the world in which they live in (Neubauer 2019) and hermeneutic phenomenology intends to understand collective meaning (Fuster Guillen 2019).

Heidegger's approach to phenomenology is that one cannot make sense of their world by remaining detached from it (Huttunen & Kakkori 2020). Heidegger believed that it is impossible to rid the mind of the researcher's background and understandings of the research topic known to them (Huttunen & Kakkori 2020). A distinguishing feature of descriptive phenomenology and interpretive phenomenology is the extent to which presuppositions, views and beliefs can be suspended. Bracketing of prior understandings, knowledge and beliefs is considered critical in the descriptive phenomenological approach (Dörfler & Stierand 2021), however, the interpretive phenomenology approach does not require this. Instead, interpretative phenomenology does not view experience as a separate entity in one's world, rather that the historical and cultural context of the experience becomes important to understand.

Table 9 outlines the key features of descriptive and interpretive phenomenology that were considered when choosing the phenomenological approach to guide this study.

Table 9 Features of descriptive and interpretive phenomenology

Descriptive (Transcendental) Husserl	Interpretive Phenomenology Hermeneutics (Heidegger)
Ontological assumption: Reality is internal to the knower/what appears in their consciousness	Ontological assumption: Lived experience is an interpretive process situated in an individual's lifeworld

Epistemological Assumption: Observer must separate him/herself from the world including his/her own physical being to reach the state of the transcendental I; bias-free; understands phenomena by descriptive means (Bracketing)	Epistemological Assumption: Observer is part of the world and not bias free; understands phenomenon by interpretive means
Exploring the way we as subject know objects	Questions about experiencing and understanding and interpreting phenomena
Recognising objects of consciousness as not having a separate existence from us	Concerned with what it means to be a person
Bracketing supports validity of the interpretation	The subject of analysis is the transaction between situation and person
Phenomenological reduction using a free imaginative variation	Interpreters impact on the derived data
Search for essences	Incorporates presuppositions or expert knowledge. Acknowledging our historical understanding
Discovering phenomena exactly as they are presented to consciousness	Meaning articulated by both researcher and participants within the focus of the study
Participants' meanings can be reconstituted via interpretation	Hermeneutic circle: understanding is circular.

Combining both the descriptive phenomenology of Husserl and the interpretive phenomenological philosophy involving the deep understanding through language and meaning, the aim of hermeneutic phenomenology is to explore human phenomena in order to understand the structure or essence of the lived experience (Fuster Guillen 2019). While Heidegger and Husserl are the founding philosophers of phenomenology, their work was continued by other philosophers in what is known as the third phase of the phenomenological movement, including Marcel, Sarte and Merleau-Ponty (Murphy 2018).

Having considered the variation between phenomenological philosophies and approaches, for the purpose of this study, hermeneutic phenomenology was chosen as a suitable methodological approach as it is conducted through the collection of experiences and analysis of their meanings (Fuster Guillen 2019) and was therefore conducive to the study's aims and objectives. Heidegger's phenomenology inquiry was further developed by Van Manen (2007, 2014), who also described this type of research methodology. For the purpose of this study, Heidegger's work was explored

more closely as a key influencer of Van Manen's stance on hermeneutic phenomenology.

4.5 Van Manen's phenomenology

Van Manen's approach (2007, 2014) has dual philosophical roots from both the German and Dutch interpretive phenomenological traditions (Earle 2010). His work combines the descriptive phenomenology of Husserl, with an emphasis on the study of the world before reflection with interpretation inherent in the process of capturing the phenomenon. He argues that a real understanding of phenomenology can only be accomplished by actively doing it by starting with the lived experience, transforming it into a textual expression of essence, and if the textual expression is written in such a way that the effect is reflexive, the reader will elicit something meaningful and end at phenomenological research (Van Manen 2017). Similar to Heidegger, Van Manen did not include bracketing and suggested that if we try to forget or ignore what we already know, we might find that the presupposition persistently creeps back into our reflections (Van Manen 2007).

According to Van Manen (1990), an advantage of his approach is the possibility of being in more direct contact with the world and gaining plausible insight by uncovering and describing a structure of the phenomenon in its truest essence. Noting that this framework has been widely used in research studies from different disciplines, Van Manen's phenomenological approach was selected for this study for multiple reasons. Firstly, Van Manen notes that researchers can be aware of the fact that the lifeworld is complex and that a complete description of it is unattainable. This is applicable to participants in this study who described various experiences of navigating complex health and social care systems for their autistic child. Secondly, the use of this approach enables the collection of detailed phenomenological interview text and observation resulting in a description with depth and richness (Van Manen 2014). Notwithstanding this, there are limitations to Van Manen's methods, for example, while reduction enables in-depth phenomenological hermeneutic research to be conducted, there are many ways in which reduction can be adapted and therefore can be quite confusing and complex (Heinonen 2015). To address this, methodological guidelines for researchers interested in conducting a phenomenological inquiry are available with this approach which was also noted as another advantage. Van Manen's phenomenological approach demonstrates the dynamic interplay of six research activities which enable a practical approach to gaining a deeper understanding of the

meaning of our everyday experience (Van Manen 2007, 2014). Notably, the intention with these guidelines is not to provide a detailed step-by-step procedure that a researcher should adhere to which is not a requirement within in this approach as some activities can be undertaken simultaneously whilst others can occur intermittently (Van Manen 1990, Van Manen 2007). Instead, the steps are seen as broad enough to allow flexibility in emphasising and minimising one step or another, dependent on the emerging data (Van Manen 1997). Table 10 outlines Van Manen's (2007, 2014) six activities and how they were applied to this study.

Table 10 Van Manen's (2007, 2014) six research activities.

Van Manen's (1990) Methodological Themes	Key Concepts	Research activities in the context of this study
1. Turning to a phenomenon which interests us and commits us to the world.	Committing to the phenomenon. Being in the world. Acknowledging pre-understandings, beliefs and experiences.	Orientation to the phenomenon through the conduct of a literature review, formulation of the research aim and objectives.
2. Investigating experiences as we live it rather than as we conceptualize it.	Exploration of the phenomenon - Consultation of phenomenological literature and research done on the chosen phenomenon. Interpretive paradigm. Reflective journal. Purposive sampling.	Collection of data first by determining personal experiences from participants who have experienced the phenomenon and have lived knowledge. The use of one-to-one semi-structured interviews helped to establish trust between the researcher and participants.
3. Reflecting on the essential themes which characterise the phenomenon.	Circle of readings. Interpretation. Understanding.	Determination of thematic statements that portray the lived experience using VMs approach to data analysis.
4. Describing the phenomenon through the art of writing and rewriting.	Reflexivity. Reflective journal Van Manen's five lifeworld existential themes to guide data analysis and	The act of phenomenological writing and rewriting. Creation of thick descriptions and interpretations of the lived experience.

	phenomenological reflection.	
5. Maintaining a strong and orientated pedagogical relation to the phenomenon.	Analysis, findings, interpretation and discussion. Rigour and trustworthiness.	Maintaining a constant reference to the study's aim and objectives. Demonstrating rigour through credibility, transferability, dependability and confirmability.
6. Balancing the research context by considering parts and whole.	Considering parts and the whole. Ensuring methodological rigour.	Movement from themes to the entire transcript of individual interviews and making constant reference to the study's aim and objectives.

Accordingly the analytical framework by Van Manen was selected for this study as it offered a template containing six steps for analysing and interpreting research underpinned by hermeneutics. The analytical framework was very detailed, structured and offered clear guidelines on how to apply the major concepts of Van Manen's work throughout the study. However, I was not fully clear as to how I would best investigate the experiences and reflect on the essential themes which characterise the phenomenon as outlined in step two and three while ensuring I am remaining truthful to the concepts of Van Manen's work. Therefore, I chose to integrate Braun and Clarkes (2006, 2013, 2022) stages of data analysis with Van Manen's six research activities. The combination of these frameworks to support data analysis and how they were applied will be discussed in greater detail in the following chapter, Chapter 5.

Overall, Van Manen's approach is designed to reach deeply into the inner person involved within a human experience (Sloan 2014) and to bring out and describe the meanings and structures within that lived experience which, in the context of this study, is to find out why parents chose to access respite care through the acute care setting. This approach was considered most appropriate as it allowed me to explore and interpret parents' experiences in light of what I already knew about the study topic. The five lifeworld existential themes proposed by Van Manen further guided the analysis and expression of the data in this study. This is discussed in greater detail in Chapter 5. In summary, applying this approach enabled the assimilation and interpretation of the data sources to portray the lived experience that Van Manen describes and was therefore critical when attempting to understand the complex experiences of parents of autistic children accessing respite care through the acute care services.

4.6 Chapter summary

This chapter discussed the philosophical assumptions and methodology underpinning the current study. Due to the limited knowledge on the issue of parents' experience accessing respite care through the acute care services for their autistic child, a qualitative research design using an interpretive phenomenological approach was chosen to explore the phenomenon under investigation. It was considered that the use of hermeneutic phenomenology would enable a deeper level of understanding to emerge from parents' experiences of accessing respite care for their autistic child through the acute care services.

Chapter 5: Research methods

5.1 Chapter overview

This chapter presents the research aim and objectives, and the research methods including sampling and recruitment, ethical approval, data collection and data analysis. As indicated in Chapter Four, Van Manen's (2007, 2014) six-stage hermeneutics phenomenological approach has been used to guide the research process, and provided the structure by which to explore the meaning of the lived experiences of parents accessing respite care through the acute care services for their autistic child. How ethical concerns were managed, trustworthiness and credibility of the research and researcher reflexivity are also discussed.

5.2 Research setting

The study was initially planned to take place in three Irish paediatric hospitals (CHI at Crumlin, CHI at Temple Street and CHI at Tallaght). However, as the study occurred during the COVID 19 pandemic this was not possible and the study setting moved from the hospital setting to the community setting, and data collection was altered to remote interviewing (see section 5.6 on data collection and section 5.8 for ethical considerations).

5.3 Sampling

5.3.1 Method of sampling

In phenomenological inquiry, choosing a sample of participants who can deeply inform the research question, have all experienced the phenomenon under investigation and who are able and willing to talk about it are essential criteria (Vasileiou *et al.* 2018). As it was necessary to conduct the study with parents who had experience of accessing respite care for their autistic child through the acute care services, a non-probability purposive homogenous approach to sampling was adopted. This involved intentionally selecting who to include in the study on the basis that those selected could provide the requisite data (Etikan & Bala 2017). In addition, purposive sampling can better match the aims and objectives of a research study by avoiding data responses that would not answer the aim and objectives of the study thus improving the rigour of the study and trustworthiness of the data and results (Campbell 2020).

It is recognised that purposive sampling is prone to researcher bias (Sharma 2017) as researchers can make subjective or generalised assumptions when recruiting participants and create findings that support their preconceived opinions. The risk of

researcher bias with purposive sampling was minimised in this study by having inclusion and exclusion criteria, eliciting the information required from participants based on the interview guide and having a data analysis framework (section 5.7) in place to guide the research study and ensure a consistent approach to the methodology.

Given the lack of published research exploring parents' experiences of accessing respite care through the acute care services for their autistic child, the aim of the study was to capture the essence of the lived experiences of this. Therefore, a non-probability purposive homogenous method of sampling was applied. .

5.3.2 Sample size

There is no means of identifying an exact sample size in a hermeneutic inquiry (Bartholomew *et al.* 2021). Generally, sample sizes in qualitative research tend to be small in order to support the potentially detailed data that can be generated from each participant and the depth of analysis (Vasileiou *et al.* 2018). The literature advocates the use of small sample sizes in phenomenology in order to engage deeply with rich data (Robinson 2014, Malterud *et al.* 2016, Saunders & Townsend 2016, van Rijnsoever 2017). This is because the richness of the data collected takes precedence over the actual size of the sample (Frechette *et al.* 2020).

Sample adequacy in qualitative research pertains to the appropriateness of the sample composition and size (Vasileiou *et al.* 2018). For this qualitative study, it was recognised that the sample size needed to be appropriate to sufficiently describe the phenomenon of interest while also addressing the research aims and objectives. The goal of a qualitative study should be to have a large enough sample size to uncover a variety of opinions, but to complete the sample size at the point of saturation (Vasileiou *et al.* 2018). Van Manen (1990, 1997) suggests that there is no optimal sample size for phenomenological research, rather, he advocates that a researcher initially becomes oriented to the phenomenon of interest, then gathers experiential descriptions through interviews and close observations (Järvinen & Mik-Meyer 2020). Van Manen prefers the term 'example' over 'sample' expressing that examples of experiential descriptions should be evident. Equally Van Manen (2014) does not advocate the use of the term data saturation as this suggests looking for patterns which is not the objective of phenomenology. Rather phenomenology can illuminate a singular theme in an experience and does not necessarily count how many times certain words appear in

text (Van Manen 2014). Therefore, the sample size for this study was not pre-determined rather it was determined by interest from participants and the need to collect adequate experiential descriptors. In the end, the sample for this study consisted of 15 participants, taking cognisance of the need to reflect deeply on each transcript while avoiding a shallow analysis. This sample size was deemed appropriate for this study as it allowed depth of investigation with larger amounts of information being obtained during interviews and in diary keeping.

Appraising sample size sufficiency with close reference to the study contributes to greater appreciation of qualitative work and can add to the rigor of research (Vasileiou *et al.* 2018). To determine if adequate examples of experiential descriptors were evident, an evaluation of the sample size as part of the appraisal of data adequacy was completed. This involved reviewing the transcripts multiple times to ensure no new data, no new examples of experiential descriptions, themes, no new coding and the ability to replicate the study could be achieved (Fusch & Ness 2015, Saunders *et al.* 2018). Furthermore, data was reviewed in terms of richness (Justice & Equality) and thickness (quantity) (Dibley 2011) rather than on the contributing sample size. On completion of the thirteenth interview, it was becoming evident that no new experiential descriptors were emerging and that a mix of rich and thick data was collected as evidenced through multiple coding phases and the nuanced data that had emerged. Two further interviews were conducted as confirmatory interviews to deem if adequate examples of experiential descriptors were evident and if sample sufficiency had been achieved and no additional new meanings were discoverable (van Manen *et al.* 2016). The interviews with these two additional participants confirmed this.

The sample size of 15 participants might be considered small, however, a small sample size is not necessarily a limitation in phenomenological studies, since the primary objective is not generalisability, but to illuminate the lived experience and context in as much depth as possible (Frechette 2020). While a larger sample size could have been used, it was recognised that there may be very little value in the data collected as no new information was emerging. Similarly, it was recognised that the global pandemic was having a disproportionate effect on families caring for autistic children as many families had lost or had their supports reduced or limited at this time. Therefore, I considered it inappropriate to include participants unnecessarily and use up their personal time .

The following inclusion and exclusion criteria were used for this study:

Inclusion criteria

- Parents/legal guardians of an autistic child who have previously accessed or are currently accessing respite care through acute care services.

Exclusion criteria

- Parents/legal guardians who are caring for a child < than 2 years⁴ old showing characteristics of autism.
- Parents/legal guardian of an autistic child who have no experience of accessing respite care.

5.4 Access

Having access to a range of gatekeepers is vital when carrying out research as they have a key role in ensuring researchers gain access to potential participants and sites for research (McFadyen & Rankin 2016). As it was originally intended to access participants through the paediatric hospitals, gatekeepers had been identified within each hospital. However, with the change to community settings from hospital settings due to the pandemic, access to potential participants was via autism support groups. A database of potential autism support groups from across Ireland was collated and organisers and co-ordinators of autism support groups were identified as gatekeepers and formally communicated with by email and letter (Appendix 3).

Gatekeepers were afforded the opportunity to ask any questions or seek clarification on the level of involvement that would be required from them before agreeing to support the study (Dempsey *et al.* 2016). However, I was informed by many of these gatekeepers that the autism support groups were not meeting or holding regular events due to the COVID-19 pandemic and associated restrictions in place at the time. Nonetheless, gatekeepers agreed to distribute participant information leaflets (PIL) (Appendix 4) to potential participants on their social media platforms and email distribution lists.

⁴ The diagnostic stability of early autism diagnosis has not yet been fully demonstrated. Although symptoms of autism can begin to emerge as young as six months of age, the average age of diagnosis is 4 years of age (CDC 2019). As some studies show that the diagnosis of autism can be considered reliable and stable in children aged 18 to 24 months Benedetto L., Cucinotta F., Maggio R., Germanò E., De Raco R., Alquino A., Impallomeni C., Siracusano R., Vetri L., Roccella M., Ingrassia M. & Gagliano A. (2021) One-Year Follow-Up Diagnostic Stability of Autism Spectrum Disorder Diagnosis in a Clinical Sample of Children and Toddlers. *Brain Sci* **11**(1), 2 years of age was identified as an appropriate age noting the reported delays in accessing assessment services for diagnosis.

5.5 Recruitment procedure

Given the impact that the pandemic was likely having on the day-to-day lives of this vulnerable study population and their families, strategically planning for recruitment was critical, and a phased approach to recruitment was adopted. Recruitment commenced in July 2020 via an extensive recruitment campaign which involved engagement with over 40 autism support groups. This also included social media engagement with some large autism support charities and groups, through interviews and the design and development of easy-to-read information pages to be published on their respective website and social media platforms. The role of engaging with these autism charities had a dual purpose. Firstly, they supported the recruitment campaign and enabled access to a platform in which the study could be disseminated to the relevant target audience. Secondly, the charities provided guidance and support in relation to effectively communicating with the target audience through the use of acceptable autistic language. The charity shared up-to-date information on acceptable autistic terms and associated language which was vitally important when engaging with participants and contributed to the overall credibility of the study. My ongoing engagement with them meant that members of the autistic community and their families were involved in all aspects of the the research process as partners rather than as research participants.

Given the large number of autism support groups that were contacted, the recruitment database was updated and maintained to keep a record of contact and follow up with all groups. All autism support groups were followed up three times over a two-month period by making contact with identified gatekeepers. Four phases of recruitment took place between July 2020 and May 2021 with each phase exploring different ways and sources to recruit participants (Table 11). Due to the evolving COVID-19 situation, recruitment remained an ongoing challenge given the prolonged impact that COVID-19 was having on this population and overall interest from the autism support groups was minimal. Due to this lack of progress, I undertook a review of electronic newspaper articles to identify potential participants who had reported on their story of accessing respite care through the acute care services for their autistic child. Through this process, I contacted the gatekeeper of their autism support group they were affiliated with, if known. From this process further potential participants were identified and either made contact with me directly or gave permission for me to contact them. Participants were informed about the study and were given the opportunity to

participate once suitability was determined and they had read the participant information leaflet. This recruitment strategy proved to be more effective and led to a small snowball effect resulting in the recruitment of 15 participants ⁵ between October 2020 and April 2021. Four potential participants expressed their interest in taking part but did not meet the inclusion criteria and therefore could not be recruited. Those recruited to the study were sent a letter of invite (Appendix 5) and a consent form (Appendix 6) in advance of arranging interviews.

Table 11 Recruitment strategy and outcome.

Phase	Recruitment Activity	Outcome
Phase 1 (July 2020)	Snowflakes Irish Society of Autism	No participants
Phase 2 (Aug 2020)	35 ASD Support Groups across Ireland	No participants
Phase 3 (Sept 2020)	As I am Family Carers Ireland Disability Federation Ireland Inclusion Ireland Media Articles	3 responses from media articles 1 participant independently contacted TCD
Phase 4 (Nov 2020- May 2021)	CHO areas, Disability Network Managers, Public Health Nurses 3 further ASD Support Groups identified Media Articles Trinity Autism and Neurodevelopment Research Group	8 responses from media articles 3 recommendations from participants 'word a mouth'.
Overall Outcome:	15 Participants (Including pilot) *4 participants did not meet inclusion criteria	

5.5.1 Obtaining consent

Obtaining informed consent is an ethical requirement for research involving human participants and involves information disclosure, understanding and a voluntary decision (Xu *et al.* 2020). Written and verbal consent was obtained from participants prior to commencing interviews (section 5.8). In light of the COVID-19 pandemic, all interviews took place remotely using video software with all participants in their own home at the time of the interview.

⁵ Participants included 14 parents and one grandparent who spoke on behalf of a parent of an autistic child with consent.

Participants were informed of their entitlement to withdraw from the study up to the point of data analysis and that associated data collected would be destroyed. This was outlined in the PIL (Appendix 4) and consent form (Appendix 6), during the initial contact with participants and at the outset of the interview.

Issues relating to data protection and processes in place to support any data breaches were also outlined (section 5.8). The procedure for the interview was discussed and permission was sought to record the interview using a Dictaphone as per ethical application (Appendix 7) and ethics approval (Appendix 8). Participants were aware that they would be receiving a copy of their transcript to ensure they were satisfied with their account of the interview.

5.6 Data collection

Hermeneutic phenomenology, in seeking to understand lived experiences, does so by staying close to the participants' worlds in order to generate an in-depth understanding (Aspers & Corte 2019) and by asking how a certain phenomenon is experienced by the person who lives through it in order to better understand the phenomenon (Neubauer 2019).

A variety of strategies can be used in qualitative inquiry for the purpose of data collection such as narrative interviews, face-to-face individual interviews and semi-structured interviews (Moser 2018). There is a strong body of evidence regarding interviews and their specific purpose in research. For example, semi-structured interviews provide more guidance and direction and involves the use of predetermined questions where the researcher is free to seek clarification (Doody & Noonan 2013). In contrast, narrative interviews provide an opportunity for the participant to narrate their experience instead of placing emphasis on a question-answer format. In using narrative interviewing I felt participants might find it challenging to tell their own story in their own words, and that being asked a series of questions may be easier for them (Anderson & Kirkpatrick 2016). Similarly with narrative interviewing participants can deviate from the overall research question easily. Focus groups were not chosen due to the nature and variance of each individual autistic child's needs and because participants may not freely discuss their feelings and opinions or might hesitate to participate (O.Nyumba *et al.* 2018). Unstructured interviews were considered a more flexible option as I could follow a guide comprising of key themes to be addressed in the interview rather than specific questions (Doody & Noonan 2013), however, this would not enable me to explore the essence of the lived experience.

Having reviewed the various interview strategies, semi-structured interviews were chosen for data collection as they afforded use of a guide to assist me as a novice researcher with exploring the phenomenon of interest. In hermeneutic phenomenology, one-on-one, semi-structured interviewing are well-supported for collecting data (Lauterbach 2018) as these types of interviews serve very specific purposes and allow for discovery with space to follow topics as the conversation unfolds (Magaldi & Berler 2020). In addition, Van Manen's conversational interviewing is semi-structured and is often seen as a more flexible interview format than structured interviews as these types of interviews allow participants to share their stories in their own words (Lauterbach 2018). Furthermore, the flexibility associated with semi-structured interviews is conducive to research carried out in the interpretive paradigm (Jong & Jung 2015). Semi-structured interviews are an effective method for data collection when the researcher wants to (1) collect qualitative, open-ended data; (2) to explore participant thoughts, feelings and beliefs about a particular topic; and (3) to delve deeply into personal and sometimes sensitive issues (DeJonckheere & Vaughn 2019). Open ended questions are commonly used in qualitative research when the researcher wants the participants to avoid yes or no answers and respond in their own words, thus enabling richer and more complex data to be collected. Given that this proposed study focused on understanding the world from the perspective of parents of autistic children, the use of semi-structured interviews using open-ended questions that were informed by the findings of the systematic review was chosen as the most appropriate method of data collection for this study.

5.6.1 Interview guide

Van Manen (2007) outlines that the interview process needs to be disciplined by the fundamental question that prompted the initial need for the interview. To support this concept, an interview guide (Appendix 9) was developed. An effective interview guide contains meaningful prompts that generate complex, nuanced thoughts and descriptions of the phenomenon of interest (Bearman 2019). The interview guide contained a number of open-ended questions that was guided by the overall research question and was informed by the systematic review, for example, the systematic review found that most parents' experiences of accessing respite care for their child spanned a number of years with various challenges along the way. Thus, in order to achieve the study's objectives, it was deemed important to capture parents' experiences at the outset of seeking respite care and up to their current situation and not just focus on the point of accessing respite care through the acute care services so that vital contextual data could be captured. While developing the interview guide I was

cognisant of the need for questions to be clear to the participant and free of suggestion (Roberts 2020). For that reason, the use of open-ended questions were applied when eliciting parents' experiences.

The interview guide ensured that each interview was aligned to the research aim and objectives in a flexible way and allowed me to set a loose agenda for the interview, and to ensure questions were framed in an open, expansive manner. It also enabled consistency in covering all topics in each interview. The use of prompts such as 'please tell me more', and 'describe that to me' were also used. The interview guide also contained a brief demographic questionnaire in which parents were afforded the opportunity to complete at the end of each interview. The questionnaire sought details of county of residence, the parent and child's age and sex, family details, details of autism diagnosis and details about respite care. The interview guide was piloted in terms of language used, phrasing of questions and the demographic questionnaire to with two parents of autistic children who had experience of accessing respite care for their autistic but did not meet the inclusion criteria for the study, as they did not access respite care through the acute care services. Nonetheless, the majority of questions in the interview guide were applicable to these parents, and enabled me to determine if the questions, the manner in which I was asking these and my use of prompts were facilitative in providing experiential descriptors. This proved beneficial as feedback pertaining to some of the wording of the questions and the demographic questionnaire was applied to the final interview guide. For example, questions pertaining to parents' educational background and occupation were removed as both parents stated that these could have the potential to make parents feel vulnerable or inferior to the researcher and should not impact much on the parents' experience.

5.6.2 Pilot interview

Pilot studies are frequently conducted to assess the efficacy of research instruments for use in qualitative research projects and can also help identify several challenges for researchers in terms of rigor and management of bias (Malmqvist *et al.* 2019).

A pilot interview was completed with the first participant who met the inclusion criteria and the interview schedule was further tested to ensure it covered key areas needed to answer the research question. The pilot interview was conducted five weeks prior to other interviews which allowed for a time interval to reflect on what worked well or not so well and amend if possible before conducting the remaining interviews. The pilot revealed that carrying out the interview remotely, with the participant in their own home,

worked well for both the participant and myself as there were limited background noises. This also provided a private setting that participants were comfortable in to discuss a potentially upsetting topic. Secondly, the audio equipment worked well when recording the interview. Lastly, the pilot interview afforded me the opportunity to become familiar with the interview guide and to review the suitability of questions, the flow of conversation and the opportunities for participants to speak freely. While I found that the interview guide had covered all the key areas of the research question and was easy to use during the interview, minor amendments in the form of additional probing questions and some further rephrasing of questions were applied to the interview schedule. For example, probing questions were added asking for more elaboration or to provide examples. The pilot interview was included in the analysis of findings as the changes following the pilot were so minimal and because the interview provided rich contributory data to the phenomenon being explored.

As the COVID-19 pandemic was ongoing during data collection, the pandemic naturally featured heavily in the first few interviews. As a result, I decided to add a specific question to the interview guide that specifically asked about the impact of COVID-19 for parents and their autistic child.

5.6.3 Interview process

At the outset of each interview, I reiterated that the purpose was for the parent to share their experiences and that there was no right or wrong answers. Notably, interviewing has its own challenges whereby participants may feel that they need to present themselves in a specific way in order to fit in with their perception of the researcher's requirements, or wish to bring in their own agenda of life-topics that do not align with the aim of the interview. For these reasons, I recognised the importance of building a rapport with the participant before starting the interview so that both interviewer and interviewee could feel at ease. This was facilitated using broad informal questions to start such as asking them to tell me about their autistic child and their particular needs and their family dynamic.

A skilled qualitative interviewer requires the qualities of open-mindedness, flexibility, responsiveness, patience, observance and being a good listener as well as giving specific attention to the tone and emotional content of the participant voice, in gaining a greater understanding of the message being delivered (Guion *et al.* 2011). My role during the interview was to create a relaxing environment and to maintain an open, conversational tone and be an active listener. Parents were encouraged to elaborate

on their responses and to further expand and clarify as needed. This fostered flexibility in gathering information from the participants. How comfortable parents felt was often elucidated in participant actions, for example whereby parents choose voluntarily to show me their child's bedroom or a particular set up in the home as well as family photos by bringing their laptops or phones around the house and enabling their camera function.

Online remote interviewing can present some challenges that do not occur during in-person interviews (Łątkowski 2021), for example, rapport building, fear of technology or technological problems, privacy and confidentiality procedural interruptions such as environmental distractions, loss of non-verbal cues and loss of embodied care (Hillman *et al.* 2015, Archibald *et al.* 2019, Krouwel *et al.* 2019, Reñosa *et al.* 2021). To help me prepare for this change in research setting, I undertook a review of the available literature on carrying out interviews remotely. The purpose of this review was to help me become aware of the potential challenges that I may encounter and ways to overcome these and to ensure that the environment could be as private and free from interruptions (Dempsey *et al.* 2016) as much as possible. Challenges include technological problems (Glassmeyer & Dibbs 2012), procedural interruptions such as environmental distractions (Fry *et al.* 2021) loss of non-verbal cues and loss of embodied care (Carter *et al.* 2021). For example, during in-person research, we use ordinary actions to show our presence and care, or to create rapport such as handing a tissue to a distressed participant or closing an encounter by walking a participant out of the building. Remote interviewing can result in the loss of this embodied care which was a challenge in this study during some interviews. For example, a few participants became upset as they shared their story. I was unable to hand them a tissue or go get a glass of water. Being aware of these potential challenges and acknowledging that researchers need to develop strategies to comfort a distressed participant, I encouraged participants to have a glass of water to hand or a tissue in anticipation that they may get upset. In addition, at times when participants did get upset, I afforded them an opportunity to discontinue for whatever amount of time they required or stop the interview altogether.

Although interviews took place remotely using video conferencing software, each interview was audio recorded using a Dictaphone because this provided an accurate account of participants' responses and could be replayed for analytic and memory purposes. Data recordings were anonymised by assigning each participant and their recording a pseudonym. On completion of the interview, parents were given the

opportunity to ask any questions they had about the interview process and were informed that their transcript would be sent out to them in the coming weeks to ensure they were happy with their account of their interview. I transcribed three interviews verbatim in total to initially allow me to further engage with the data. I also made reflective notes throughout the course of all interviews including participant tone of voice, body language, laughing, crying as well as my own response to their stories and words. These reflective notes proved to be useful during data analysis allowing me to personally reflect on this aspect of the research process to ensure I was not influencing the participants and that I was applying the chosen methodology correctly. In view of time constraints with the study, the remaining interviews were outsourced to a transcription service with a confidentiality agreement in place. On receipt of the outsourced transcribed interviews, these were checked against the recorded interview for accuracy purposes and non-verbal aspects were also added on these transcripts. Once the interviews were transcribed and sent back to participants for the purpose of factual accuracy purposes (section 5.9), the transcripts were prepared for the analysis stage.

5.7 Data analysis

The analysis of study data was informed by the philosophical work of Van Manen in phenomenological research (Van Manen 1997, 2014, 2017).

Data analysis was assisted by using the software package NVIVO. The use of computer assisted software in research allows for improved efficiency and supports the production of an audit trail which in turn can add to the trustworthiness and credibility of a study (Maher *et al.* 2018). Furthermore, data analysis software supports transparency throughout all stages of data analysis (O'Kane *et al.* 2019). However, it must be noted that the use of data analysis software does not surrender the hermeneutic task to the computer but rather the computer is used for efficiency purposes and not as a tool for conducting analysis and drawing conclusions (Yin 2011).

The following section outlines the data analysis approach and process applied to the study as well as the operationalising of Van Manen's 'five lifeworld existential' (Van Manen 1997, Van Manen 2014) themes as a means of capturing the essence of the phenomenon in question.

5.7.1 Data analysis approach

Thematic analysis offers a way of identifying and uncovering the underlying themes in a given data set (Braun & Clarke 2022). Clarification, however, on how themes are derived from textual data, is less clear and should be outlined (Philipsen *et al.* 2018).

Data analysis of this study involved two phases. The first phase used an inductive thematic analysis approach as defined by Braun and Clarke (2006/2013/2022). This method was chosen as it provided clear guidance on the practical aspects of analysing a qualitative data set (Table 12).

Table 12 Braun and Clarke's (2006, 2013, 2022) approach to thematic analysis used in conjunction with Van Manen's (2007, 2014) six research activities.

Braun and Clarke's Six Phases of Analysis (2006/2013/2020)	Practical Application
1. Importing and Familiarising	• Transcription of data as close to the time of interview as possible. • Immersion with data through repeated reading of the transcripts noting down initial ideas. • Importing of interview transcripts and related memos into data management tool NVivo.
2. Generate Initial Codes (Open Coding).	• Extracting and coding words from participants' transcripts across the entire data set. • Each transcript was initially coded twice for as many potential coding words as possible • Extracts of surrounding data were coded inclusively to ensure context was not lost.
3. Searching for Themes (Developing Categories)	• Reordering of codes into categories of codes by grouping related codes. • Distilling, re-naming and merging of categories to ensure that their definitions reflected coded content.
4. Reviewing Themes (Drilling Down)	• Checking if the themes work in relation to the coded extracts and the entire data set. • Generating a thematic map of the analysis. • Breaking down restructured categories into subcategories to enable more in depth understanding
5. Defining and naming themes (Data reduction)	• Data reduction involving ongoing analysis to refine the specifics of each theme and the overall story. • Consolidating codes to create a framework of themes
6. Writing analytical memos	• Writing analytical memos against the higher-level themes to accurately summarise the content of each category and its codes.
7. Validation	• Validating and revising analytical memos to self-audit proposed findings by seeking evidence in the data

	• Interrogation of data

The second phase of data analysis used Van Manen's 'five lifeworld existentials' to analyse the stories of the parents through the different lenses of lived experiences. These lenses include: 'lived-body' (corporeality), 'lived-space' (spatiality), 'lived-relation' (relationality), 'lived-time' (temporality), and 'lived-things' (materiality) (Van Manen 2014). These five existential themes have been used as a guide for reflection on the data analysis process in many phenomenological research studies, predominantly in the later stages of analysis (Rich 2013) and have helped to interpret the meaning of what was said and to capture the essences underlying the phenomenon described (Van Manen 2017).

As neither of these data analysis frameworks comprise of systematic rules and can be applied with some degree of flexibility, they were both selected as an appropriate data analysis approach for this research study.

5.7.2 Data analysis process

Using Braun and Clarke's thematic analysis framework (2006, 2013, 2022), initial open coding followed by detailed categorisation facilitated the identification of themes. This was achieved by initially reading all the transcripts several times to immerse myself in the data (Appendix 10). To support the reliability of the coding process and to assess the consistency of the process, a pilot coding exercise was first independently undertaken by me and by two supervisors, manually. This process gave reassurances of consistency in my approach to coding as a novice researcher and also added rigour and credibility to this stage of the study. Once the pilot coding exercise was completed, all the transcripts were imported into NVivo.

Cognisant of the aim to understand each experience as it was told by the parent without predetermined, theoretical or conceptual influences on what any meaning should be, prior to coding I familiarised myself with the different lenses of Van Manen's five existential themes: lived other, lived space, lived body, lived time, and lived things. This helped to focus on the meaning of what was said as I began to immerse myself in the data and throughout coding and also helped in capture the essences underlying the phenomenon described (Van Manen 2017).

Two phases of open coding were originally completed by reading each transcript line by line within NVivo highlighting any meaning units in phrases or paragraphs that related to parents' experiences of accessing respite care through the acute care

services. Extracts of surrounding data were also coded to ensure context was not lost. Phase one of open coding yielded 127 codes and phase two of open coding yielded 184 codes. I then interpreted the meaning of these phrases in context, labelled them, categorised them and further analysed them into thematic clusters and listed them as major themes and subthemes (Appendix 11 and Appendix 12).

During this interpretation process, I focused not only on what participants said explicitly, but also looked for implicit meaning. For example, one parent described their child as not fitting the profile of a 'nice to have child' for respite care services as they couldn't support the child's particular needs and challenging behaviours. This was labelled as maintaining respite. In other words, this child could access respite care, however, maintaining respite care was an issue as services were not able to meet the needs of the child and as a consequence acute care services were accessed for respite care.

Applying Braun and Clarke's (2006, 2013, 2022), approach, phase one of the analysis helped me identify themes and subthemes associated with parents' experiences of accessing respite care through the acute care services for their autistic child (Appendix 12). However, I questioned if I had identified the experiential descriptors that would enable me to really understand the essential meaning of parents' experiences as an existential phenomenon since it could have potentially become lost under the fragmented themes and subthemes. Therefore, I carried out a second phase of analysis using the method proposed by Van Manen (1997, 2014) by more explicitly focusing on the 'five lifeworld existentials' to advance my interpretation more. These were: lived space (spatiality); lived body (corporeality); lived time (temporality); lived relation (relationality) and lived things (materiality) (Van Manen 1997, 2014). Van Manen (2014) argues that these five existential themes belong to everyone's lifeworld and form an intricate unity called 'our lived world'. Applying this structure to the second phase of analysis provided universal themes to explore the meanings of our lifeworld and of the particular phenomena (Van Manen 2014). To achieve this I re-clustered the overarching themes and subthemes I had identified from the analysis into the five existential aspects. This enabled me to speculate about the interrelations between the themes, see more clearly the interactions between body and mind, person and world and explicate their lived experiences in a more holistic way. I also reviewed the transcripts again through the lens of each existential to ensure all relevant data had been captured from this approach. The existential theme of lived things (materiality) was not included in the initial stages of data analysis as very little data was identified to reflect the material things that influence parents' experience of accessing respite care

through the acute care services when this lifeworld existential was initially explored across all transcripts. However, by reflecting on the other existential themes and examining the lifeworld in its entirety, material things that were more abstract in nature emerged as influencing parents' experiences and subsequently the existential theme of materiality was included. Table 13 outlines how Van Manen's 'five lifeworld existentials' were operationalised during phase two of data analysis.

Table 13 Operationalising of Van Manen's existential themes during data analysis.

	Lived Other 'Relationality'	Lived Body 'Corporeality'	Lived Space 'Spatiality'	Lived Time 'Temporality'	Lived Things 'Materiality'
Van Manen's existential themes	How we as humans relate to one another within an interpersonal space and how we develop an impression of what others like and how this can be affirmed or altered in interactions with each other from a relational and non-relational status	The body, when gazed upon by others may respond in a variety of ways depending on how the gaze is perceived. The physical body presence can reveal or conceal aspects about the individual, but does not always show on the outside what is going on inside.	'Felt space'. We do not ordinarily reflect on it but we know that the space in which we find ourselves affects the way we feel. (more open and lateral way of thinking-thinking beyond the physicality of space in terms of proximities and locations and considering other applications of space such as emotional space and invasion of personal boundaries)	Lived time refers to subjective time as opposed to clock time or objective time and is our temporal way of being in the world. It also considers the effect of time.	How things are experienced in day-to-day life. How do the experiences of things and world contribute to the essential meaning of the phenomenon. The moral force that things exert in the lives of the participants.

Method	Data identifying and exploring the human relations parents chose to discuss and the ways in which they described, interpreted and experienced the phenomena.	Data exploring parents' experiences of caring for an autistic child. Participants' experience of accessing respite care through the acute care services through their lived bodies.	Data exploring the atmosphere or mood in which parents encounter the felt space.	Data which describes circumstance, settings and chronological age. Data exploring past experiences that determine perceptions of the world. Previous respite care experience. Experiences of trauma.	Data describing the impact and influence of certain things on the situation. Things to describe their experience. Reference to material things.
Data Descriptor	How parents spoke about other people when they tell their story. Their interactions with others when accessing respite care through the acute care services.	Data exploring the way in which parents discussed and described being a parent of an autistic child. The impact of the physical presence of the child on the situation. The impact of the child and the physical presence of people encountered when accessing respite through the acute care services. Impact of the physical environment(hospital/ED) on the child and parent	How parents felt their personal space was impacted when accessing respite care (emotional space). The felt space of the interactions with ED/hospital services What it is about acute care services that influences decisions. Last resort space/finite.	How long they have been trying to access respite care. How long they spent in hospital. Point in time at which they sought respite care Turning point for accessing respite care. Previous experiences of respite care	Things that assisted parents to access respite Absence of things. Things that parents want for their child when accessing respite care.

	Interactions with emergency services	Challenging behaviours	Emotional impact of accessing respite care through acute care services	Continuous process of accessing respite services Maintaining respite services Losing respite services	Social Media
					Information
					Choice of Respite
					Move away from medical model
	Interactions with multiple healthcare services: general, psychiatry.	Parents health	Rationale and defining moment	Defining moment for accessing respite care through acute care services	Equal access
	Interactions with health and social care services	Physical impact of caring for an autistic child.	Exposing the situation	Journey leading up to accessing respite care through acute care services	Support Network/Parents group
	Parent support groups	Feeling alone/isolated		During and After attending acute care services	Forward Planning
Themes	Complex system of multiple interactions with services and health and social care professionals. (Relationality)	Parents experience of caring for an autistic child: Lived-Body (Corporeality)	Accessing acute care services for respite care: A last resort (Spatiality)	Accessing respite care: An ongoing process across the lifespan (Temporality)	Acquired Knowledge and Information: Requirements for effective respite provision (Materiality)

Sub themes	The influence of health and social care professionals (HSCPs). Policing autism	Physical, mental and emotional impact of caring for an autistic child. An isolating experience	Defining Moment Dehumanising Process: Emotional impact of accessing respite care through acute care services	A never-ending process. Respite care-a time sensitive, fragile, precious commodity. Uncertainty about the future	What parents have learned through their experiences. Social media as a tool in accessing respite care services

Phenomenological themes are not generalisations (van der Meide *et al.* 2020) and are described by Van Manen as knots in the web of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes (Van Manen 1990). The collection of themes then leads to a rich description of the phenomenon. The themes identified through data analysis were further finalised by means of reflective writing, aimed at disclosing the phenomenon and illuminating the lived experience of individuals (Van Manen 2014).

In summary, a combination framework using Braun and Clarke's (2006, 2013, 2022) thematic analysis steps and Van Manen's five existential themes guided the data analysis process for this study. The use of both analytical processes offered accessible and theoretical flexibility in analysing the qualitative data. Braun and Clarke's (2006, 2013, 2022), thematic analysis process provided clear guidelines around the process of analysis. Van Manen's data analysis approach to parents' in-depth descriptions of their experiences allowed me to discern the meaning given to their experience of accessing respite care for their autistic child through the acute care services. Collectively, these approaches enabled me to discover the phenomenological themes that make up the experiential structure of the lived phenomenon. Findings in relation to data analysis are discussed in detail in the following chapter, Chapter 6.

5.8 Ethical considerations

In a qualitative study, ethical considerations have a particular resonance due to the in-depth nature of the study process and application of appropriate ethical principles is important (Mohd Arifin 2018). The following section outlines how ethical approval was obtained, the major ethical principles that were applied throughout the study and the ethical challenges encountered when undertaking the study.

5.8.1 Ethical approval

Ethical approval for this study was granted by Trinity College Dublin's School of Nursing and Midwifery Ethics Committee in June 2020 (Appendix 8) and recruitment commenced in July 2020.

5.8.2 Ethical principles

This study applied the major ethical principles of respect for persons/autonomy, beneficence and non-maleficence, justice, veracity, fidelity and confidentiality. Each of these principles are discussed in the context of how they have been applied to this study.

Autonomy

The principle of autonomy aims to respect participants right for choice (Artal & Rubenfeld 2017). This ethical principle includes the right to self-determination and a right to full disclosure and was addressed in this study by obtaining informed consent (Appendix 6) and maintaining confidentiality. The principle of self-determination refers to the right of potential participants to decide voluntarily whether to take part in the research without concern for the consequences of their decision and the right to seek information, ask questions and to withdraw from the research at any stage (Manti & Licari 2018).

As part of the recruitment process, participants received a letter of invitation (Appendix 5) and a PIL (Appendix 4) containing all the relevant details about the study. I also spoke with potential participants over the phone at recruitment stages to ensure they had a full understanding of the study, discussed the benefits and possible disadvantages, what was required of them and how their information will be collected and processed. This afforded participants the opportunity to ask any questions and seek clarification if required.

Written and verbal informed consent for this study was obtained by speaking with the participants in advance of the interview and informing them about the purpose of the study, procedures to be undertaken, potential risks and benefits of participation, expected duration of study, confidentiality and anonymity of data gathered. Participants were also informed that participation was entirely voluntary and that no payments or other incentives will be afforded in return for participation and that they could withdraw from the study at any time. There was a time interval of one week afforded to participants between giving information and obtaining consent, which allowed participants time to consider their involvement in the study, however, the majority of participants responded within a few days.

Participants were advised that interviews would take place remotely via Zoom software but that digital recording equipment would be used to record the interview as it could not be recorded using computer software functions due to data security issues. Data security measures in place to protect participants' anonymity and confidentiality were outlined and reiterated at the recruitment and interview stage. Participants were advised that recordings would be stored in a data encrypted file on a computer and the original file would be deleted. All participants were informed that they would receive a copy of their transcript to ensure it was a factual account of their interview and for member checking purposes.

Beneficence and non-maleficence

The principles of beneficence and non-maleficence refers to the need that engaging in research should not harm participants and should contribute to the welfare of the participant (Parahoo 2014, Pieper & Thomson 2016). This study afforded participants the opportunity to tell their story for the benefit of themselves and future parents who may also experience accessing respite care for their autistic child through the acute care services and gave a voice to parents who have experienced this. During the course of data collection, a number of participants became upset as they recalled their experiences and shared their stories. While this was anticipated to some extent, it became apparent that reliving and sharing the experience was difficult for some. It was clear that participants were under immense stress and pressure while caring for their autistic child and often spoke about the impact these stressful situations were having on their own physical and mental health. The manner in which some participants described how they might cope with their situation was difficult to hear at times and it was clear that some participants were struggling more than others.

My experience as a registered children's nurse in supporting parents at challenging times helped me to recognise participants who were getting upset and offered ways to support them in sharing their story even if it was upsetting them while balancing this with the need to allow them to stop, take a break or discontinue the interview. In addition, to ensure participants had access to appropriate supports or help for them I asked if they were linked in with a

General Practitioner and strongly advised some participants to contact their GP based on some of the conversations.

During the course of data collection, the practice of inappropriate placement of children in adult psychiatric wards and services was highlighted as well as incidents associated with police having to restrain a child as their challenging behaviours were presenting a risk to themselves and their parents. Recalling these events was deeply upsetting for some parents, and raised some concerns for me as a researcher in relation to child protection issues, and the possible need to respond to such concerns. Consequently, I discussed my concerns with my supervisors to determine, if any or what action might be necessary. Following discussions, it was decided to link in with a child and adult psychotherapist as a subject expert in relation to my specific concerns around the inappropriate placement of children in adult services, from which it became apparent that the practice of placing children in adult psychiatric wards was not entirely unusual. Inadequate resourcing of child mental health services and appropriate respite care facilities, unfortunately was contributing to this. However, this practice is subject to regulatory review and observation by the Mental Health Commission. Having discussed the outcome of this meeting with my supervisors it was identified that while it did not require escalation as the practice was subject to regulatory review, it was noted as an important unanticipated finding of the overall study that highlights the deficit in appropriate mental health services for autistic children in Ireland and the associated impact of this on the child and family.

Some parents' mental health and how they described their ability to cope and respond to stressors was also discussed anonymously with a child and adult psychotherapist to help me identify and differentiate between a passive or immediate risk to parents' welfare. Having these discussions with my supervisor and linking in with a child and adult psychotherapist enabled me to understand the system parents are currently facing but also supported me to manage difficult and somewhat concerning information while ensuring parents had access to appropriate support needs. Some of the information disclosed by parents also outlined areas for further exploration as part of the study.

Protecting participants from harm was also upheld by ensuring that participant data was collected and stored in a confidential manner and by implementing the

necessary measures throughout the study to ensure this. At the outset of this study, a data management plan (Appendix 13) and a data protection risk assessment (Appendix 14) was conducted to identify any risks to data security, implement the necessary controls required and evaluate these controls for their effectiveness. I also completed General Data Protection Regulation (GDPR) training and child protection awareness training in advance of commencing data collection. I also communicated with data protection officers within Trinity College Dublin for advice and guidance on remote interviewing and safe storage of data. For example, interviews could not be recorded on the videoconferencing software as the protection of data could not be guaranteed, therefore other means of recording, i.e. using a Dictaphone, was discussed and safety measures were put in place to ensure data provided during the interview remained safe. Approval for these changes was granted by the data protection officer (Appendix 15). As per local (Trinity College Dublin) policy, data will be securely held for a period of ten years after the completion of a research project.

Justice

The principle of justice suggests that participants are treated fairly before, during and after the research (Tajir 2018). This principle was adhered to in that parents self-selected to participate, voluntarily and free from coercion. Justice and fairness were also upheld by affording equal opportunity for all eligible participants. For example, one parent wanted to share their experience of accessing respite care for their autistic child but did not want to do the interview and wanted the child's grandfather to speak on their behalf as his role in the family was that of an advocate and communicator for the child's particular needs. This was facilitated by obtaining consent from both the mother and grandfather to participate in the study. Another example of how justice was upheld occurred through the factual accuracy process when a parent expressed that the information they provided in their interview may have made their child more identifiable than they would have liked. The participant requested to amend their transcript in order to protect the identity of their child, which was facilitated to the parent's satisfaction.

Veracity

Veracity is closely linked to autonomy and refers to comprehensive, accurate, and objective transmission of information (Amer 2019). This was achieved by being open and honest about the study at the outset and ensuring participants

had all the necessary information available to make an informed decision about participating in the study and what this would involve.

Fidelity

Fidelity refers to the concept of trust and loyalty with the greater burden placed on the researcher to be worthy of the participant's trust and loyalty (Beauchamp & Childress 2013). It is essential that researchers gain the trust of the participants in their research by being open and honest about possible risks and burdens. This was achieved through outlining the risks and benefits at the outset to parents and maintaining my responsibility to the parents throughout the various stages. For example, affording parents the opportunity to view their transcripts to ensure it was an accurate account of their interview.

Confidentiality

The principle of confidentiality entails an obligation on the part of the researcher to ensure that any use of information obtained from or shared by human subjects respects the dignity and autonomy of the participant (Bos 2020). At the outset of the study, parents were assured that they would remain anonymous at all times, that data would be stored securely and that their experiences would be collated, and recommendations presented with those of other participants. Confidentiality was upheld in this study by assigning a code to each participant, thereby making the data pseudo anonymous. No personal identifiers were used in the transcripts and all names were assigned a pseudonym to protect participant identity. Participants were also informed that demographic data was only collected to provide context for the study and that it would be presented collectively and that parents or their children should not be identifiable. Furthermore, when reporting findings from the study and selecting illustrative quotes to support these findings (Chapter 6), every effort was made to ensure that selected quotes would not risk identification of participants.

Parents were informed that confidentiality would be maintained at all times by not disclosing the information shared to any other parties, without consent and by avoiding attributing information in the findings which would identify the participants. As interviews took place remotely, I respected parents' choice not to enable the camera function on the computer if they chose not to although almost all parents turned their camera function on with the exception of one participant who chose not to.

5.9 Quality and rigour

Rigour is a broad term that considers the quality of the study. The goal of rigour in qualitative research can be described as ensuring that the research design, method, and conclusions are explicit, public, replicable, open to critique, and free of bias (Leung 2015). The following principles have been applied when establishing the rigour of the study: credibility/trustworthiness; transferability; dependability and confirmability.

5.9.1 Credibility and trustworthiness

Credibility of research demands that the methodology chosen should be well explicated and justified (Stenfors *et al.* 2020). For research to be accepted as trustworthy, qualitative researchers must demonstrate that data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible (Nowell *et al.* 2017).

Credibility in this study was established by using purposive sampling to include parents who had experience of accessing respite care through the acute care services, and by affording parents the opportunity to review their transcripts for factual accuracy purposes or offer further information they may have omitted. Member checking, which involves returning the collated study findings to participants to check for resonance with their experience (Birt *et al.* 2016) was also considered, however, it was deemed unsuitable due to the complexity of the analysis framework and participants' understanding of same. In addition, member checking is reportedly limited in that participants might not disagree with the researcher's interpretations of the interview due to the power dynamics between researcher and participant (DeCino & Waalkes 2018) as they may feel inferior and less knowledgeable (Buchbinder 2010, Birt *et al.* 2016). Member checking also imposes an additional time demand for participants, which is limited as is the case for many participants of this study.

Discussing and reviewing the data collection and analysis approach and outcome with my academic supervisors also increased credibility. Reviews and

discussions, which took place at key stages (e.g., following pilot interview, after the first few interviews, etc.) helped me examine (and adjust if needed) accuracy in methodological and methods' alignment. As mentioned in section 5.7.2, credibility was further enhanced prior to data analysis when my supervisors and I independently carried out a pilot coding exercise on one transcript to examine congruency in coding, or otherwise. This involved coding one transcript independently, and then coming together in a meeting to compare and discuss codes. The outcome of this resulted in the use of different wording, but coda meanings were very similar which provided reassurance in relation to the data analysis method.

Providing thick description of the phenomenon using rich descriptions of details, the setting, and quotes from participants in the study, supported by analytical memos (Appendix 12), also helped ensure credibility (Lincoln & Guba 1985).

Credibility and trustworthiness of this study was further enhanced through the maintenance of a reflective journal (Appendix 10) which enabled me to reflect on strengths, weaknesses and feelings that influenced the research study at various stages. It also enabled me to document my preconceptions and explore and reflect on any potential bias. The constant reflecting back and clarification process throughout each interview and when reviewing the transcripts supported my understanding of the parents' meaning.

Finally, being familiar with the phenomenon and research context can also add to the trustworthiness of the study. I had experience of working with parents of children with disabilities, in addition to previous interview experience which can be essential for establishing credibility of research findings.

5.9.2 Transferability and generalisability

Transferability in qualitative research is closely associated with generalisability. Qualitative findings are not generalisable, rather the intention is to provide in-depth explanations and meanings (Carminati 2018).

Transferability refers to the degree in which findings may be transferred to another setting, context or group (Stenfors *et al.* 2020). Transferability can often be challenged in phenomenology due to small sample sizes (Charlick *et al.* 2016, Noon 2018). While I was not aiming for transferability, it is anticipated that the

findings will have some degree of transferability and relevance to other countries by providing insight into why parents chose to access respite services for their autistic child through the acute care settings. By making prominent in the text the rich descriptions of parents' experiences of accessing respite care for their autistic child, foundational knowledge about whether a transfer of the findings can be made to other parents of autistic children in similar situations is possible.

Although conventional generalizability (i.e., that expected in quantitative research) is elusive, and acceptably so, theoretical generalisability is considered possible (Carminati 2018) whereby the findings may provide insights that are useful to other disabilities. As this study uncovered parents' experience of accessing respite care through the acute care services, the findings have the potential to reflect similar experience in other disabilities. For example, difficulties accessing services is often reported by parents of children with disabilities yet it is the same health and social system that parents are trying to access these services from. These systems have similar structures and processes that parents must navigate however it is the child's particular need that may distinguish one experience from the another. Nonetheless, parents will have experienced the overall health and social care system, therefore, a level of theoretical generalisability can be inferred from the data.

5.9.3 Dependability

Dependability refers to the need to ensure that qualitative findings are repeatable if the inquiry occurred within the same cohort of participants (Forero *et al.* 2018). Dependability of this study was enhanced by detailing each process in detail in order to enable another researcher to repeat the same methodology and achieve similar results.

Using my reflective journal to record details on all research activities undertaken as well as my reflections on the research experience helped me assess whether the study's findings were grounded in the data, which also aided dependability.

Establishing an audit trail through the maintenance of records pertinent to this study also contributed to the dependability of this study. This was achieved at various stages as highlighted throughout this chapter and demonstrated in corresponding appendices such as recruitment (section 5.5), data collection (section 5.6) data analysis (section 5.7) and the use of reflective diary. A record

of decisions and an action log was generated at every meeting with my supervisors also. Collectively these records provide open transparency in relation to the study and also provide an audit trail.

5.9.4 Confirmability

Confirmability is concerned with establishing that the researcher's interpretations and findings are clearly derived from the data, requiring the researcher to demonstrate how conclusions and interpretations have been reached (Nowell *et al.* 2017). Confirmability was also ensured through the maintenance of pertinent records, that collectively formed an audit trail, to reflect various stages of the study and demonstrated how each decision was made. This was also supported through the use of data analysis software (NVIVO) as it provided a record of decisions during the analysis phase of the research and produced a codebook demonstrating each stage of analysis (Appendix 11 and Appendix 12).

Confirmability was further enhanced through the use of data analysis frameworks which provided a structured approach to data analysis and transparency in producing the findings.

5.10 Chapter summary

This chapter provided a detailed description of the methods used to explore parents' experience of accessing respite services through the acute care services for their autistic child. Data was collected and analysed as per hermeneutic phenomenological principles. The chapter described how the use of Braun and Clarke's thematic analysis process along with Van Manen's five lifeworld existential themes guided the data analysis process which enabled the phenomenological themes emerge that make up the experiential structure of the lived phenomenon. The ethical and methodological rigour examined and applied in this study has been discussed to uphold the quality of the study. The findings of the study are presented in the next chapter (Chapter 6).

Chapter 6: Findings

6.1 Chapter overview

This chapter is divided into two sections. The first section provides a description of the participants recruited to this study. The second section presents the existential themes and associated sub-themes that express the lifeworld of parents' experience of accessing respite care through the acute care services for their autistic child. The interpretation of the data is supported with exemplar quotes from participants which provides an insight into their lived experience.

6.2 Description of participants

The 15 participants of study comprised 13 mothers, one father, and one grandfather who participated on behalf of a mother with her consent.

Participants were from diverse geographical regions across the Republic of Ireland. The majority of participants (n=8) resided in Dublin while the remainder of participants (n=7) resided in the south, west and midland regions of Ireland. The average number of children per family was 2.66 (2 families with one child only). Five families had more than one autistic child. Less than half of the autistic children had an associated intellectual disability ranging from mild to severe as reported by participants, however, more than half of children had some form of a co-morbidity (e.g., epilepsy, diabetes, gastrointestinal disturbances or mitochondrial disease). The average age of a child when respite services were initially sought was 8.7 years however this varied greatly depending on the child's needs.

The majority of children accessed paediatric acute care services. However some participants presented to general acute care emergency departments where they remained for a considerable time before being admitted or discharged. In the absence of appropriate paediatric services in one general hospital, one child was admitted to an adult psychiatric ward. One child attended general mental health services.

Interview duration ranged from 21 minutes to 66 minutes. At the time of interviews, age ranges of participants' children or grandchildren with an autism diagnosis varied from 7 years to 25 years. The average age of the child at time of diagnosis was 2.3 years with ages ranging from 2 to 5 years. The overall median age of the child at time of interview was 17 years. Three participants' children were now adults but had accessed respite care through the acute care services in their late teens and therefore were included in the study.

The type of respite participants' children were in receipt of varied with more than half of participants in receipt of more than one type of respite. Eleven children were in receipt of residential respite care on a short term or a full term basis with the majority in receipt of short term residential care. This ranged from one to four overnight stays in a respite facility either on a weekly or monthly basis. Four children were in receipt of home respite in the form of a set number of hours per week provided by a key/support worker from a respite service. Two children attended day respite services in addition to other respite services. In addition to formal respite services, one child also was in receipt of informal respite care in the form of childminder for a set number of hours per week.

Additional characteristics of the 15 participants are presented in Table 14.

Table 14: Overview of participant profile

Characteristic	Overall Sample (N=15)	Percentage of Profile (N=%)
Participant		
Mother	13	86.67%
Father	1	6.6%
Grandfather	1	6.6%
Child profile		
Male	10	67%
Female	5	33%
Parent relationship status		
Lone Parent	6	40%
Mother and father together	9	60%
Health system in which diagnosis was made		
Public	10	66.8%
Private	4	26.6%
Public and Private	1	6.6%

6.3 Themes

The five themes and 11 corresponding sub-themes, with illustrative codes, that were identified during data analysis are outlined in Table 15.

Table 15 Themes and corresponding subthemes of the lived experience of parents accessing respite care through the acute care services for their autistic child.

Existential Themes	Thematic Area	Sub-themes	Codes	
Lived Body 'Corporeality'	Parents experience of caring for an autistic child.	Physical, mental and emotional impact of caring for an autistic child.	Financial impact Impact on parent's work Sacrificing family's private life Impact of autistic child on siblings Impact of Covid-19 Physical injuries Violence Aggressive behaviours Losing my mind Crying Suicidal Dehumanised	Envy of other conditions Feeling alone Grief, denial Manage by ourselves Not wanting to take respite away from others Acceptance of behaviours Concern for others Constantly 'on' Hyper vigilant Constant stress
		An isolating experience	Feeling alone Manage by ourselves Getting on with it A minority population Culture of autism in Ireland	

Lived Other 'Relationality'	Complex system of multiple interactions with services and health and social care professionals.	The influence of health and social care professionals (HSCPs).	Schooling Lack of information No training Lack of awareness Multiple agencies Lack of control Doing the right thing Grief process No say/choice Loss of autonomy Feelings of guilt Not being believed Giving up parental rights	Need to show how bad it is Frustrated Accessibility No confidence Threatening Strangers Parental worries
		Policing autism	Criminalising autism Being treated badly Call the police Professional advice	Little value Distressing Traumatic Last resort
Lived Space: 'Spatiality':	Accessing acute care services for respite care: A last resort	Defining moment	In need of respite No longer coping Crisis respite When problems started Emergency respite No step-down facility	Inappropriate and inadequate services Transition Increasing respite need with age Medication Inadequate allied health service provision Losing respite

			Unsafe environment Feeling insecure Home not safe Invasion of personal space Personal boundaries	Moving
		Dehumanising Process: Emotional impact of accessing respite care through acute care services.	Lying on the floor Feeling guilty Dehumanised ED as an environment to influence decisions Needing to stay strong Refusing to take child home	Finite Last resort Exhausted all routes No other option
Lived Time 'Temporality'	Accessing respite care: An ongoing process across the lifespan	A never-ending process	Years Campaigning The system Will never get it Fight for needs Paper work Waiting lists Shout the loudest Alternative pathways On your own	No follow up Lack of communication Filling out forms Inappropriate options Short term solutions
		Respite care-a time sensitive, fragile,	Negotiating Parents called for as child acting up	Loss of respite No respite at transition of services

		precious commodity.	Maintaining respite Parents finding the solution Distance to respite	Short lived No say
		Uncertainty about the future	Exhaustion Years Loss of physical ability New onset of challenges	Doubt Uncertainty Worry Who cares for the autistic child
Lived Things 'Materiality'	Acquired knowledge and information: Requirements for effective respite provision	Social media as a tool in accessing respite care services.	Influence of radio, TV and Facebook Satisfaction Feeling heard Seen and heard by everyone Compromising privacy	
		What parents have learned through their experiences	Equal access Emotional support Need for change Holiday respite Need for access to additional supports Changes to the system Need to be flagged Need to mind the carer Planning ahead Supporting other parents	

As pointed out by Van Manen (1997), while each of the lifeworld existential themes offer a different point of focus, they are not separable but rather interwoven as they interact with one another in the exploration of the lifeworld. This was reflected in the process of operationalising the existential themes within this study, where corporeality, temporality, spatiality, relationality and materiality, although explored individually, do not exist as mutually exclusive dimensions (Rich *et al.* 2013) but rather as interrelated aspects of the phenomenon. Consequently, quite often aspects of the lived experiences of parents which were coded as corresponding to the human relations existential had also been previously coded as corresponding to one of the other lifeworld existential themes. For example, themes identified in corporeality could correspond to both the lifeworld existential themes of lived time and lived human relations. Therefore, while identified themes have been coded to the most appropriate existential that supports the aims and objectives, interrelated aspects have been acknowledged throughout the findings.

6.3.1 Lived-Body ‘Corporeality’: Parents experience of caring for an autistic child.

The existential theme of corporeality reflects how participants experienced, described and discussed their bodies as parents caring for an autistic child. The lived body is more than a physical entity that remembers the past hurts, smells, and experiences (van Manen & Adams 2010). As such, through bodily senses, one encounters and understands the world, which could influence the perception of one’s lived space. Of the five existential aspects, participants most frequently talked about caring for their autistic child and how this impacted on their lives and ‘their body’. The data surrounding corporeality and the impact this had on family day-to-day life was a dominant theme in the study comprising rich contextual data.

Two sub-themes were identified from the existential theme of the lived-body (corporeality). These included: ‘The physical, mental and emotional impact of caring for an autistic child’ and ‘An isolating experience’.

6.3.1.1 Physical, mental and emotional impact of caring for an autistic child.

Corporality (the physical existence) between the parent and their autistic child was described by parents in terms of the physical, mental and emotional impact of caring for their child. While the severity of autism can vary from person to

person, the majority of parents described their child as having a severe form of autism. Parents described significant difficulties managing the challenging behaviours associated with their autism, including self-injurious behaviours, meltdowns, severe sleep disturbances and aggression, which seemed to get worse for some parents as their child got older.

Physical impact

Parents spoke about how their child's behaviour was often unpredictable and could become more aggressive and violent. Many parents described how they had received physical injuries as a result of their child's aggressive behaviour.

'...there's a child screaming her head off, and wouldn't stop crying. She just wouldn't. Hitting me, hitting everybody, flinging stuff around...'
(Participant 2)

'So then the meltdowns got worse and he was becoming violent at this stage. He was attacking us and he's a big lad. It was getting impossible to manage' (Participant 5)

Parents, it seemed, had begun to accept and tolerate such extreme and aggressive behaviours. Such behaviours had become, to an extent, normalised as they became a recurrent feature of the day-to-day life of caring for an autistic child. Although parents were aware that being subjected to aggressive behaviours had become the norm in their life and part of their reality, this realisation was to some extent heightened as they spoke about it and reflected on it during the interview process. This realisation was expressed in different ways, for example, some parents chose humour as a coping mechanism to describe their everyday lives as they reflected on some of the challenging behaviours they had experienced.

'...he's just, he's going around the house here and he basically wrecks the place like...You know, we call him here, the boys call him human tornado' (laughing). (Participant 15)

'Because she eats the non-edibles. And the danger. She has quite a fondness for chemicals and fire lighters that have to be under lock and key, like that kind of stuff. She loves that kind of chemical' (Laughs) But it

*is like that would be her level. So we have to watch her (Laughs).
(Participant 12)*

Four parents became visibly upset when they spoke about their experiences and became even more upset when I expressed empathy towards the situations they were describing. For example, one parent told me about the recurrent episodes of challenging and violent behaviours they had experienced and became visibly upset and placed their head into their hand and began to cry.

'...there should be a counselling process to help parents out of the denial and go through the grief process of having to let go of that child. Now, I'm actually starting to get upset as I talk to you about it' (Participant 3)

As each parent spoke of the challenging and violent behaviours they experienced, it became apparent that they had developed a distorted expectation of violence and the type and amount of violence they were willing to tolerate within the 'lived-body' of a parent of an autistic child. Furthermore, it would appear that there was almost a separation of the 'body of a parent' and 'a body of a parent of an autistic child' in that there were almost different expectations that parents with autistic children had to tolerate that would not be tolerated as a parent of a non-autistic child. Some parents spoke about their bodies in a state of near self-forgetfulness. It was as if they disregarded their injuries as it had become somewhat normalised. In essence, they had accepted that this was what the body of a parent of an autistic child has to deal with. For example, one parent spoke about an episode of challenging behaviour in a very dismissive tone discounting the severity of what they had been subjected to.

'I nearly got my nose broken one day in her temper tantrum. And kicked in the teeth and it was just a spat of really bad behaviours' (Participant 10).

As parents described their experiences, it became evident that the life of a parent of an autistic child is not dominated by the concern for their own body, despite some being subjected to violence, but rather concern for everybody else. The following extract outlines how one parent was concerned about the safety of others during an episode of violent behaviour with their child on the beach, in which the parent received facial injuries.

'There's a granny and two or three children and their mother who was heavily, heavily pregnant. She was very clearly, really pregnant. She came close saying, "Can I help?" I was screaming at her to get away because I was terrified that he would hit her.' (Participant 4)

Similarly, another parent describes how they had to look out for the welfare of hospital staff while their child was in hospital.

'... I would say before he went... if there is anybody pregnant in the room (hospital) or you know we need a couple of porters in here because he could smash up the place. So I would sort of manage it...' (Participant 7)

Despite the time that had passed for some of these parents who had received physical injuries, it appeared as if some parents never had time to process the gravity of what happened to them at the time of the incident as their main focus was the safety of the child or the family at that particular time.

'I was essentially, I was suffering but being really quiet about it. So I was doing what every mother does, oh just get on with it, you know.' (Participant 13).

Mental and emotional impact

Many parents spoke about the need to be constantly 'on' at all times and for constant vigilance due to their child's behaviour. Monitoring their autistic child and scrutinising the environment for possible dangers that may affect the child and the family had become central activities in many parents' daily lives. Because of this vigilance, parents never really had the opportunity to 'switch off'. The requirement to be alert on a 24-hour basis often left parents physically and mentally exhausted and impacted on the time available with other children.

'You're on guard all the time, even during the night. So (Laughs) like it's been quite funny when other people are over and they see us. If you fall asleep you're up and functioning in seconds. It isn't like, oh my god what's that noise, let me rub my eyes, stretch a little. You're up and running. So it's, so even in your deepest sleep you're still on guard. You're still ready to work. And work at pace.' (Participant 12)

'It affects your whole family, it does, it affects the whole family.'
(Participant 9)

A number of parents spoke about how they had to give up work or how their ability to work was impacted by caring for their autistic child.

'You know I actually ended up in tears one day and I just said I have to ring somebody and talk to them. So that's when my husband decided he'd leave work and retire early because of care needs.' (Participant 10)

The constant demand on parents' caring abilities also impacted on their mental health. Parents were very open and honest about the mental health struggles they faced while caring for their autistic child and spoke about the emotional impact of a particular episode or event that necessitated them to access the acute care services for respite care.

'I was losing my mind; I was going to...I actually tried to do away with myself once...' (Participant 1)

'Yes. I thought about driving into a wall when I was going through that. I was so worn out at that stage. I was basically having a managed nervous breakdown at that stage'....'I was so distraught at that point. I was so dehumanised at that point.' (Participant 3)

The findings from this study show that the constant stress these parents experienced as a result of the physical, emotional and mental impact of caring for their autistic child was causing them to view their world in a different way. This stress appeared to be interfering with the way parents viewed their bodies and was consequently distorting their world. For some parents, even at the most dreadful and traumatic times in their lives they could not get support in terms of access to respite care and were perhaps unable to make sense of the difficult experience they were going through at the time. This was described particularly well by one parent who had more than one autistic child and had experienced an unexpected bereavement of a close family member and had no access to respite or support services to help the parent or child deal with this difficult situation.

'I didn't have the privilege of having a proper funeral, or leaving the funeral. I just left the funeral, and I went home in a fog, and I sat here in the fog, taking care of my kids like it was the same thing, different day. It was like every other day, and it was like it never happened, except for the bit that I had lost a person I adored more than anything in the world. To me, it was like.... I'm sitting here, and I can't even mourn him properly, because I'd come home to take care of my three children like I did yesterday, the day before, the day before, because there was nothing, and nobody, and no place to turn to even give me that for one day' (Participant 2).

The lived body experiences of the participants reflect a very difficult and stressful situation that impacts every aspect of their lives. As each parent told their story, it was evident that some parents had accepted that this was their reality. Parents described a different experience of corporeality as parents of an autistic child to that of a parent with a non-autistic child. There is almost a distinction between what a parent of an autistic child should or has to tolerate, compared to that of a parent of a non-autistic child. This conclusion was drawn by the way in which parents within the study spoke about the differences in parenting their autistic child compared with their non-autistic children or their children's peers. One parent voiced that they were even 'envious of other conditions' that other children may have that would perhaps not subject them to as much physical, mental and emotional effects that being a parent of an autistic child would.

6.3.1.2 An isolating experience

The lived body experiences of parents also reflected an isolating situation. Parents described their lived body experiences in the context of their child's body, that being the body of an autistic child and how being and living in this particular body often left them and their family feeling isolated in many ways.

Due to some of their child's autistic characteristics such as challenging behaviours, the uncertainty of how the body might behave makes social interaction uncertain and often something to be avoided. Parents' narratives show that social activities for many families are restricted and that staying at home for some is the preferred option. Parents and their autistic child are nervous about leaving the house and going into the unknown. Some parents described not being able to meet with friends or their other children being unable

to have friends in their house. It became apparent that the child's presentation as an autistic child can draw attention to the child's unpredictable body and detracts from enjoyable participation in activities as it could lead to perceived socially unacceptable situations. The following extract captures how one family are impacted and limited in terms of social activities.

'Absolutely, so do you know what, the kids they want to be normal sometimes. They want to have their friends over. But they don't want to explain, like a naked teenager running past you know...Or why is your you know your sister eating out of the bin, or why is....Nobody wants to; none of the kids want to show that to their friends... like we can't go out to a restaurant....We couldn't go to the cinema.' (Participant 12)

Some parents had essentially become housebound because they need to anticipate and avoid triggers of challenging behaviours. This avoidance isolates them from social interactions due to potentially triggering environments and activities. Consequently, the bodies of the parent and child have somewhat become trapped.

'Because his life is so restricted, compared to his brother and his sister who have their friends and their outings and lots of stuff going on. And you know his life was just so restricted and so dependent on me and my husband'. (Participant 5)

Some parents described their living conditions similar to that of a prison as the environment had become so restrictive for the safety of everybody and therefore, families had essentially become imprisoned in their own homes.

'I ended up having a lock on the door, a padded door, Perspex across the window. That's just not okay.' (Participant 3)

'We'd every glass removed from the cupboards, everything that could be fired, every mirror, every curtain, every painting, every book. So the whole house by that November had become, we were all prisoners within the house.' (Participant 6)

Parents spoke about the autism spectrum and how it varies in capability and visibility within society reporting that those having the most severe and challenging behaviours are often not visible within wider society. Some parents believed that the public has a stereotype about autism as a mild condition because they are familiar with only certain forms of autism (e.g., Asperger's). Such stereotypes were in stark contrast to their experiences of autism and to some extent isolated parents even more.

'...we are quite a minority. I don't think everybody has the same level of needs as we do.' (Participant 12)

The majority of parents reported that having an autistic child can be isolating in the sense that it is an invisible experience that is difficult to share even with family and friends often as a consequence of people's lack of awareness and understanding of the condition. Because autism is not a visible physical disability some parents outlined that their child's behaviour was often misunderstood as bad behaviour instead of a characteristic of their autism. Consequently, parents often experienced a lack of understanding and support from family and people in general about their child's autism and about how difficult their situation can be and the lack of support available.

'...one of my brothers even said I was a bad mother with a bold child, so you know, so I don't have any family support.' (Participant 1)

Parents also spoke about how isolating having an autistic child can be in the context of navigating the health and social care support system. Trying to access supports and help was a challenge that was left to parents to figure out rendering it a very lonely and isolating experience. Parents felt most alone at times when they sought help for their child's challenging behaviours or following certain aggressive episodes or traumatic events when they needed crisis or emergency respite. Other parents reported being left to manage situations and find alternative respite supports when respite care providers could no longer manage their child's behaviours which again left parents feeling alone.

'Basically, I was alone. I was absolutely, 100%, I have to say, alone. I'd never felt more alone in my entire life.' (Participant 2)

Parents described their various experiences and encounters with services when accessing and maintaining respite care for their autistic child. For example, one parent reported that due to their child's specific challenging behaviours, services often struggled to meet the child's needs and would favour other children with less challenging behaviours or specific needs. Consequently, the parent often struggled to maintain respite for their child and was left on their own to source appropriate services.

'...these are often 'the nice to haves. You know the 'easy children'. They're nice to have apart from (son's name) who wasn't nice to have.'
(Participant 4)

Summary of lived body 'Corporeality'

The data presented as part of the existential theme of lived body has provided an in-depth insight into the lives of parents caring for an autistic child and has been important in terms of providing context for the study. The lived body experience of the day-to-day lives for these parents painted a very complex, challenging, exhausting and isolating experience as they care for their autistic child. The physical side of dealing with challenging behaviours, although perhaps most visible, was often disregarded as parents described this as a recurrent feature of their day-to-day lives and had to some extent become normalised. The need to be constantly 'on' and dealing with daily challenging behaviours was clearly having an adversarial impact on the mental health of these parents. Parents' experiences also showed that the physiological impact of having an autistic child can be both visible and invisible as some parents chose to suffer in silence and 'get on with it' as they had other competing demands.

6.3.2 Lived Other: 'Relationality': Complex system of multiple interactions with services and health and social care professionals.

The existential theme of lived other offered insight into parents' relational aspects of their day-to-day experience of trying to access respite care for their child. All life revolves around being and dealing with relationships and we meet other people in a corporeal by gaining an impression of the way they represent themselves to us (Tembo 2016). Lived relation or relationality is described as the lived relation we maintain with others in the interpersonal space that we share with them (Van Manen 1997).

Data presented here reflects the human relations parents themselves chose to discuss, and the ways in which they described, interpreted, and experienced their interactions with others as parents trying to access respite care for their autistic child with. Parents narratives described their experiences of the many health and social care professionals and services (police, emergency services, acute hospitals, psychiatric hospitals) encountered at various stages when trying to access respite care for their child.

Two sub-themes were identified under the construct 'lived relation'. These are: 'The influence of health and social care professionals' and 'Policing autism'.

6.3.2.1 The influence of health and social care professionals (HSCPs)

Relationality resonated throughout this sub-theme', as it reflected parents' lived relation with HSCPs and their influence when accessing respite care. Parents of autistic children meet many HSCPS over their lifetime and every parent spoke about their various encounters with a range of HSCPs including General Practitioners (He *et al.*), pharmacists, doctors, nurses, social workers, key workers and carers.

The theme begins by examining the relationship that exists between parents and HSCPs. According to Van Manen (1990) embedded in time are encounters of the past that always remain as memories, or as near forgotten experiences that somehow leave their traces on ones being, such as their mannerisms, the words they speak and the language that ties them to the past (Van Manen 1990). In the context of this study, it is the behaviours and mannerisms of the HSCPs encountered by parents and the way in which parents were spoken to that is being referred to. Parents distinctly remembered and recalled exact details about their interactions with HSCPs in terms of how they were made feel when seeking respite care for their child. Parents described dynamics with professionals as supportive and less supportive. Supportive relationships refer to those interactions between parents and HSCPs where parents experienced positive encounters and found these relationships as vital in assisting them to cope with the challenges of caring for their autistic child when accessing respite care. Positive encounters reported by parents involved HSCPs often going above and beyond for the parent in a crisis situation. One parent spoke about how they were

encouraged to access acute care services for respite care for their child by their healthcare professional.

'well...erm I had a chat with (name of specialist consultant paediatric psychiatrist) and I was advised...as much as I hated to and as hard as it would be for me...maybe leave him there... and say that I'm not going to bring him home until he gets the help he needs,...now I know that is so hard (shaking head)...I left him then. (Participant 1)

The development of a positive therapeutic relationship appeared to be dependent on the HSCP demonstrating specific attributes that were important to the parent. Accessibility to HSCPs at a time of crisis was one of the main attributes identified as important to the parents in this study which resulted in a positive and supportive relationship. A small number of parents described how they had access advice from HSCPs outside of routine working hours which was imperative in aiding them to cope particularly in a crisis situation. These parents were quick to state that they would only contact these professionals out of routine working hours in an emergency but the sense of reassurance that this offered parents was evident in their facial expressions during interview as parents smiled and acknowledged how fortunate they were to have such an arrangement in place.

'Yea, it's a new lady that has come in she is a bit better and as I was saying it sounds terrible but....I could ring her at 8 o clock on a Saturday night if I wanted to.....you know kinda?' (Participant 1)

Equally, many parents recalled less supportive encounters with HSCPs. This was mainly described in the context of professionals lacking information and training to assist parents. The majority of parents expressed frustration with the lack of information and awareness among some professionals about accessing respite care services for their child. Some parents had also been misinformed about services and as a result had no access to supports. The lack of information among HSCPs emerged as one of the biggest existential threats for parents accessing respite care. This appeared to place some parents in a more vulnerable and exposed position as many parents recalled exact details and times when they sought help and guidance from professionals and when this was not received, it created anxiety, worry and frustration for them. Feelings of

vulnerability often created mistrust of other health and social care professionals and impacted on future expectations and relationships with healthcare services. Consequently some parents lacked confidence in the ability of HSCPs. For most parents, this further exacerbated the loneliness or isolation they experienced as parents of autistic children. It became clear that for some parents, their relationship with HSCPs had broken down at a very early stage in their journey towards accessing respite care due to less supportive encounters with professionals.

'Not one, I mean these are qualified people you know, nurses you know. So over the years we just stopped asking because we kept getting the same answer, so. No point in knocking on the same door and getting it shut in your face all the time'. (Participant 10)

A small number of parents recalled how they were felt threatened by HSCPs into bringing their child home when they had presented to the acute care services. Parents reported that they were threatened with the prospect of social services taking their child away from them and vividly recalled what certain professionals said to them.

'I remember one of the doctors saying to me at one stage well if you leave him here we'll call TUSLA, you know?'. (Participant 1)

'And like years ago I was told that if I did bring her into acute care into the hospital I'd be reported to social services. Yea I was told by a nasty old medical director I'd be reported if I dropped my child off'. (Participant 12)

Feeling vulnerable and threatened portrays how parents endure less supportive relationships and the meaning it holds for them. This threatening feeling was likely further exacerbated by the vulnerability that parents felt as a result of lack of guidance, support, information and trust from their previous encounters with HSCPs.

Evidently, parents will always have some form of connection with HSCPs and services across the lifespan because of their relationality as a parent of an autistic child and this may not be by choice. HSCPs were initially viewed as strangers by parents and in certain circumstances where parents reported less

supportive relationships, parents were unable to move beyond viewing them as strangers. Yet, parents have to engage with these strangers, let them into their home, let them make decisions about their child and can influence their ability to access respite care. Consequently they may feel that they lack autonomy over their child. They feel that they do not get a say in their child's life and may be surrendering their parental role as decision makers for the interest of their child to these 'strangers' which can be difficult. The concept of the HSCP being viewed as a stranger was more prominent in the community setting than the acute care setting as parents shared their experiences of receiving respite care for their child in their own private homes and spoke about how health and social care staff could change all the time.

'it's like having a stranger in your house watching everything that is going on.' (Participant 1)

Interestingly, there was no single type of HSCP identified as being more supportive or less supportive to parents in their role as various experiences with a range of professionals were outlined by parents. However, the presence of a good supportive working relationship with a HSCP either in the acute care setting or within the community setting did not mean that parents were less likely to attend the acute care services which was an interesting finding. In a small number of cases, parents reported how it was their HSCP (e.g., doctor or social worker) who encouraged them to attend the acute care services for respite. Therefore, it could be argued that parents who report having a supportive relationship with their HSCP could potentially be more likely to attend the acute care services for respite care for their autistic child.

Policing autism

Similar to how parents described their interactions with HSCPs, parents also vividly recalled their encounters with the emergency services prior to their child being brought to hospital in a crisis situation. Five parents had experienced the police coming to their house in a crisis situation and bringing their child to the acute general and psychiatric care services. Parents recounted that calling the police was a last resort for them in a crisis situation as this resulted in a very difficult and distressing situation for both the parent and child.

'I had to get the police and he was wrestled out of the house by three police'.

(Participant 1)

'That's incredibly distressing to reach that point. My son was taken out of here ...totally deranged with something over his head. Handcuffed to a trolley and he was 14 years old at the time'. (Participant 3)

Parents spoke about how they were advised to call the police in a crisis situation by HSCPs yet questioned the value of this and the role the police had in these situations. From the parents' perspective, these were people who knew very little about autism, had no specific training in autism and yet were the first responders in a crisis situation.

'Like they (hospital healthcare professionals) would just be like well he's ok now so bring him home or whatever then like things might kick off again and it's back to like call the police, call the police...you know like...the police like when you would call them when he was getting bigger, they would say we can't do anything, and I am saying yeah I know but they are saying to call the police....you know..... what are we supposed to do, who is supposed to help us, I mean the police can't help us, they are not, not.....psychiatrists or you know, people to help?'

(Participant 1).

Parents strongly felt that calling the police was in no way in the best interest of the child and is not an appropriate intervention particularly in the context of children with additional needs and that such an approach was so invasive for the parent and child in terms of the intrusiveness on the child's environment and privacy of the parent's home and the manner in which the situation was handled.

'There's no way you should ever have to reduce yourself to having, or your special needs child, to the police coming into your home and having to go through that invasion of a very, very... what's the right word? It's a personal, you know, this is somebody that you love, it's not somebody that you're pawning off.' (Participant 9)

Another parent described how having to call the police in a crisis situation was to some extent criminalising autism and felt that her child was being treated as a criminal both in the way in which the parent was advised to call the police and the way in which their child was managed when the police came to the house.

'Why should we have to go to police...being carted out here like a criminal? It's crazy, completely insane. I consider it penalizing. It's the penalizing of disabled people for being disabled. It is criminalized in Ireland. I've had the police handcuffs multiple times.' (Participant 3)

Summary of lived-other 'relationality'

Using the relationality existential to understand parents' experience not only uncovers the phenomenological views of parents but consolidates the landscape of existence and how being the parent of an autistic child affects the whole person. Findings showed that parents' relationships with HSCPs can affect their daily life and how past experiences with HSCPs can influence current and future relationships and expectations. Equally parents described a loss of autonomy and decision making for their child by virtue of their relationality as the parent of an autistic child as they would always have to engage with HSCP regardless of choice. Being advised by HSCPs to call the police in a crisis situation had a profound impact on parents who were forced to do this in the absence of an alternative option. For these parents, their child was being treated as a criminal as parents and all parents questioned the value and appropriateness of such an intervention.

6.3.3 Lived Time: 'Temporality': Accessing Respite Care: An ongoing process across the lifespan

Lived time refers to subjective time as opposed to clock time or objective time (Tembo 2016) and lived time is our temporal way of being in the world (Van Manen 2006). We get to know people by learning what constitutes their past, present and future as these represent horizons of their landscape (Van Manen 1997). The temporal things of the past determine the present and the future perceptions of the world (Tembo 2016).

The existential theme of temporality describes how time is experienced by parents when accessing respite care for their autistic child. The influence of time,

or temporality, is a significant finding of this study as time has a notable impact on parents' experience of accessing respite care for their child. This experience influenced how they perceive the future for them and their child.

Themes involving temporality are classified according to parents' experience of accessing respite care for their autistic child in the past, present and future. Three subthemes emerged from lived time (temporality). These were '*A never-ending process*' which reflects parents' journey of accessing respite care from when the need for respite care was first identified up to the point at which they accessed acute care services; '*Respite: a time sensitive, fragile and precious commodity*' which reflects parents' experience of accessing respite care through the acute care services and there onwards; and, '*uncertainty*' which reflects how the time spent accessing respite care over the years has made parents feel about the future.

6.3.3.1 A never-ending process

Being in a never-ending process is a theme that elucidates parents' experiences of accessing respite care for their child since the need was first identified. This never-ending process was essentially characterised by parents as waiting lists, refusals and 'fighting the system'. Parents distinctly recalled the amount of time this took and how the process spanned many years.

'Yeah, it took that amount of time (5 years) for him to get the placement.'

(Participant

11)

"Ten years eventually, after about ten years we would've got a week at a time'

(Participant 10)

Through parents' narratives it became apparent that their lived time was spent waiting in many aspects. The majority of parents had experienced being told that services were not available at the outset of seeking respite or that they would be placed on a waiting list. Some parents spoke about how these waiting lists continued for years with no formal updates or transparency about how the waiting

list was operationalised. Parents expressed frustration of having to wait to access respite care services and they constantly had to chase for updates in relation to progress with these waiting lists. It became apparent that the idea of 'lack of services' or 'waiting lists' and possibly not receiving respite services was being somewhat normalised or accepted among HSCPs and parents.

'I looked for respite and was told there was a two-year waitlist' (Participant 2)

'So the social worker came to the house and I filled out forms and she said, she just said to me you may never get it (respite). You may never get it, I just thought it was bit of a strange response. I was like okay; well I'm going to fill out the forms anyway and try.' (Participant 15)

'Fighting the system' elucidates the descriptions and meaning parents attached to the experience of accessing respite care for their autistic child which was described as a complex, never-ending process that took years to navigate. For the majority of parents, their experience of 'the system' comprised inadequate communication, no follow up, lack of respite options, lack of choice when choosing a respite service, short term respite solutions and inappropriate respite options. Parents described having to constantly fill out forms to apply for respite despite being told that their chances were minimal. Other parents spoke about how they were refused respite care time and time again. Many parents who had spent their time fighting the system, completing application forms and enduring long waiting periods stated that they had, through no fault of their own, made very little progress in securing respite care for their child. As time is part of how parents live in this world, waiting for respite care was in essence losing time and to some extent caused a sense of discontinuous existence for parents. Through waiting, parents knew and felt that their chances of getting respite care were minimal. However, they also knew that if they did nothing they may never get respite care for their child.

Out of necessity and self-protection against a state of discontinuous existence, parents explored various ways to access respite care. This provided them with a purpose in life although their entire effort was experienced at the same time as fighting a losing battle. Parents described the various routes they had used or had been advised to use to access respite care services. As each parent told

their story, it became apparent that there was no one single point of access for parents to access respite care as parents reported trying multiple avenues. One parent described how they had arranged for their child to get a hearing test through the acute care services which was not required but the parent did this as a means of attaining a specialist referral to a mental health clinic for their child which would support their case for respite care.

'I applied to (name of children's hospital). I knew from friends they had (name of mental health clinic) at the time. But she could only get into (name of mental health clinic) if you were in the hospital. Even for a broken bone or whatever. So I arranged a private hearing check with a consultant (Laughs)... I had no doubt that there was any issue with her hearing.. And in the end I got, I got into the hearing consultant. He said would you like a referral to (name of mental health clinic); I'm like absolutely, please that would be great'. (Participant 4)

Another parent reported how they had plans in place to move abroad for respite care for their child because no service would accept their child.

'Yea, so she ended up there by default really. Because there was nowhere else for her to go, with the plan that (daughter's name) would eventually, in a number of weeks move to a UK facility' (Participant 6).

For parents within this study, time spent trying to access respite care, coupled with the prospect of potentially long waiting periods, no defined pathway and lack of information were identified as motivating factors to accessing respite care through the acute care services. While the amount of time spent waiting and fighting the system emerged as a contributing factor at a superficial level, the impact of this had a more profound and deeper meaning for parents. The sense of discontinuous existence that comes from the lost time spent trying to access respite and making progress was ultimately what motivated parents to seek alternative routes to accessing respite care.

6.3.3.2 Respite care-a time sensitive, fragile, precious commodity.

This theme reflects parents' experiences after attending acute care services, from which many parents received some form of respite care. While this was initially viewed as a positive outcome for many parents, for some this victory was short

lived and for others it brought about a new set of challenges. Parents reported that they had very little say in the type, duration, location and frequency of respite.

Many parents spoke about how the respite service that they received were located far from the family home and that they were required to travel long distances. Parents felt that they just had to accept what was offered as they acknowledged how difficult it was to access respite and parents were equally aware of the demand for respite.

“look, it’s a three-hour drive, it’s in the middle of nowhere, absolutely nowhere.”

(Participant 9)

‘the driving up and down, its fifty miles from here you know. So that was a bit long.’ (Participant 4)

Other parents described how they had been subjected to constant movement between services and changes to the child’s respite location which was often disruptive for the family and child.

‘....so he was in one apartment right and the lease was up on that....,then he had to move to another apartment and the lease was up on that...then they moved him to a third house....hoping and praying that I would take him home, and I said no...., stand firm’. (Participant 1)

Through parents’ narratives, respite care was emerging as a support that was quite fragile and highly sensitive to time in a number of ways. For example, an inevitable change in their child’s behaviour meant that the hard-fought position could be lost at any moment in time. Some parents described how their child ended up losing respite or being deemed inappropriate for the respite service they had accessed because of a sudden change in their behaviour that meant that the child could be a risk to another service user or that adequate staffing was not available to meet the child’s needs. Other parents described how no alternative options were presented when their child was deemed no longer suitable for respite care.

'The service decided to discharge her with nowhere for her to go. They were planning on sending her to an A&E department'. (Participant 6)

Some parents spoke about how they had managed to access respite care for their child previously but reported that they had been left or will be left without respite care services at the point in which their child had transitioned or is due to transition to adult services. From this perspective, their respite care had an expiry date.

'Yea once he left children's services it (respite) stopped'. (Participant 5)

'But I'm arguing at the moment to try and get it (respite) set up for her as an adult.' (Participant 3)

Parents described how they were often the ones left having to look for respite for their child as an adult and called for a more seamless transition and continuation from children to adult respite services, thus highlighting the need for integrated care services. Consequently, the fragility of respite care coupled with the potential of an expiry date and lack of choice and decision making meant that many parents were left feeling uncertain about their child's future.

6.3.3.3 Uncertainty about the future

The temporal things of the past determine the present and the future perceptions of the world. Van Manen (1990) argues that hopes and expectations give us a perspective on life to come whereas desperation and lack of will to live may result in loss of such perspective. Similarly, in the context of this study, parents' experience of accessing respite care through the acute care services affected their perspective of the future. The lived time spent accessing respite care for their autistic child strongly influenced how they felt about the future which was predominantly filled with doubt and uncertainty.

It became apparent that despite the journey parents had been on, the extreme measures that some of them had gone to accessing respite care for their child and the traumatic experiences described by some when accessing the acute care services, the influence of time did not pave the way for certainty in the

future. While parents past experiences of trying to access respite care for their child over a number of years led many to the pathway of accessing respite through the acute care services, their present experiences of accessing some form of respite following interactions with acute care services created a new set of challenges. For these parents, their past and present experiences of accessing respite care for their child had been relentless. Time reaches a never-ending cycle of challenges to encounter, and over time, they have learned that arising from each challenge there is a level of uncertainty. Uncertainty for these parents was related to the inability to see beyond their existing challenges and see the future.

'There's definitely an element of parental exhaustion at this age. You've been doing this for a long time now at this point, 12 years, and parents are older at that point. You just don't have the stamina'. (Participant 3)

Lived time proved to be a significant aspect in parents lived experiences, with parents discussing their future as older parents and the concern of not being able to care for their child in old age. Losing their physical ability to care for their child was a worry for all parents. Parents also questioned what would happen to their autistic child in the future as parents themselves became too old or unable to look after their child due to an illness. Parental worries and the long-term implications of caring for an autistic child was highlighted by parents whose children had now become adults and they continued to be the primary caregiver while fighting for supports such as respite care.

'...if I die my husband will still have to carry on caring into his eighties, until he dies. And then (child's name) will be taken into residential care. It's because I'm at the other end of it and my child is no longer a child. She's now an adult and we're of a retirement age.....so I think respite is vital. They (HSE) said to us that if we became so incapacitated like through stroke or whatever or died, that they would be the only reasons that they'd consider taking her into respite, into residential'. (Participant 10)

Summary of Lived Time

The existential dimension of lived time referred to the objective and subjective experience of time. Lived time is a felt time, and reflected parents' experience of

accessing respite care for their child and how they perceived it. Parents in this study reported their time from the past to the present moment and future. Overall, accessing respite services was described by all parents as a never-ending process with time spent navigating and fighting a complex system. This was identified as a motivating factor for them in accessing respite care through the acute care services. While many parents reported that they did manage to access some form of respite service, maintaining this respite service was challenging for some parents.

By further exploring the impact and meaning of time on parents' experience temporally, it emerged that the concept of lost time and sense of discontinuous existence that comes with waiting and navigating a complex system over years was also a motivating factor that led parents to access respite care through the acute care services. The experiences of parents reflects a never-ending cyclical journey towards accessing respite care and despite the years and lived time spent, uncertainty about the future dominated the lives of these parents.

6.3.4 Lived Space: 'Spatiality': Accessing acute care services for respite care: A last resort

The existential theme of spatiality reflects the lived or 'felt' space (Van Manen 1990) which affects our experience of the world. This is the feeling provoked by the space in which one finds oneself and how it affects how one feels. The mood in which we encounter lived space can influence the way we experience and interpret the particular space be it our home or a hospital (Tembo 2016).

Although lived space initially appeared the more abstract of the existential themes, through data analysis it proved to resonate strongly with parents' lived experiences.

Data presented in this theme reflected the atmosphere or mood in which parents encountered the felt space particularly at the point in which their child accessed respite care through the acute care services. Data also reflects on and considers what is it about the acute care services that parents felt that such an environment could influence decisions or actions.

Two essential sub-themes emerged in this theme: 'Defining Moment' and 'Dehumanising Process: Emotional impact of accessing respite care through acute care services.'

6.3.4.1 Defining moment

The mood in which we encounter lived space can influence the way we experience and interpret the particular space be it our home or a hospital. For example, the space of home gives us a special experience of being safe and by ourselves (Van Manen 1990). However, while our home can offer a sense of protection and security, it can also change and be frightening depending on the circumstances under which we encounter our home. Parents spoke about a defining moment or a particular turning point that resulted in them accessing acute care services for respite care as their home could no longer provide that sense of security or protection for them, their autistic child and their family due to their child's challenging behaviours.

"Oh he fractured his skull, that's what the tip of the iceberg was. So I'd left the room for three minutes to go to the toilet and he fractured his skull. So he ended up in hospital. It was a key player the fact that he fractured his skull. That was the big turning thing". (Participant 8)

'he had a major outburst when he was brought down to the adult psychiatric ward, he got me around the neck and wrestled me down and held me there for I don't know....5-10 minutes or something I don't know....and then another time he got a kitchen knife and he went to go stab me and himself' (Participant 1)

Throughout the interviews many parents referred to space in terms of physical and emotional space. Invasion of personal space or loss of personal boundaries gave meaning to many parents' experiences as they described the impact of having to call the police to their home in a crisis situation. The presence of these strangers (police) in their home, trying to manage their child in a difficult situation resulted in their personal space no longer having the privacy that it once had.

6.3.4.2 'Dehumanising Process': Emotional impact of accessing respite care through acute care services

Within this theme, parents' narratives described the atmosphere or mood in which parents encountered the felt space particularly at the point in which their child was being brought or had been admitted to the acute care services for respite. The hospital becomes the felt space for the parents and their child while they are hospitalised and parents distinctly recalled how they felt at this moment in time.

Emotional space evoked a mix of feelings for all parents, although these feelings were predominantly negative in nature.

'But there were periods of the day where she found it very difficult to have staff in her space. And they needed to restrain her during those times. Which was horrendous. But that was the way...It was the hardest thing for me to do like...' (Participant 6)

One parent recalled how being provided with a mattress to lie on the floor while their autistic child was in the ED. This parent had gone through a particular challenging time in trying to access respite care for their child and being provided with a mattress to sleep on the floor conceptualised how trying to access respite care felt for this parent.

'They give you this piece of shit to lie on the floor on. I didn't, I just sat there on the armchair, so I literally sat there.' (Participant 2)

Parents often described that they were made feel guilty about wanting respite or choosing to seek it in such an extreme way by accessing acute care services.

'Yeah, and I had to stick to my guns like and just kind of, like they tried to get me to take him back, "oh he's missing you, he's crying for you" and you know "will you take him back?" and do you know, "you've abandoned your child" and all this kind of craic and I'm like "no, I didn't", like do you know?. I left him there safely' (Participant 11).

Another parent referred to the process of accessing respite care through the acute care services as a dehumanising process because of how they were made feel by healthcare staff when they refused to take their child home.

Some parents became visibly upset as they described the guilt they felt when accessing respite care for their child. For many parents, presenting to the acute care services for respite had a profound impact on them as a parent with some parents feeling that they were not able to care for their child and to some extent were surrendering their parental duties. This guilt was palpable during interviews as parents became upset and described a sense of shame associated with this.

'It's wracked with guilt. And so you have a lot of mother's guilt. I don't think anybody else felt it like I did. You're you know it's actually horrific, the first few times. Like I'm tearful thinking about it' (visibly upset and shaking head)... 'It's just like you know I can't articulate it. It's just really hard. It's like you're not able to mind your own child'. (Participant 12)

Interestingly, this guilt was an ongoing feature of parents' experiences of accessing respite care in general even when they had accessed respite care after the acute care services. This guilt never left parents. Despite having fought hard to access respite services and the extreme approaches they had gone through as well as their experiences of going through the acute care services, parents still felt guilty about placing their child in respite care.

'....you feel like you failed. You feel like you have failed your child that it has come to that level, that you have to put them into respite. I do look at the side that is if there was a choice between her going into respite or harming my other two kids and me, no matter how guilty I would feel, I would have to do it. Yes, it eats me inside. It makes me feel like I failed her...'. (Participant 2)

While parents often described the emotional impact of having to access acute care services for respite as a last resort, some parents stated that they would still use such an approach despite the process being described by some as dehumanising. Parents appeared to recognise this approach as a finite moment that would result in some outcome if they were able to be persistent. It became apparent that parents felt that being in an environment like the ED or wider hospital environment had the potential to influence decisions or actions.

'Yea (hesitant tone)...I would... (hesitant tone) I would tell a parent to go that way but I mean no family should have to go through that, no child, I

mean....he should not have been down in an adult psychiatric ward'
(Participant 1).

Summary of Lived Space 'Spatiality'.

This existential dimension of 'lived space' is concerned with parents' life and the space their life occupies. In the first sub-theme, concerning physical space, parents identified how the lived space of their home in terms of providing privacy and security for them and their family can become unsafe due to their child's challenging behaviours. Having to call the police to manage a crisis situation meant that parents' personal space and the autonomy they have as the parent of this child in their personal space is taken away from them. In the second theme, emotional space was experienced through feelings of being dehumanised and feelings of guilt as parents described how the lived space felt as they access respite care through the acute care services.

6.3.5 Lived Things: 'Materiality': Acquired knowledge and Information: Requirements for effective respite provision.

The final existential theme is materiality. Van Manen (2014) noted that our possessions are extensions of our bodies and mind. The existential theme of materiality reflects the material things that influence parents' experience of accessing respite care through the acute care services. Two sub- themes emerged from the existential dimension of 'lived things', these include: 'Social media as a tool in accessing respite care services' and 'Knowledge gained: What parents have learned through their experience'.

6.3.5.1 Social media as a tool in accessing respite care services.

Parents described how social media, although abstract and intangible, assisted with accessing respite care services for their child. Some parents described how they specifically used social media when in receipt of respite care within the acute care services in an attempt to secure a more suitable and longer-term respite option.

Nine parents outlined how they had used social media to assist them accessing respite services.

'I did a Facebook live video a night before I left (to go into hospital with child for respite). It took me to actually go public and make a Facebook live video that got 160,000 hits.....spent five weeks running a Facebook campaign...'

(Participant 3)

...it was more because I went all over every radio station..... It ended up being taken by the papers, it was in... Jesus it was in every paper'.

(Participant 2)

Parents described the positive impact that social media had for them in terms of accessing respite care.

'So and it (social media) did work, because I did get respite after the article'.

(Participant 12)

'Then just literally the week that because of the story being on TV)...he got offered a residential placement...it was definitely a key player.

Working in parallel with keeping in touch'. (Participant 4)

Of the parents who had used social media as a tool in supporting them to access respite care, it became apparent that social media gave these parents more than access to respite care. Social media gave parents an independent visible platform for their story. It offered insight from a non-health and social care perspective from a wider audience who witnessed at first-hand the essence of what the parent and child were going through in a non-clinical and medical way. Social media appeared to remove the parent away from the isolated feeling, sense of discontinuous existence and dehumanizing process experienced by parents in this study. In essence, the use of social media empowered parents and enhanced their confidence at a time when they felt most vulnerable and exposed. This was apparent during several interviews with parents as the tone switched from helplessness and desperation to a more hopeful and optimistic tone. Some parents spoke with a sense of pride and achievement as they smiled and laughed when talking about how they had received a form of respite care for their child having used social media.

Although using social media for parents did have a positive impact, this was yet another action that compromised the privacy of parents and impacted on the felt space by having to share their personal circumstances in such an open way, yet the potential benefit outweighed the negative impact. One parent expressed the negative side of having to share their personal circumstances in such an open way.

*'That's why I went on the radio, and this is why. I'm not the type to go on the radio. I'm actually one of them people that will hide, you know, (husband's name) was very, very private, that's why we never involved anybody in our lives. Our house was our fortune and we kept it like that'.
(Participant 2)*

All parents who had used social media to assist them in accessing respite care stated that they would use it again having experienced the positive impact it can have. However, for parents who attributed accessing respite care quicker to the use of social media and other media platforms, they were still faced with the same challenges that other parents were faced with who had not used social media. For example, they were still subjected to a lack of choice in the type, frequency and location of respite care. Furthermore, these parents also experienced other challenges such as retaining respite care and difficulties transitioning from children's services to adult services. Therefore, it could be argued that the use of social media has a very limited impact on accessing respite care.

6.3.5.2 Knowledge gained: What parents have learned through their experiences

A prominent, although intangible, lived-thing related to parents improved knowledge of the system as a result of navigating the pathway to respite care services for years. Not only did their journey provide them with ways of accessing respite care but parents became knowledgeable of the weaknesses within the current system and their experience enabled them to develop a knowledge base of what pathways for accessing respite care should look like. Parents were reflective of their experience and described what they would now do to access respite care.

Despite many parents describing accessing respite care through the acute care

services as a last resort, it became evident that parents would still choose this pathway with some expressing that they would advise other parents in similar situations to do the same.

'Yea (hesitant tone)...I would... (hesitant tone) I would tell a parent to go that way but I mean no family should have to go through that, no child,... I mean, I mean....he should not have been down in an adult psychiatric ward' (Participant 3)

Parents' experiences and acquired knowledge equally enabled them to identify the requirements for an effective system of accessing respite care for autistic children and what respite should offer. Planning ahead, proactive identification of the need for respite, responsive respite to the needs of autistic children, clear guidelines for accessing respite care, a shift away from the medical model and appropriate staff training were highlighted as requirements for effective respite care services.

'there should be clear guidelines you know, as to what should happen..... But once you have that then, it should be kind of clear cut, do you know? There should be clear steps. There doesn't seem to be anything like that'. (Participant 11)

Another parent emphasised the need to have access to respite care well ahead of any crisis situation.

'You're not starting it when people are in crises. That's what's really important as well in terms of... respite should be in place long before a crisis emerges so that if something happens that could be a family crisis, one of us could be sick. Behaviours can emerge. Whatever. That stage, the service should know the child and should be able to ramp up services accordingly, but if they've never laid eyes on him before and something happens and you're trying to start drafting the care plan while you're in this crisis situation, that causes so much more stress on the person and all of the rest of it. It's all these things' (Participant 4)

Many parents wanted a shift away from the medical model to a more social model centred around developing life skills for the child.

'The medical model is institutionalization and dehumanization. It's what we should be moving out of. There's no excuse anymore. Not with the global information that we have'. (Participant 3)

All parents spoke about the importance of having access to respite and that the provision of respite services is not just for the autistic child but also for the parents and wider family.

'The word respite means a break from. We can have a break from each other. It's as much for the family as for the child in terms of the family' (Participant 4)

Parents' sense of improved knowledge of the system became a source of confidence for parents and they expressed satisfaction in how they could use this acquired knowledge and information to assist other parents. Some parents used these support networks as an outlet to provide support to themselves. Parents were able to speak with other parents in similar situations and seek out advice in terms of helping them access additional supports as well helping them manage the needs of their wider family. Some parents subsequently became advocates for other parents and were heavily involved in parent support groups.

'We've a good network here we'll do it for each other, you know we go to the meetings with each other because you know to help and support' (Participant 4)

6.4 Chapter summary

In this chapter, Van Manen's five existential themes were used to uncover an in-depth understanding of parents' experience of accessing respite care through the acute care services for their autistic child. Identified themes from parents' narratives were then presented, along with associated sub-themes, supported by illustrative quotes and interpretive comments. .

The findings of these existential themes reflect a deep orientation to the parental experience through constantly asking "what is it like?" (Van Manen 1990) and probing further for parents' experience of accessing respite care through the

acute care services for their autistic child. By doing so, not only has it assisted with remaining true to the research methodology but it has provided context to circumstances that have led to parents accessing respite care through the acute care services for their child. The following chapter discusses these findings in the context of existing literature.

Chapter 7: Discussion

7.1 Chapter overview

This chapter presents a critical discussion of the main findings of the study. Relevant literature, initially presented in Chapter 2, is revisited and discussed in relation to the current findings. The findings are also discussed in the context of findings of the systematic review in Chapter 3. Novel contributions and findings unique to this particular study are considered. Findings in the context of national and international policy and best practice guidelines, where available are discussed. The strengths and limitations of this study are addressed, followed by a critical reflection of the research process.

7.2 Discussion of findings

7.2.1. Parents' experience of caring for their autistic child.

The current study emulates many of the findings identified in previous research; that is that parenting an autistic child is stressful and challenging, can involve social isolation, difficulties in managing the unpredictable nature of the behaviours with autism, and that parents of autistic children have an elevated risk of experiencing physical health and mental health problems, including stress, anxiety, and depression in relation to their child's potentially dangerous and unpredictable behaviour and functional dependency (Falk *et al.* 2014, DePape & Lindsay 2015, Bessette Gorlin *et al.* 2016, Eapen & Guan 2016, Padden & James 2017, Pattini *et al.* 2019, Samsell *et al.* 2022).

Although the literature review (Chapter 2) and systematic review (Chapter 3) identified many difficult experiences of parents caring for their autistic child, the analysis of data from the present study revealed more extreme and distressing situations associated with caring for an autistic child. Many parents described situations whereby their own lives and the safety of that of their family were put at risk by particular episodes or incidents related to their child's behaviours.

Parents' mental health was also impacted, although feeling able to disclose their personal mental health struggles was a positive aspect of this study. This finding contrasts to a study carried out by Currie *et al.* (2020) who found that parents may not be comfortable disclosing feelings of being overwhelmed or struggling in meeting pervasive care challenges as it could be perceived that they are not coping with their parental responsibilities (Robertson 2014). While a dearth of

literature and best practice guidelines recommend the role of mental health professionals in helping parents manage their child's behaviour, findings from this study and that of the systematic review (Chapter 3) support the requirement to address the child's mental health needs as well as the mental health needs of parents and the wider family affected by the child's autism. This is supported by numerous studies that found improving the parents' mental health and wellbeing enhances the potential of the child to also achieve a better quality of life (Vohra *et al.* 2014, Catalano *et al.* 2018, Yilmaz *et al.* 2021).

A systematic review and meta synthesis of qualitative evidence on parents' experiences of caring for an autistic child by Samsell *et al.* (2022) found that families of autistic children make life adaptations in a variety of areas, including structuring activities around their child's behaviours, physical modifications to homes for safety, and intentional social isolation. Loneliness appears as a significant problem for autistic individuals and differs from their tendency to self-isolate or seek aloneness (Kasari & Sterling 2014). Parents within this study experienced social isolation for their family and their autistic child for a variety of reasons such as lack of understanding from others including their wider family in relation to their child's needs and inadequate community supports. This mirrors findings from similar research which has shown that parents of children with intellectual or neurodevelopmental disabilities often experience social isolation (Kasari & Sterling 2014, Brock 2015, Barnert *et al.* 2017, Baumgardner 2019, Currie & Szabo 2020, Devenish *et al.* 2020). Reasons for this pertain to reduced opportunities for community participation and restricted opportunities for social activities (Egilson *et al.* 2017, May *et al.* 2018). All of which can negatively impact on the child and family's wellbeing (Galpin *et al.* 2017). Furthermore, parents within this study reported challenges with accessing community and family supports due to a paucity of services which also led to feelings of exclusion and isolation which is congruent with findings from Barnert *et al.* (2017) and Brock (2015).

In this study '*getting on with it*' and '*managing by ourselves*' were recurrent phrases voiced by parents. Parents had accepted that not only were they to manage difficult home and community situations, but they also had to be resilient and redemptive while caring for their autistic child. This idea is supported by Fernandes & Robertson (2019) who suggest that parents can become further marginalised and excluded if they are not seen to possess resilient traits and

characteristics. Brock (2017) also reports, based on parental narratives, how parents perceive that they must meet their children's care needs as part of their accountability and responsibility for having children with special needs. However, this warrants further investigation to explore at what point parents experience this, how, why and who has made them feel like this. Furthermore, the implications of creating a culture of '*getting on with it*' can have adverse consequences for the child, parent, and wider family particularly in the context of parents' mental health. Findings within this study have shed some light on how the '*getting on with it*' culture can impact on parents' mental health and impact on the child. Therefore, there is a requirement to shift the discourse of parents having 'to get on with it' and reduce the unrealistic expectations for these parents especially as this can lead to disconnection and vulnerability (Ellis *et al.* 2019).

The present findings and findings from the systematic review support the concept of respite care (discussed in Chapter 2) as a service that is not just for the child but equally benefits the parent and wider family (Whitmore 2017a). Findings highlight the need to adopt a holistic family centred approach in the provision of respite care services for autistic children – one that incorporates the specific needs of the whole family by recognising the physical, mental and emotional impact that caring for an autistic child can have. Such an approach is consistent with some of the core principles that are recognised in practice guidelines as important interventions for autistic children (NICE 2012, 2016, 2017 and New Zealand guidelines).

7.2.2. A complex system of multiple interactions with services and healthcare professionals.

Over the past decade, the rising prevalence of autism has overwhelmed service systems for families of autistic children. Autism policy has been described as an arena of extraordinary complexity and conflict for those navigating within it alongside a bewilderingly complex arena of actors at work (Marmor 2017). This conflict can be attributed to the complexities of multiple public policies designed to provide needed services for autistic people and the potential overlap with autism policies and disability policies. Furthermore, the neurodiversity and heterogeneity of autism results in a wide range of individual needs and support requirements and therefore it is unlikely that there is a 'one fit' approach to respite care models. In the absence of appropriate services and defined

pathways to support services such as respite care, overwhelmed parents and community providers of mental health resources may not be in a position to meet the specific needs of autistic children. A recent report on autistic children's access to healthcare services in Ireland found that 76% of autistic children were not receiving any support from mental health services (As I am 2021). A consequence of this, as evidenced in the present study, is that parents may be forced to access the acute care services for supports.

7.2.3 Role of health and social care professionals (HSCPs)

Findings from both the study and systematic review demonstrated how HSCPs can impact parents' experience of accessing respite care for their autistic child in various ways. These findings add to a growing body of literature, albeit specific to the Irish context, that has previously explored the role of HSCPs in the context of seeking support services including respite care for their autistic child (Hodgetts *et al.* 2013b, Mann 2013, Minhas *et al.* 2015a, Gona *et al.* 2016).

In the present study, parents who experienced less supportive relationships with their HSCPs attributed this to lack of understanding of autism, lack of training and an overall lack of knowledge and information in relation to accessing support services like respite care. The findings from my study align with those of Hodgetts *et al.* (2013) and Minhas *et al.* (2015) who found that parents' experiences of medical professionals included HSCPs having limited information about autism and a lack of understanding about the condition (Hodgetts *et al.* 2013b, Minhas *et al.* 2015a). In this present study, the lack of information among HSCPs emerged as one of the biggest existential threats for parents accessing respite care as it created anxiety and frustration and appeared to place some parents in a more vulnerable position as they became unsure of where to go for advice and information on accessing support services, in particular respite care, for their autistic child. The lack of information and transparency of service options created an environment in which parents lost trust and felt resentment towards HSCPs. This can have significant implications as a lack of awareness of services required for autistic children may also suggest that HSCPs could be less likely to advocate for much needed services for autistic children such as respite care services.

In addition, some parents reported that they were made feel inferior by HSCPs as they were essentially being told to 'get on with it'. Consequently, some parents

lacked confidence in the ability of these HSCPs which impacted on future expectations and relationships with HSCPs. The implications of this are adverse outcomes (potentially) for the child and family. For example, parents could be less inclined to seek out supports for their child based on these interactions and experiences with HSCPs. Therefore, empowering families with information through existing services might decrease stress and burden on families to search for this information elsewhere. An incidental finding from this study relating to the influence that HSCPs can have on accessing respite care is how they could be inadvertently (by virtue of limited information and awareness of autism and services) adding to the 'getting on with it' culture and consequently have an important role in shifting the discourse of 'getting on with it' so that parents feel more supported to ask for help rather than suffer in silence.

Parents of autistic children in a study carried out by Russell and McCloskey (2016) articulated strategies which relate to their positive experiences with HSCPs when the following occurs: 'having them really listened to, really looked at, focussing, that people look at the positives, and that there aren't really limitations'. Therefore, understanding the factors that influence a supportive and positive HSCP parent relationship is important. In the present study, parents described attributes such as good communication and having the necessary knowledge and information as having the potential to create a positive supportive relationship with their HSCP which is consistent with previous research (Straus et al. 2019, Coussens et al. 2020). In addition, as is characteristic for autistic children, change is difficult and because of this having a consistent relationship with a HSCP or service provider was viewed by parents as being equally important. Although findings might be similar to many comparable studies, parents within this study specifically described having access to a designated and consistent HSCP, with appropriate training and knowledge of autism and services available, particularly at a time of crisis, as an indicator of a positive professional relationship.

Parents who reported good relationships with their HSCPs appeared to be able to cope better at times when their child's behaviour was challenging by navigating the challenges, reaching out for professional advice and support and implementing any interventions made by their HSCP. These findings are similar to research carried out by Templeman (2019) who found that parents of autistic children who reported higher professional partnership satisfaction sequentially

reported higher prosocial levels and fewer behaviour problems for their children (Templeman 2019). Explanations for this are evident from previous studies which show that parents become more resourceful and constraints are reduced with medical and social supports from care coordinators and multidisciplinary providers and specific care models and pathways (Pordes *et al.* 2018). Furthermore, families receiving appropriate social, psychosocial, and financial supports can more easily navigate challenges and tackle the uniqueness of their family barriers (McConnell *et al.* 2014, Pordes *et al.* 2018).

Although parents' experiences provided only a glimpse into the interaction between child, parent and HSCPs, there is strong evidence from this study to suggest that these professionals may not fully understand what parents are enduring on a daily basis when caring for their autistic child. Parental reports of challenges experienced may be at odds with professionals' perspectives of their own practice. This may be the case particularly for professionals who may not have much experience or exposure to the complex needs of autistic children. Furthermore, HSCPs may not be aware of what they do not know about autism. Although this finding was not readily evident in the literature, it appears reasonably plausible particularly in the context of the heterogeneity and the neurodiversity of autism and is supported by Boschoff *et al.* (2021) who suggests that healthcare providers may not recognise the need to increase their knowledge and skills for working with autistic children. Coupled with the prevailing culture of '*just getting on with it*' and the potential for parents not to disclose their struggles, HSCPs (particularly in the primary care setting) may not have enough exposure to the spectrum of autism and associated challenges. In order to balance the complex care needs of the autistic child, it is necessary for HSCPs to understand the parents' concerns related to the management of their child. Therefore, as an initial starting point, it is necessary to address the potential barrier that HSCPs may not be aware of what they do not know about autism.

In summary, findings associated with the role of HSCPs have enriched our understanding of how individual, interpersonal, and systemic factors influence parents' experiences of accessing respite care for their autistic child. Findings suggest that HSCPs' competence, visibility, accessibility and knowledge about autism and specific support needs and overall involvement in an autistic child's care could prevent a crisis situation and avoid unnecessary hospitalisation by

being more proactively involved in the child's care within the primary care setting. Findings in this regard are congruent with the wider literature which identifies the wider need to increase HSCPs knowledge and training in relation to autism and available services across the primary, secondary and tertiary interface.

The importance of the parent and health or social care professional relationship on their journey towards accessing respite care for their child has been highlighted. Armed with the knowledge that parents in this study may find it difficult to trust HSCPs and emergency services, the question arises as to what it means for the child and family to have multiple HSCPs involved in the care and management of autistic children. The following section discusses the need for a more integrated and interdisciplinary approach to the delivery of services for autistic children.

Requirements for integrated and accessible care pathways

Findings from this study and from the literature clearly demonstrate that families of autistic children often experience challenges navigating multiple systems to access services. In this study, parents views of accessing services, in particular respite, for their child are similar to that of Green (2018) who suggest that the current pattern of care provision for autism internationally is patchy, reactive, usually received too late, short-term focused, and commonly not evidence-based. Complex care systems, lack of knowledge and awareness of autism among HSCPs and sourcing accurate, appropriate information on the respite services and supports available as identified by parents has been repeatedly highlighted in the literature as challenges faced by parents when accessing respite care services (Finnegan *et al.* 2014, Southby 2017, Whitmore & Snethen 2018b, Gadd 2019, Cooke *et al.* 2020, Malik-Soni *et al.* 2022). Similar to findings from Brenner *et al.* (2015) parents reported confusion and lack of transparency over points of accessing care and a lack of effective systems to document and access information on care needs across acute and primary care services. Difficulties experienced by parents navigating autism services, in the present study, contributed to increased stress and feelings of isolation and being dismissed by HSCPs which also aligns with findings from (Byrne *et al.* 2018, Legg & Tickle 2019). Recent research highlights that most autistic individuals do not have access to the care required to address their diverse health needs (Malik-Soni *et al.* 2022) and overall experience barriers to effectively accessing healthcare

services (Mason *et al.* 2019). Consequently, this can often result in unmet needs for autistic children.

Research to date demonstrates the effectiveness of the interdisciplinary approach and multidisciplinary approach in the diagnosis, management and co-ordination of autistic individuals (Cascio *et al.* 2016, Gerdts *et al.* 2018). Autism specific best practice guidelines, and recommendations from Irish reports continue to highlight the requirement for services to be more integrated and work in a more collaborative manner (HSE 2009, 2012, 2018, NICE 2013, 2021, AS I AM 2021). However, findings from this study indicate that evidence-based practice and national policy recommendations in relation to implementing an integrated care approach for the care and management of autistic children in Ireland are not effectively in place and that the current system is not meeting the health, social and mental health needs of all autistic children and their families.

In Chapter 2, the requirement for an integrated approach to the delivery of autism support services, in particular respite care, was highlighted. Several frameworks and models that have been suggested as effective models and care pathways for the care and management of autistic children were also discussed in Chapter 2. Paediatric primary care is a principal point of care for autistic children and is best placed for the initial identification and ongoing monitoring of a child's particular needs. Effective implementation of an integrated model similar to that of 'Stepped-Care' which offers less intensive intervention as a first-line treatment, and more intensive care only when clinically indicated (Wainer *et al.* 2021a, Wainer *et al.* 2021b) is a potential solution to targeting timelier service linkage for autistic children and reducing the requirement to attend the acute care services. Integrated care is an umbrella term that can encompass many different care arrangements. Emerging support exists for integrated healthcare approaches for autistic children to facilitate addressing unmet specialty healthcare needs, including those for mental health (Stadnick 2019).

Parents within this study also called for a more integrated approach to service delivery for autistic children that places the needs and the needs of the family at the forefront. Parents identified a number of essential elements necessary for the effective implementation of such an approach including but not limited to:

- Collaboration between HSCPs across the primary, secondary and tertiary services.
- The need for respite care services to be responsive and adaptive to changes in an autistic child's behaviour
- The need to have access to planned and emergency respite particularly in a crisis situation
- The need to have respite services that are in a reasonable distance to the child's home
- The need for respite services to adapt a social model and encourage the development of life skills
- The need for forward planning during the transition from children's to adult services.
- The need for fair and transparent access policies.

Overall, there is a critical need for effective implementation of integrated healthcare systems for autistic children who have many service needs, including the need to access effective mental health care, given high rates of co-occurring psychiatric conditions. Paediatric primary care is an ongoing point of healthcare that is well positioned to identify mental health concerns and facilitate linkage to mental health services for autistic children.

Policing autism

Research demonstrates that autistic people of all ages experience high rates of police contact (Cheely *et al.* 2012, Ellem & Richards 2018, Tint *et al.* 2018, Salerno & Schuller 2019). The reasons for this are varied, for example, autistic individuals can display behaviours that do not conform to expected social norms such as aggression, self-injury, repetitive behaviours (i.e. hand flapping) and elopement (Gray *et al.* 2014, Matson & Cervantes 2014, Baumeister *et al.* 2016). These behaviours have the potential to be interpreted as non-compliance or threatening behaviour resulting in police intervention. However, encounters with the police can heighten stress and anxiety levels for autistic people given that they function best with knowable, well-rehearsed, and scheduled daily circumstances.

In this study, four parents had experienced the police coming to their house in a crisis situation and transferred their child to the acute care services. Some of these parents had experienced police encounters on more than one occasion.

Aggressive and self-injurious behaviours were the primary concern necessitating police involvement for their child. Notably, autistic children who had experienced these encounters were more likely to be older and have a history of aggression.

A small number of studies have explored the experiences of parents and caregivers when their family member with autism had contact with the police (Crane *et al.* 2016, Tint *et al.* 2017, Wallace *et al.* 2020). These studies report mixed results, ranging from parents being satisfied with police interactions (Tint *et al.* 2017), to being dissatisfied (Crane *et al.* 2016). One of the main reasons for discrepant reports of satisfaction with police encounters reported in the literature and supported by findings within this study relates to a lack of training or general awareness of autism (Crane *et al.* 2016). A further concern highlighted by parents related to the inappropriate management of their child and a lack of awareness of autism could result in the misinterpretation of behaviours which could aggravate or escalate a crisis situation. The potential for misinterpretation of behaviour has been highlighted in previous studies, not only from the perspective of autistic people but also from police officers themselves (Mogavero *et al.* 2019; Railey *et al.* 2020). Recent research carried out by Wallace *et al.* (2020) using data from a survey of parents, guardians, caregivers and professionals in the USA, found that 60% of respondents were fearful of future police contact. Specifically, participants were fearful of the potential for police officers to misunderstand behaviours and means of communication common amongst autistic individuals. Participants also reported being fearful of emerging aggressive behaviours from autistic individuals and the potential for police misuse of force (Wallace *et al.* 2020). A UK-based survey found 74% of parents of autistic children were dissatisfied with police interactions, citing perceived discrimination, a lack of information provided by police, and inappropriate physical accommodations (Crane *et al.* 2016). Some parents within this study felt that calling the police was, to a certain extent, criminalising autism. The potential for misinterpretation of behaviour has been highlighted in previous studies, not only from the perspective of autistic people but also from police officers themselves (Mogavero *et al.* 2019; Railey *et al.* 2020).

Police officers have a multitude of roles in the community, however, role-specific autism training is often lacking (Crane *et al.* 2016). A recent qualitative study by Railey *et al.* (2020) suggests that police officers desire training that encapsulates knowledge about autism, empathy training, best practices for encounters with

autistic individuals and the autism community in general. These findings are consistent with Gibbs and Haas (2020) in which participants suggested that police need a better understanding of autism and that police use appropriate interventions in their interactions with autistic people.

The evidence presented in this section suggests that the practice of calling the police for an autistic child in a crisis situation is not supported by some parents, can potentially aggravate the situation further, can result in undesired outcomes and has been described by some parents as criminalising autism. Parents equally questioned the overall value of calling the police in a crisis situation and reported being very dissatisfied with this approach with some parents reporting being told by the police that they cannot do anything despite HSCPs repeatedly advising parents to contact the police in a crisis situation. These findings highlight a discrepancy in understanding the role of the police in crisis interventions for autistic individuals. In addition, the evidence from parents within this study suggests that there is ambiguity from health and social care providers across all sectors, parents and the police as to what the expectations are when the police are contacted to intervene in a crisis situation. Notably, Irish best practice guidelines and policy documents reviewed as part of this study did not find recommendations or guidelines that supports this intervention. Therefore, based on these findings it would be considered timely to review the practice of calling the police to intervene in a crisis situation for autistic individuals and evaluate the suitability, effectiveness and outcomes of such an intervention and whether the practice is in line with international standards or best practice guidelines for autism. It has also highlighted the need to ensure that those tasked with the responsibility of responding to a crisis situation for autistic people have the ability, resources and necessary training and knowledge to effectively assist and manage the situation.

In summary parents in this study expressed a reluctance to contact the police in a crisis situation due to issues surrounding misunderstanding, communication, and inappropriate management on the part of the police or their child during police contact which have been similar to other findings in the literature. The implications of not having a suitable intervention in a crisis situation are serious as it can result in parents placing their child and families life at risk. Consequently, parents are bypassing this option and going straight to the acute care services. Overall, there exists very little evidence within the literature relating

to parents experiences of these encounters. Findings from this study, albeit from a relatively small number of parents and autistic children, who had actually experienced these yielded important insights into this practice and the impact of such an intervention; an aspect arising from this study that warrants further investigation.

7.2.4 Accessing acute care services: a last resort

Defining Moment

ED presentations by autistic individuals is increasing (Vohra *et al.* 2016). Autistic children are reportedly nine times more likely to visit an ED for psychiatric problems and can have longer hospital stays compared to children who don't have autism (Siegel & Gabriels 2014). Evidence presented in Chapter 2 and 3 and from this study highlight that autistic children of all ages interact with emergency services, such as EDs and police at higher rates than typically developing peers for medical and psychiatric reasons (Iannuzzi *et al.* 2015, Schlenz *et al.* 2015, Deavenport-Saman *et al.* 2016, Vohra *et al.* 2016, Liu *et al.* 2017, Rava *et al.* 2017). Physical aggression, disruptive behaviour, running away and hurting oneself are the main reasons for such visits (Siegel & Gabriels 2014). Similarly, predictors of ED presentations in the current study related to significant incidents or 'defining moments' that were characterised by self-injurious behaviour and physical aggression causing harm to another person or family distress. Studies carried out by Iannuzzi *et al.* (2015) and Liu *et al.* (2017) reported a greater likelihood of ED visits in older autistic individuals, however this finding is not consistent with Schlenz *et al.* (2015) who found that psychiatric care was more likely for youth with autism in both the preadolescent and adolescent cohorts which would be comparable with findings from this research study.

Eleven parents in this study described a crisis situation as the defining moment which resulted in the parent accessing respite care for their child through the acute care services. The majority of these situations coincided with a time when the parent or family were experiencing significant distress. For example, three of these parents had previously presented to the acute care services but suitable respite arrangements had not been put in place after discharge and their child's challenging behaviours continued or worsened resulting in them representing to the acute care services. On their second presentation to the ED, these parents refused to take their child home until suitable respite arrangements were put in

place. These findings are similar to that of Lunskey *et al.* (2017) who investigated predictors of ED use by autistic adolescents and adults and found that ED visits for any reason among autistic individuals were reported to have greater family distress at baseline and a history of visiting the ED during the previous year. Considering the link between previous and future ED visits, findings from this study support the need for effective care plans to be in place following the first presentation of an autistic child to help deal with future crises (Venkat *et al.* 2016).

Overall, increased knowledge amongst HSCPs and emergency services about the crisis situations parents of autistic children experience and an awareness of how negative life events (such as the sudden loss of a family member) can impact the child, may alleviate some need for attending acute care services. When parents indicate that they are approaching crisis, this can also signal future emergencies, and primary care providers and HSCPS should be in a position to proactively help such families. This is the premise of which the stepped care model operates as discussed in Chapter 2.

Findings relating to higher rates of ED visits among autistic children demonstrates that many autistic children do not have access to or are not in receipt of sufficient and adequate primary health care resources such as respite care and outpatient mental health care to prevent and manage the type of crisis that is resulting in parents accessing acute care services in desperate need of help. Approximately 70% of autistic young people experience mental health issues (Lever & Geurts 2016). Timely access to adequate primary mental health care resources is essential considering that mental health challenges can significantly impact children's daily life, and cause debilitating distress for children with neurodevelopmental conditions, of which autism is one (Baraskewich & McMorris 2019). Community-based services that provide relief to families, such as respite care, can help reduce stress on families and, in turn, reduce emergency service use among autistic individuals (Mandell *et al.* 2012).

Dehumanising Process

In this study, parents described how presenting to the ED can be extremely stressful as parents recalled seeing their child distressed, sedated and restrained. Research suggests that autistic individuals are restrained or sedated

in approximately one in four ED visits (Lunskey *et al.* 2015). Parents in this study were aware of the potential of the hospital environment to further exacerbate their child's behaviour and were often reluctant to use this pathway noting that the high-intensity environment of the ED can be extremely challenging for autistic children who may present with sensory, social communication and behavioural difficulties (Nicholas *et al.* 2016). Despite the majority of parents reporting negative experiences while attending the acute care services such as inadequate care processes, communication issues, insufficient staff knowledge about autism, inappropriate placement of their child and unsuitable environments for autistic children, parents reported that they would most likely choose this pathway again. While it is apparent that parents have exhausted all other options prior to this which is the obvious explanation, findings in relation to the theme corporeality (section 6.3.1) provide another level of understanding as to why parents choose this dehumanising avenue. It could be seen that the dehumanising process is more manageable and productive than a state of non-existence that can come with caring for an autistic child.

An unanticipated finding from this study related to the inappropriate placement of autistic children in adult acute care services and adult psychiatric services. In this study, three parents reported that their child was inappropriately placed in adult services in the absence of appropriate and available children services. In Ireland, Section 25 of the Mental Health Act, 2001, as amended, allows for the involuntary admission of children and sets out that the HSE may make an application to the District Court for an order authorising the detention and treatment of a child, who is suffering from a mental disorder and requires treatment which they are unlikely to receive unless this order is made (Mental Health Commission 2003). However, some of these children are often placed in adult psychiatric services due to insufficient bed capacity in the child and adolescent mental health services. In 2020, The Mental Health Commission reported that 27 teenagers between the ages of 15 and 17, were admitted to nine adult mental health units (Mental Health Commission Annual Report 2020). Notably, this number was down from 54 children in 2019, and 84 in 2018, however, these figures continue to demonstrate the lack of appropriate mental health services for children in Ireland. In the absence of such services, parents in this study were left with no other option but to attend the acute care services as a point of access when seeking respite care for their autistic child particularly in a crisis situation.

Using the findings of this study, the systematic review and the wider literature, this section discussed possible explanations as to why parents of autistic children continue to access acute care services for respite care despite parents reporting that it is their least desired pathway. Time spent navigating complex and fragmented health and social care systems, lack of awareness amongst HSCPs and emergency services, and defining moments such as a family crisis or their child's increased challenging behaviours emerged as strong predictors of ED utilisation. Findings also highlighted that the decision to access acute care services for their child was not an easy decision to make as it brought about other challenges and difficult feelings. These findings have important implications in terms of identifying and better understanding predictors of ED utilisation among autistic children. These insights and findings can better assist in the identification and provision of appropriate primary care interventions for autistic children that reduces the necessity to present to the acute care services.

7.2.5 Accessing respite care: An ongoing process across the lifespan

A never-ending process

Caring for an autistic child can bring many challenges for parents, which persist across the life course, and which can change over time (Ooi *et al.* 2016). In this study, parents repeatedly highlighted the adversarial nature of the system and the need to '*constantly fight*' for appropriate respite care which caused increased stress and anxiety and was described as 'never-ending'. The '*fight*' to access services has also been highlighted in similar studies investigating parents' experiences of accessing services for their child with special needs (Chadwick *et al.* 2013, Galpin *et al.* 2017, Brown *et al.* 2019). Galpin *et al.* (2017) reported similar results for parents of autistic children with many describing how they felt it was the people who shouted the loudest who got access to respite care which was also reported by some parents in this study. Similar to parents' descriptions of accessing respite care as 'jumping through hoops' in a study carried out by Doig *et al.* (2009), parents in this study described it as a '*never-ending process*'.

With the exceptions of parents who had their child in full time residential care, additional respite care was desired by all parents. Although most parents appeared to access some form of respite care, all parents had experienced

changes in their type, frequency and access to respite care. All these issues have been repeatedly highlighted throughout the literature (Chadwick *et al.* 2013, Whitmore & Snethen 2018b, Gadd 2019). The majority of parents expressed some level of dissatisfaction in relation to some aspects of respite services their children had experienced. For a small number of parents, this resulted in them removing their child from the service and having to seek other options. Equally some parents had refused an identified respite service for their child as they felt the service could not adequately meet their child's needs. Parents called for more appropriate settings for respite care-one that moves away from the medical model to a more social model that promotes the independence and self-determination of their child and meets their individual needs. Evidence suggests that parents can be hesitant to use respite care for various reasons such as 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 (Chapman 2013). Similar to findings in this study, research has found that parents are unwilling to leave their child in respite care if they are not assured that the child will be safe, receive their needed care and monitoring (Virdun *et al.* 2015) and have a good experience, attributes that are critical for respite care to be effective.

Respite care-a time sensitive, fragile, precious commodity

In this study, parents' journey to accessing appropriate respite care for their child did not stop after they received respite care for their child. Many parents reported the difficulties they encountered trying to maintain respite care for their child. Parents reported that they had very little say in the type, duration, location and frequency of respite. Parents felt that they just had to accept what was offered as they acknowledged how difficult it was to access respite and parents were equally aware of the demand for respite care. This, in turn, made them and their child more vulnerable as they were sometimes forced to accept respite care even if they felt that it did not meet their child's particular needs.

Inadequate and lack of coordinated transitions between child and adult services was a considerable concern for parents which emerged as another key finding. Healthcare transition is a delicate time when autistic children outgrow the services of paediatric programs and enter a fragmented healthcare system that is unfamiliar, insufficiently knowledgeable, and underfunded for their needs (Enner *et al.* 2020). Disruptions of healthcare during the transition from paediatric to

adult healthcare may put autistic children at higher risk of medical emergencies (Ames et al. 2021) and can result in poor consequences in social support, education, vocational training and employment, housing, and healthcare (Enner et al. 2020).

At the time the interviews were taking place five parents described challenges they had or were currently experiencing in relation to the transition process. Despite recommendations, poorly coordinated transitions between child and adult services are repeatedly highlighted in the literature and in national and international reports (Brown et al. 2019, Gadd 2019, Ryan et al. 2020). Overall, the experience of transition continues to be negative for people with complex disabilities and their families (Ryan et al. 2020). Research calls for transitions between child and adult autism services to be easier to navigate (Gadd 2019). A review of international evidence revealed that parents are often forced to drive the fragmented and poorly managed transition process (Brown et al. 2019). These findings reflect parents' experiences in the present study in which they described how they were often left having to look for respite for their child as an adult and called for a more seamless transition and continuation from children to adult respite services. These findings show that, for parents to benefit as much as possible from respite services, they need to be designed to meet their child's initial individual needs (Nankervis et al., 2011) as well as being flexible and adaptive to the changing needs of autistic children across the lifespan.

A large body of research informs the criteria set out to support children with various complex needs in transitioning from children to adult services (Quin et al. 2005, Westbrook et al. 2014, Campbell et al. 2016, Kerr et al. 2020, Ryan et al. 2020). In addition autism specific best practice guidelines highlight requirements necessary to support the transition phase (NICE 2016, 2017). These studies and clinical guidelines highlight the importance of early person-centred transition planning, multidisciplinary collaboration and coordination, access to information, support for families and carers, dedicated transition at a single point of contact and continued focus on transition. However, a study from the Centre for Disease Control and Prevention (CDC) found that few adolescents receive the recommended guidance for transitioning from paediatric to adult health care (Powell et al. 2021). The study concluded that greater coordination among healthcare programs and offering interdisciplinary training could expand access to services and increase provider comfort in treating the unique healthcare needs

of autistic adolescents and support healthcare planning as they transition from paediatric to adult health care. Overall, the steady rise in the number of children diagnosed with autism in the last decade necessitates the need for further research on examining transition of care considerations specific to the autism population. Improved understanding and guidance addressing these needs will enable service providers to optimise medical, social and mental health outcomes for autistic children.

Uncertainty about the future

The fragility of respite care as depicted by parents within this study coupled with a lack of transitioning planning and lack of choice regarding their child's respite care service meant that many parents were left feeling uncertain about their child's future. Recent research has also highlighted parental concern for the future of their autistic child such as self-sufficiency, transitioning to adulthood and education and training (Minhas *et al.* 2015a, Ooi *et al.* 2016, Gobrial 2018, Fallahi-Khoshknab *et al.* 2020). In order to alleviate these concerns, research suggests designing and implementing effective interventions across a multitude of areas such as education, rehabilitation and welfare in order to promote their self-sufficiency and respond to the specific needs of autistic children (Fallahi-Khoshknab *et al.* 2020).

7.2.1.5 Acquired Knowledge and Information: Requirements for effective respite care provision

The themes which emerged from parents' experiences of accessing respite care are broadly consistent with findings from previous studies. While a variety of respite care services and programs were discussed by parents in this study, no consistent strategy for addressing the respite care needs of autistic children was found in the literature. It remains unclear what is the most effective type of respite care to meet the needs of the autistic child. This is consistent with the idea that there is no 'one size fits all' approach and respite care services need to be flexible and responsive to the particular needs of autistic children and their families. However, parents were consistently clear about the requirements for effective care pathways to accessing support services such as respite care for their child and outlined a number of recommendations for improvement which have been included in Chapter 8.

7.3 How the current study's findings inform and advance knowledge from the studies included in the systematic review.

The systematic review (Chapter 3) identified seven studies that explored parents' experiences of accessing respite care for their autistic child at the acute and primary care interface. In general, there are several similarities across both pieces of research with the most prominent finding being an immense need for but an inability to access appropriate respite care services for autistic children. The first similarity that can be drawn relates to the participant profiles from each study. For example, the majority of autistic children were male and mothers accounted for the majority of parents who volunteered for interview. This is consistent with demographic data from similar studies reporting that autism is 4.2 times as prevalent among boys as among girls (Maenner *et al.* 2021) and that mothers are more often the primary caregiver and main supporter for autistic children (Hoefman *et al.* 2014, Nicholas *et al.* 2015, Chen *et al.* 2022).

The role of HSCPs in accessing respite care services was a prominent finding across both the review and present study, thus reinforcing the requirement for HSCPs to be more supportive and have a better awareness of autism as well as being able to provide information to parents in relation to support services for autistic children. Both pieces of research noted that the need for respite care often increased as the child got older or entered adolescence and coincided with increased physical size and challenging behaviours. Another common finding to both was that parents' perceived that respite was beneficial for themselves, their child and other siblings in the family, however, parents expressed dissatisfaction with aspects of respite service provision. This primarily related to the type and frequency of respite care. Finally, barriers to accessing respite care was a prominent outcome of both the review and study.

While both pieces of research share a number of similarities, the current study offers a more in-depth insight into the lived experiences of parents accessing respite care for their child through the acute care services. Furthermore, this study offers further explanations as to why parents are choosing this route. Additional motivating factors for attending the acute care services not identified in the systematic review have been highlighted, for example, the occurrence of a

significant life event characterised as ‘defining moments’. In this study, a small number of parents had experienced significant life events such as the death of a close family member or a change or deterioration in their physical and mental health which necessitated them seeking emergency respite care for their autistic child. Interestingly, some of these parents had never sought respite care up until this point as they reported that they had heretofore managed by themselves. This highlights the need for respite care services to be responsive to family situations and be in a position to provide emergency respite care in order to provide temporary relief to parents when faced with unpredictable situations. Another significant finding of this study is that three parents had represented a second time to the acute care services with the same issues and challenging behaviours with their child as the first presentation. These findings support the requirement for further research of service utilisation before and after ED visits for autistic children in order to develop a more effective intervention for children and parents in need of access to planned and emergency support services such as respite care.

A subtle difference found between the parents of the studies included in the systematic review and those of this study, was that although the needs of parents were often put aside, parents of this study did realise the importance of addressing their own needs as significant to being able to care for their child and their wider family. Although parents were self-sacrificing and tolerated a lot of physical aggression, they equally recognised that they had to address their own needs and saw respite care as a means of doing this. Some parents had sought professional help to help them deal with the stresses, pressure and burden of caring for an autistic child. However the *‘getting on with it’* culture still prevailed across parents’ narratives.

Considering the additional findings from the present study and the current autism landscape, it would be reasonable to suggest that this study’s findings could impact the collated systematic review evidence in a number of ways. For example, it is necessary to consider what has occurred in the autism community since the initial systematic review search was carried out in 2020. Key considerations that have the potential to impact on the findings from the systematic review include but are not limited to;

- an increased awareness of autism in society

- the explosion of autism research across all areas with a greater emphasis on the necessity to involve autistic individuals in autism specific research
- the occurrence of a global pandemic and how this has exposed and exacerbated the challenges that many autistic individuals face
- the development of autism specific strategies and action plans within many countries
- expansion and development of autism best practice guidelines that focus on the care and management of autism across the lifespan and not just assessment and diagnosis.

The Covid-19 pandemic has undoubtedly influenced the availability and accessibility of respite care services for autistic children. Characteristics of autism place autistic children at greater risk for being negatively impacted by the pandemic as they can experience difficulties with social communication and they often cope better with structured daily routines and predictable environments (Hyman *et al.* 2020) The need to incorporate this into the present study was recognised as parents' narratives from the first three interviews was heavily dominated by COVID-19 and the impact this was having on the child and family. Subsequently, a question relating to how the COVID-19 pandemic was impacting the family was added to the interview guide (Appendix 9) following the third interview. To ensure the impact was captured, a qualitative thematic analysis of data specifically relating to this question was completed (Appendix 16). Data analysis identified four themes that reflect an adverse pandemic impact. These were: World gone; Alone and isolated; Constantly fighting and Negative and positive impact of COVID-19 on child and family. Few parents reported positive outcomes of the pandemic such as social distance requirements. Five parents (42%) reported an increase in the amount of respite care received. Three parents (25%) reported a decrease and four (33%) parents reported no change in their access to respite care.

Notably, the COVID-19 pandemic exposed and further exacerbated the challenges discussed in the systematic review that parents face when accessing respite care services for their autistic child. It could be argued that more children may have presented to the acute care services during this period as access to support services were not available. Equally, the opposite could be suggested as findings from the data analysis of the impact of COVID-19 demonstrated that parents of autistic children were further isolated and marginalised from society.

Consequently, the full impact may not be known at present. Therefore, it could easily be suggested that findings from the thematic analysis of the impact of COVID-19 along with findings from the current study could influence the overall findings of the systematic review (e.g., in an update) for various reasons.

Overall, while similarities exist between the systematic review and the current study's findings, acknowledging the post COVID-19 transitional phase that is occurring worldwide and the likely impact this is having on the autism community in terms of mental health and access to support services more time is needed to evaluate this. At the same time, Ireland is developing an autism strategy and action plan which is due to set out priorities to improve the overall quality of life for autistic individuals. This is a significant step for the autism community in Ireland. Furthermore, the future direction of healthcare as articulated in the *Slaintecare Report* (2017) is aimed at developing a more integrated approach to services. Finally, there is a shift in research studies carried out in the autism community with a focus on participatory research with direct involvement of autistic individuals. Therefore, it could be suggested that the autism community is going through a significant transitional phase in which the outcomes of the above developments have yet to be determined or evaluated.

Both the systematic review and the current study highlights the suitability of qualitative research for obtaining the views of parents of autistic children when accessing respite care services. Further research is recommended in this area, particularly in determining how services may improve and what the views of children, where possible, using the respite services and their parents are regarding respite.

7.4 Reflexivity

The reflective process should begin from the start of the research process, this is particularly important in phenomenology to ensure that the phenomenon of interest is approached with openness. Through reflexivity, researchers acknowledge the changes brought about in themselves as a result of the research process and how these changes have affected the research process (Palaganas *et al.* 2017). Reflexivity is considered a way of questioning our attitudes, thoughts, reactions and positionality to strive to understand our roles

about others and can be both a concept and a process (Palaganas *et al.* 2017). The concept of reflexivity indicates a thoughtful, self-awareness of the ways in which personal assumptions, positions, values and social background impact on the dynamics of the research process (Kelly *et al.* 2017b). It is about the recognition that researchers are part of the social world that we study and recognizing, examining, and understanding how their social background, location and assumptions affect their research practice (Holmes 2020). Reflexivity was enhanced through keeping a reflexive journal (Appendix 10) to identify potential bias and raise awareness of influences on the interpretation of data and to reflect on the entire research process. This was maintained throughout the research journey.

Considering the nature of this inquiry, without self-disclosure there is a substantial risk of producing research that could be dominated by personal prejudice and bias, therefore, it is important to assess the degree of reflexivity and determine what potential bias I could introduce to the findings. In keeping with the hermeneutic method, rather than bracketing, my *priori* understanding was acknowledged as part of the methodological processes (Appendix 10). I have worked as a children's nurse in an acute children's paediatric hospital for ten years and have been actively involved in the care and management of autistic children. In addition, I have a young family member living with autism. Therefore, I feel having this professional and personal experience enabled me to establish a rapport with parents during the recruitment and data collection stages of this study. This was also an advantage in relation to understanding the language and terms used by parents caring for their autistic child as specific language or terminology can easily be misunderstood by someone. However, I aimed not to allow my previous experiences and values influence parents in any way and to remain neutral when collecting and analysing data.

During data collection, I noted my own reflections about my questioning techniques, verbal and non-verbal responses, as well as my personal thoughts, feelings and ideas regarding the participants' stories and words. While these observations were not data in the formal sense, they were of extreme value in the process of interpretation and analysis of participants' data. These notes were invaluable as a reminder of my earlier thought processes and initial impressions of concepts. By continuously reflecting on the interpretations of my personal experiences and the phenomena being studied and through immersing myself in the participants' narratives, I was able to move on from the partiality of any

previous understandings. Through questioning and challenging the emerging interpretations, I was able to reflect on the assumptions that have been made in the course of the research. I was mindful of not imposing any personal assumptions or vocalising any leading statements during the interviews, although there was a time during the first interview when I was tempted to interrupt and offer advice and experience but recognised the need to refrain from doing so.

The data collection method also contributed to the validity of the study design as participants were helped to understand the question and could be asked for clarification and were encouraged to communicate their underlying attitudes, beliefs and values that are so central to this method. On reflection, the use of semi-structured interviews was beneficial as it provided me with the opportunity to change the words but not the meaning of the question because it acknowledges that not every word has the same meaning to every participant and that participants can use varied vocabulary (Mainz 2017). For example, respite care can have numerous definitions depending on each individual's understanding of what constitutes respite care. Furthermore, the use of open-ended questions enabled me to further probe parents and facilitated revealing aspects of the questions that were relevant to the parents. Hearing some of the difficult and upsetting challenges that parents encountered I did reflect on my reactions to these after the first few interviews, particularly in response to exhibiting shock in relation to some of the difficult situations parents had faced. Conscious that these reactions may be reflective of a novice researcher I did recognise the need to not influence parents' narratives by my reactions while also relating to their difficulties on a human level. Following this, I managed my emotions by acknowledging the difficult situation that parents faced and used scenarios to probe more about how this made them feel and asked them how they felt, reacted or responded. At times, I found it challenging to bring the parents back to the moment of accessing respite care through the acute care services so I could explore their experience of this because parents were very enthusiastic to talk about their journey of accessing respite care in general, however, there was considerable discussion about their journey in general which I felt contributed to the context of the interview.

The change in research setting for data collection proved beneficial to the study as not only was it more convenient, efficient, cost-effectiveness and flexible, it enabled recruitment from a wider geographical location. Furthermore, Van Manen (2016) argues that it is necessary for participants to feel comfortable in

the research environment due to the highly personal nature of the interview. It became apparent that participants were comfortable with this research setting of their own home as demonstrated by some participants willingness to show me family photos and their child's bedroom with the relevant facilities and equipment to meet their particular needs.

On further reflection, the many challenges faced when completing this study has no doubt developed and strengthened personal skills particularly in relation to resilience and endurance. There were many setbacks along the way that impacted on an enormous amount of work that was completed. For example, obtaining ethical approval from the three paediatric hospitals which then could no longer be used due to COVID-19 and the inability to access people in person. Not alone did this require a new application process but data protection regulations had since been introduced which required me to attend training and learn about the implications of these new regulations for carrying out research before I could even begin to apply for ethics again. This set me back by approximately one year by the time all the relevant training, application, supporting documents, processes and controls were effectively in place.

As a healthcare professional myself, I naively had thoughts based on my clinical experiences as to what effective respite care for autistic children may look like and how such a model could be provided. However, having completed this study and engaging with the participants through the chosen methodology, I have learned that it is far more complex and that a one size approach would not be effective given the diverse range of needs of autistic children expressed by parents within this study. This has been huge learning for me and required me to reflect on what type of model or what essential elements or principles are required. Equally, I have learned the value of engaging those who have direct experience of the system and the phenomenon under investigation as well as associated stakeholders as it contributes to more meaningful findings.

7.5 Limitations and strengths of the study

At the time of completing this research and to the best of my knowledge, this is the first study to explore parents' experiences of accessing respite care for their autistic child through the acute care services in Ireland. The study provides a distinctive insight into the lived experience of Irish parents who have accessed

respite care for their autistic child through the acute care services while giving a detailed account of the day-to-day lives of these parents and their families.

The use of Van Manen's existential themes, which enabled the depth of parents' experiences to be uncovered, was an added strength in this study. It allowed me to explore the lived experiences of parents and the meanings they have attributed to these experiences, offering an insight in their 'life world'. The application of Van Manen's data analysis framework and use of the existential themes facilitated me to discover the phenomenological themes that make up the experiential structure of the lived phenomenon. Van Manen's framework also supported flexibility in the study's approach to exploring the research question, and to identify novel areas for future research and recommendations in relation to accessing respite services for children with autism.

Another related strength is that I was not known to any of the parents prior to the research and was not affiliated with the services providing respite care for their autistic child. Therefore, it could be considered that this enabled 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 accessing respite care for their child.

There are, however, several potential limitations to the current study. The reported findings are based on a small sample of parents who agreed to participate in the research and be interviewed. Therefore, these findings cannot be considered generalisable or representative of all parents' experiences of accessing respite services for their autistic child as the findings represent the perspectives of these parents only. However, noting that the findings of the current study were largely consistent with findings of other studies it would be reasonable to assume a degree of transferability for other parents of autistic children in similar situation. Furthermore it is important to note that interviewing participants can generate different interpretations due to varying degrees of ease that the participants have with the researcher, the sense of rapport, each person's mood, the time of day and the setting (Van Manen 1997).

To date, there has been relatively little research carried out exploring the experiences of parents of autistic children who have accessed respite care through the acute care services and associated outcomes. Therefore, in the

absence of such literature, I have drawn on similar literature that explored the experiences of parents of children with other complex care needs and palliative care needs as well as experiences of adults with autism accessing respite care services. This limited the ability, albeit minimally, to enable a comprehensive discussion of the study's findings in the context of explicitly similar wider literature.

It is recognised that the completion of a literature review and systematic review in advance of data collection may be viewed as a limitation of this study.

Undertaking literature reviews and systematic reviews in phenomenology prior to commencing a study has been the subject of much debate (Fry *et al.* 2017).

Questions raised are mainly attributed to; when the review should be undertaken and how extensive the review should be. This critique has further been compounded by the lack of definition and interchangeable use of various terms for reviews (Schofield *et al.* 2021). The current proliferation of review types has resulted in many corresponding terms used to describe them (Munn *et al.* 2018), for example, systematic, rapid, conceptual, scoping, meta-analysis, systematised, umbrella and overview.

Another key argument central to this debate relates to the possibility of researchers being influenced by existing literature which can create bias or can limit the research focus and range. It has on occasion been proposed, mainly with regard to phenomenological and grounded theory research approaches, that a literature review should be avoided as previous knowledge may contaminate the data (Dunne 2011, Ramalho *et al.* 2015). Similarly it has been argued that systematic reviews can be misleading if the data is inappropriately handled (Quereshi *et al.* 2022) and can become out of date or misleading if they are not kept up to date (Stokes *et al.* 2022).

Conversely, it has been suggested that a literature review constitutes a necessary step within the research process recognising that its purpose is to inform the researcher of the existing literature available (Paré *et al.* 2015) on the relevant research topic and identify gaps in knowledge to substantiate the rationale for the research. Furthermore, it also provides the researcher with information regarding the methods used in previous studies that might influence a certain methodology (Paré & Kitsiou 2017). Some researchers advise against avoiding a literature review recognising that most researchers begin an inquiry at

a new, starting line, deliberately ignoring previously conducted research (Giles *et al.* 2013).

Following an analysis of the debate concerning whether a literature review should be undertaken, I concluded that a review of the literature was necessary to enhance knowledge and gain a broader insight of the research topic and that avoiding “contamination” was to a certain extent impossible. Therefore, a literature review was completed at the outset to give a general overview of the research topic and specific areas within the research question. For example, respite care and autism. Having completed the literature review, it was evident that there was paucity of literature on the specific research question, yet there was a plethora of evidence on the individual aspects of the research question, for example, there was a significant volume of research available on respite care or on autism as standalone topics but not collectively and in the context of accessing respite care through the acute care services. To provide some degree of assurance that there was minimal research carried out on the specific research question, it was decided that a systematic review would be most beneficial to assist with determining if very little research was available, thus substantiating the rationale for the research. Furthermore, I recognised that there was a risk of getting distracted by the abundance of literature available on standalone topics within the research question and therefore carrying out a systematic review with a focused question would help to reduce the risk of getting lost in the literature. On reflection, the systematic review, although limited in studies, substantiated the rationale for the study and helped focus the research study more by ensuring the aims and objectives of the study were met. Furthermore findings from the systematic review were beneficial to informing the study methodology.

Acknowledging the argument that systematic reviews can become out of date or misleading if they are not kept up to date, it was considered updating the systematic review following completion of data analysis. However noting the transitional phase that the autism landscape was experiencing at the time data analysis was completed (section 7.4), it was recognised that updating the systematic review at this time was potentially premature and that the passing of more time would support a better evaluation.

Overall, with regard to the lack of consensus in relation to qualitative research as to whether or not to undertake a literature review, undertaking a literature review and systematic review was beneficial to this study. As a result of the lack of

existing research focusing specifically on this area, the literature review broadened my knowledge on the various topics within the research question whereas the systematic review kept me focused on the research question and assisted me to not get distracted by the abundance of literature available on the standalone topics within the research question.

Hermeneutics phenomenology recognises that the researcher should openly acknowledge their preconceptions and recognise how these can influence the analysis process in order to avoid intentional bias (Neubauer *et al.* 2019). These preconceptions are not limited to previous experiences but also includes knowledge and perspective gained from reviews of literature carried out in advance of data collection. In order to avoid potential bias that was influenced by the literature review, systematic review and previous experiences, I applied multiple strategies to avoid possibly contaminating the data. These included acknowledging and writing down my preconceptions and maintaining a reflective journal throughout the entire study. This has been discussed in detail in section 7.4.

A further strategy employed to avoid bias included critical discussion of findings with my supervisory team at various stages of the study. For example, on completion of the literature review, systematic review, data collection and data analysis. Findings from these relevant stages were also discussed at peer support days within my college where research findings are discussed with student peers and academic staff. This enabled me to discuss the findings while being challenged in a constructive way and overall added to the validity of findings.

The systematic review (Chapter 3) identified seven studies that explored parents' experiences of accessing respite care for their autistic child at the acute and primary care interface. While Braun and Clarke's (2006, 2013, 2022) stages of data analysis were used for data analysis within the systematic review, I felt a different analytical approach was required for analysis of the interviews within this study in order to capture the essence of parents' experiences and to avoid any bias of the data from the literature review and systematic review. Therefore, I chose to integrate Braun and Clarke's (2006, 2013, 2022) stages of data analysis with Van Manen's six research activities. Applying Braun and Clarke's (2006, 2013, 2022), approach, helped me identify themes and subthemes from the studies within the systematic review associated with parents' experiences of

accessing respite care through the acute care services for their autistic child. However, I recognised that a more interpretive approach was required for the purpose of analysing interviews from this study to enable me to really understand the essential meaning of parents' experiences as an existential phenomenon since it could have potentially become lost under the fragmented themes and subthemes. Therefore, I carried out a second phase of analysis using the method proposed by Van Manen (1997, 2014) by more explicitly focusing on the 'five lifeworld existentials' to advance my interpretation more. This enabled me to speculate about the interrelations between the themes, see more clearly the interactions between body and mind, person and world and explicate their lived experiences using a more holistic and interpretive approach.

The use of a two phased analytical approach in this study enabled a deeper analysis from participants' interviews. This supported the generation of new insights into participants experiences that had not been identified in the literature review or the systematic review. For example, additional motivating factors for presenting to acute care services, the need to review the effectiveness of calling police in a crisis situation and the impact the 'getting on with it' culture was having on parents' mental health. These are discussed in greater detail in Chapter 7. New insights into participants' experiences compared with findings from the systematic review are discussed in section 7.3.

A final limitation for consideration makes note of the study's inclusion and exclusion criteria. It is possible that the experiences and needs of parents who were not considered eligible to take part or who chose not to take part, differ from the findings presented in this study. For example, four parents expressed interest in taking part in the study but had not specifically accessed respite care through the acute care services or their child was now in their mid-twenties. Therefore, it is possible that these parents may have different experiences of services. It is equally recognised that 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 speak about their experience and outline their concerns. Finally, considering that interviews took place during the COVID-19 pandemic, it is possible that some parents, who may otherwise have taken part, may have decided not to participate to avoid adding to the existing demands associated with their parenting demands.

7.6 Chapter summary

In this chapter findings from the research have been discussed in relation to the existing literature on parents' experience of accessing respite care through the acute care services for their autistic child. Findings were also discussed in the context of how the findings from the systematic review (Chapter 3) have translated to the overall study's findings.

In light of the findings of this research the following chapter draws together the evidence from this study and that of the systematic review relating to parents' experiences of accessing respite care for their autistic child through the acute care services and presents a number of implications based on the overall findings.

Chapter 8: Conclusion and study implications

8.1 Introduction

This chapter provides an overall summary of the general conclusions based on the findings of this study. Key implications of this study are also presented.

8.2 Summary of findings

This study aimed to explore parents' experience of accessing respite care through the acute care services for their autistic child. To the best of my knowledge, this is the first in-depth study to reveal the overwhelming experiences of parents accessing respite care for their autistic child in this particular way in Ireland. At the outset of this study it was outlined that not all autistic children require respite care.

However, noting the diversity of the autism spectrum and the incidence of occurring co-morbidities, some autistic children do require respite care. A comprehensive review of the literature and a systematic review identified that respite care is one of the greatest unmet needs of parents of autistic children and is considered an important support service for both the child and family. A review of the available literature identified limited research on parents' experiences of accessing respite care for their child which further substantiated the requirement for this study.

Collective findings from the literature review and systematic review identified barriers to accessing respite care for autistic children. These included the role of HSCPs in supporting parents to access support services like respite care, health and social care providers unable to meet the complex needs of autistic individuals, complex and fragmented pathways to respite care, inadequate supports around transitioning of services and geographical variances in the availability of respite care services. The literature review also identified motivating factors for acute care service utilisation amongst autistic children and identified a potential profile of an autistic child that may be more at risk of requiring respite care and subsequently presenting to the acute care services in the absence of defined pathways to respite care services.

The use of the hermeneutic phenomenological inquiry enabled a deeper understanding of what it is like to be a parent of an autistic child accessing respite care through the acute care services. By carrying out semi-structured interviews it was possible to capture their lived experiences of accessing respite care and explore their motivating factors for accessing respite care through this particular pathway. While this was the overall aim of the study, parents' narratives were dominated by the many challenges they faced while caring for their autistic child which became a prominent finding of the study vis-à-vis rich contextual data.

For parents, the impact of caring for an autistic child required them to be constantly vigilant and 'on' at all times and impacted on all aspects of family life. A prevailing culture of '*getting on with it*' created an environment in which there was a normalisation of deviance for these parents as they took on complex care tasks such as managing behaviours that challenge. Consequently, many of these parents became more isolated and marginalised from society.

Findings from this study highlight an immense need for but inability to access suitable respite care services across the lifespan of autistic children and adults. All parents spoke about how their child and family benefitted from respite care, however, the never-ending process of accessing respite care was characterised by multiple challenges and barriers. Parents reported repeatedly facing issues such as a persistent lack of or refusal of respite care, difficulties with scheduling due to respite being offered at very short notice, gaps in service provision, and insufficient levels of support and funding. Parents also described inflexible supports, delays in provision or long waiting lists, restricted or unreliable services, inequality of respite distribution and lack of emergency respite in a crisis situation. These challenges have been repeatedly highlighted throughout the literature by parents trying access respite care for their child for various reasons including autism (Virdun *et al.* 2015, Southby 2017, Whitmore & Snethen 2018b, Gadd 2019, Cooke *et al.* 2020)

Most parents specified a preference to care for their child at home. Consistent with a plethora of evidence and Irish reports on autism services, it was clear that there was no defined pathway to respite care for autistic children. Adding to parents frustration of the system was a lack of confidence in HSCPs ability to provide the necessary support and information. Consequently, parents reluctantly resorted to accessing respite care through the acute care services. During acute

care presentations and subsequent admissions, the inappropriateness of the acute environment did not deter parents from leaving their child there with a number of parents refusing to take their child home because of a lack of access to appropriate respite care.

The findings from this study propose that there is no one-size-fits-all approach to providing a model of respite care for autistic children which is plausible considering the heterogeneity of autism and associated diverse range of needs. In this study, age and profile of the child is an important consideration in the provision of respite care services as the need for respite emerged when the child got older, bigger and challenging behaviours became more difficult to manage. This was a significant finding as up until this point parents reported that they were able to cope by themselves and the child may not necessarily have been linked in with support services such as respite care. Consequently, respite at times was often being required in an emergency situation. These findings are pertinent in the context of developing effective pathways for access to respite care as well as effective models of respite care for autistic children. By understanding the trajectory of needs for autistic children, in particular respite care needs, models and pathways must plan for an increase in demand of respite for some autistic children for early adolescents through to adulthood. Such pathways should include formal assessment, evaluation and intervention at the early adolescent phase to proactively identify additional supports that may be required rather than reactively trying to find supports in response to a crisis.

In summary parents highlighted the need for clear, accessible and integrated care pathways with interdisciplinary input from HSCPs who have an awareness of autism and who are trained in specific autism interventions. Such pathways would include access to effective mental health care, given high rates of co-occurring psychiatric conditions among autistic children. Access to emergency respite care in a crisis situation was also a priority for a number of parents within this study. In addition findings from this study suggest that the quality of respite care should be equally as important as the quantity of respite care and this should be considered when improving access to respite care services for autistic children. Lastly, parents called for effective transition planning from children to adult services to ensure the needs of their child was being met across the lifespan.

8.2 Study implications

The findings of this study give rise to implications for policy, practice and service delivery, research and education and training.

8.2.1 Implications for policy

While a number of national policies for children with disabilities inclusive of autism exist, very few provide adequate information and guidance on accessing respite care services for autistic children. Specifically, key policy documents aimed at progressing disability services for children and young people in Ireland have not clearly identified respite care as a support service. Furthermore, despite a number of reports highlighting the requirement of respite for autistic children, there remains a dearth of accurate and contemporaneous data relating to the provision of respite for autistic children.

Based on the findings of this study, it is recommended that policy makers:

- Develop systems for data surveillance relating to autism in Ireland.
(Implement proposals in progress for an autism registry so that the data available can be used to estimate the projected need for services including respite care noting that the need for respite care most likely occurs at the early adolescent stage).
- Identify where and how respite care is currently provided for autistic children.
- Develop, update and implement policies to include recognition of respite care as an important support service for autistic children.
- Progress the implementation of the Autism Bill and Autism Innovation Strategy.

8.2.2 Implications for practice and service delivery

Findings from this study have highlighted that access to respite care services in Ireland for autistic children are complex with no clearly defined effective pathways. Practice implications may include, first, recognising the unique needs of each autistic child and their family. Findings from this study highlight the need to:

Establish formal and defined pathways to respite care

- There needs to be a consistent clear pathway to respite care services that is accessible through a single point of access for autistic children. This pathway should have equal access arrangements in place for planned and emergency respite 24 hours a day irrespective of geographical location.
- There is a need to provide families with a designated point of contact/individual who can provide support to the family as required from point of diagnosis up to and including transitioning into adult services.
- There is a need to introduce effective integrated care models with greater communication and interagency collaboration at the primary and tertiary care interface whereby care is predominantly provided in the community but can be increased, intensified and adapted as required.
- There is a need for improved psychological support by health care providers to mitigate family stress and isolation.
- There is a need to ensure respite services are tailored and personalised to each individual child and their family and that the child and family are central to decision making.
- Pathways to respite care should include a formal assessment of specific services that may be required and should be formally re-evaluated at certain intervals (for example, pre adolescence and prior to transitioning of services) to proactively identify additional supports that may be required and to support forward planning.
- There is a need to ensure that effective transition planning occurs a timely manner for the child.
- 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.

Provide access to up-to-date, reliable and accurate information on accessing support services (particularly in the context of access to respite for autistic children)

- There is a need to design and develop autism specific information leaflets for parents and HSCPs that reflect the delivery of autism services and clearly outline the process for accessing support services with respite services documented as such a support.

Review current systems in place for the management of emergency or crisis situations

- The practice of calling the police in an emergency or crisis situation requires urgent and formal review to evaluate its purpose, suitability, effectiveness and to determine the outcomes for autistic children and their families. practices involving calling the police in an emergency or crisis situation.
- There is a need to ensure that those tasked with the responsibility of responding to a crisis situation for autistic people have the ability, resources and necessary training and knowledge to effectively assist and manage the situation.

Promote a shift away from the '*getting on with it*' culture

- It is essential that HSCPs recognise the struggle that many parents face when caring for an autistic child. HSCPs should encourage a culture that empowers parents of autistic children to be resilient while seeking out support services
- Parents, HSCPs and autism advocacy and support groups are best placed to drive the move away from a society that tolerates the challenges that parents of autistic children face to one that looks out for the welfare of them and the wider family.
- 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.

8.2.3 Implications for research

Areas for further research have been highlighted throughout the study based on findings from the various pieces of research completed as part of this study. Key areas for further research should include more autistic children, where appropriate, and focus on:

- The effectiveness of respite care models considered suitable for autistic individuals.
- ED/ acute care service presentations for autistic children with a particular focus on interventions pre and post presentation.

- Exploring specific factors that may affect or modify the risk of hospitalisation in autistic children and improve outcomes.

8.2.4 Implications for education and training

The findings from this study highlighted the need for HSCPs to improve their awareness knowledge and competency to work with autistic children. Parents also expressed the need to be educated and trained about their child's autism.

- All professionals working with autistic children and adolescents should receive training in autism awareness and management, to include behaviour that challenges, risk assessment and communication.
- Use multiple platforms (e.g., online, workshops) to provide training to staff working in primary and community care settings. These may include General Practitioners, Public Health Nurses, Psychologists, Speech and Language Therapists, Occupational Therapists, Teachers and employers.
- Provide educational and training opportunities to parents and families about autism, approaches to challenging behaviour and self-care strategies.

8.3 Overall conclusion

This study has contributed new knowledge on parents experiencing of accessing respite care for their autistic child, as well as contributing to the overall body of evidence and literature on the topic of parental experiences in caring for an autistic child. Specifically this study has explored this in the context of acute care services, thus making a novel scientific contribution to this area.

This study adds to the existing body of literature that highlights the importance of respite care for autistic children and their families. Findings suggest that lack of or insufficient access to respite care results in a greater likelihood of acute care service utilisation among autistic children.

This study presents new insights and contributes to the profile of acute care service utilisation among autistic children and adolescents. Prominent findings from this study considers the role of HSCPs and the requirement for a more integrated and accessible care pathway when accessing respite services for

autistic children. The importance of access to coordinated, comprehensive, and patient-centred care to address the complex care needs of autistic children and prevent acute care service utilisation has been addressed.

To conclude, findings from this study can be used to reduce the need for autistic children presenting to the acute care services for respite care. Policy interventions aimed at increasing availability and access to respite care for autistic children and adolescents is needed to reduce presentations to the acute care services as a point of accessing respite care.

The focus should be on designing integrated primary and tertiary care services across a spectrum of interventions and across the lifespan to meet the complex needs of some autistic children and their families. Effective pathways to respite care that include timely assessment and re-evaluation of service needs at certain ages along with better co-ordination of comprehensive services for autistic children and their families is necessary to reduce acute care service utilisation for respite care. Findings suggest that particular attention should be paid to the transition to adult care for late adolescents and the provision of respite care in emergency and crisis situations.

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Appendices

Appendix 1

A Review of EU and UK strategies for Autism Spectrum Disorder; Where and how does respite care feature?

Abstract

Autism Spectrum Disorder (ASD) is a lifelong neurological condition characterised by repetitive and characteristic patterns of behaviours and impairments in communication skills and social interactions. An increasing number of countries are passing specific legislation for people with ASD and developing strategies with the intent of improving the quality of life for people living with an ASD. The need for respite care for some people with ASD has been highlighted as a significant unmet need.

This review found that an increasing number of countries have developed specific strategies for people with ASD, however, the pace at which this has occurred and the extent to which respite care is referenced varies across countries with some at a more advanced stage than others.

Introduction

This review aims to determine whether ASD strategies are in place across the United Kingdom (UK) and the European Union (EU) and if, and how, the concept of respite is portrayed within these strategies.

ASD is a lifelong neurological condition characterized by repetitive and characteristic patterns of behaviours and impairments in communication skills and social interactions (American Psychiatric Association & Association 2013). Population prevalence estimates by the World Health Organisation (Lavelle *et al.*) suggest that 1 in 160 children worldwide has an ASD (WHO, 2019). This suggests that ASDs represent a serious health problem as prevalence rates are increasing with time and more individuals are seeking additional supports such as education, medical and social supports to help with the challenges associated with ASD.

Increased prevalence rates can be attributed to multiple factors such as better analytic tools, better identification and screening methods, changes in diagnostic criteria, variability of prevalence study methodologies, increased awareness among parents and

clinicians, and changes in the availability of services (CDC, 2012; Rice, Rosanoff Dawson et al., 2012; Matson and Kozlowski 2011). The Rising prevalence rates of ASD implies the necessity for increased service availability including training of professionals and the identification of additional resources (Boswell, Zablotsky and Smith 2014) which has led to an increase in the types of services available for people with ASD (Yasmin, 2014). However, the availability, affordability, and accessibility of these services continues to be reported as barriers to accessing appropriate services for people with ASD (Platos and Pisula, 2019; Anderson, Lupfer and Shattuck, 2018).

The rights of people with ASD are supported in Europe under the European Union Charter of Rights for Persons with Autism, and internationally by the United Nations through the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (UN General Assembly, 2007). The UNCRPD is an international treaty that aims to promote, protect and ensure the rights of persons with disabilities so that they can fully participate in society and enjoy the same freedoms and opportunities as others.

In May 2014, the Sixty-seventh World Health Assembly adopted a resolution entitled 'Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders (ASD)' (Lavelle *et al.* 2014) which was supported by over 60 countries. The resolution urged the WHO to collaborate with Member States and partner agencies to strengthen national capacities to address ASD and other developmental disorders (Lavelle *et al.* 2014). The WHO and partners' agencies recognised the need to strengthen countries' abilities to promote the optimal health and well-being of children and adults with ASD. Priority areas included enhancing the commitment of governments and international advocacy on ASD, providing guidance on creating policies that address the care of people with ASD and contributing to the development of evidence on effective strategies for the assessment and treatment of ASD and other developmental disorders.

Respite care has been cited as one of the greatest unmet needs of families caring for people with ASD (Cooke, Smith and Brenner, 2020; Whitmore and Snethen, 2018; Dyches et al., 2016). Respite care is defined as temporary relief from the responsibilities of caregiving and can be provided by professionals (formal) and non-professionals (informal) in a variety of settings (Dyches et al., 2016). Respite care has a positive impact on the well-being of caregivers and is associated with lower levels of stress, reduced levels of depression and anxiety, and more time for rest and rejuvenation (Mc Grath 2019). However, accessing respite care can often be difficult and contribute to this stress (Hodgetts *et al.* 2013a). Furthermore, the respite services available may be

inappropriate or inadequate for people with ASD (Gadd 2019). Without respite care, those caring for people with ASD are at risk of burn out within a short period of time (Woodgate et al., 2015) as they take on complex care tasks such as behaviour and emotional challenges. Daily routines can be complicated, family vacations may be harder to plan, and families may find themselves no longer able to do some of the things they were once able to do (Hartmann, 2012). Families can also find themselves accessing acute hospital services as an initial point of contact or in a crisis situation for support (Deavenport-Saman, Lu, Smith and Yin, 2016; Cohen-Silver, Muskat and Ratnapalan, 2014). Respite care is not without its own challenges with research often citing issues around transitioning of care (which has been described as service-driven rather than person-centred), (Brown, Higgins and Mac Arthur, 2020) lack of choice around the type and frequency of respite received and inadequate capacity to support individuals with complex care needs (Gadd 2019).

While some policies and guidelines recognise the need to provide short breaks or respite for people with ASD and their families, (Crowe and Salt, 2015; Ministries of Health and Education, New Zealand, 2016) others do not explicitly identify respite as a required support and often lack guidance on respite services. Consequently, the lack of clarity around type, need and frequency of respite can impact on how respite features in national policies and plans across countries.

Methods

Search strategy and selection criteria

The scope of this review was limited to the United Kingdom (UK) and the European Union (EU). Data collection consisted of two main phases with governmental websites forming the primary source of data collection. The first phase was to identify the countries that had ASD strategies in place. The second phase was to review the content of identified ASD strategies to ascertain if and how the concept of respite featured within the overall strategy. No limitations were applied to the year the strategy was published and strategies applicable to both children and adults were included. Data retrieved was collated into one single data repository. In circumstances where ASD strategies were not available in English, respective governments were contacted through their websites to assist with translation. Autism Europe, an international association whose main objective is to advance the rights of people with ASD, were also contacted to assist in retrieving English versions of strategies where available and to provide further information and clarity where possible. In total, 31 countries were included in this review (27 EU countries

and the four divisional countries of the UK; England, Scotland, Wales and Northern Ireland).

What is an ASD Strategy or Plan?

A strategy can be described as a high-level plan to achieve one or more goals (Barad, 2018) and the terms strategy and plan are often used interchangeably. Notably throughout this review, some countries referred to their strategy as a plan. Therefore, for the purpose of this review, from here on, the term strategy has been adopted and is taken to mean strategy or plan. An ASD strategy aims to achieve meaningful inclusion and empowerment of people with ASD within wider society (As I Am, 2020). National governments are usually responsible for the development and implementation of such strategies. ASD strategies examined as part of this review outline key areas where people with ASD are facing particular challenges. Plans and actions are drafted following consultation with relevant stakeholders ranging from healthcare professionals, academics, educators, advocates, families and people with ASD. A strategy is developed for a specified number of years (usually ranging from three to ten years), detailing what actions are needed to address a particular challenge within a key policy area. Responsibility for implementation of actions is assigned to relevant bodies and individuals and is described within some strategies. Some countries also publish progress reports in relation to their respective strategies. Countries with strategies in place are internationally recognised as leaders in implementing best practices for people with disabilities (ASDEU, 2020) as it offers a road map towards progressing the lives of people with ASD.

Results

Countries with ASD strategies

This review found an increasing number of countries have developed ASD specific strategies to respond to the specific needs of individuals with ASD (See Figure 1). However, some countries were at a more advanced stage than others as illustrated in (See Table 1 and Table 2).

An important finding of this review is that while some countries may not have an ASD specific strategy, they have opted to include ASD explicitly in the definition of disability at national level. Many countries have enacted legislation, which may not make direct reference to ASD, but include ASD under the umbrella of disability and have amended the definition of disability in their relevant legislations to include explicit reference to ASD.

In Ireland, for example, the Disability Act 2005 places legal obligations regarding assessment of need and services for all individuals with a disability, including individuals with ASD (The Government of Ireland Disability Act, 2005).

(Add Figure 1)

The European Union

The average estimated prevalence of ASD in Europe is reported as 12.2 per 1,000. This equates to one in 89 children aged seven to nine years having an ASD (ASDEU, 2020).

At the time of this review, six of the included 27 EU countries only were found to have ASD specific strategies currently in place (See Table 1). Summary details of these ASD strategies are outlined in Table 2. The majority of these strategies have either a legal basis, in so far as they are provided in a legal act and have been adopted by government, or have been derived from policy and adopted by governmental departments.

(Add Table 1)

(Add Table 2)

A survey conducted in Europe in 2016 showed considerable variation across countries regarding both access to interventions and type of intervention received for children with ASD across Europe (Salomone, Beranova, Bonnet-Brilhault et al., 2016). These findings could be attributed to a lack of strategic direction in developing and implementing ASD services. Accordingly, there is a need to adopt cross-sectoral national strategies to respond to the needs of people with ASD in response to increasing EU ASD prevalence rates and the need to coordinate policy approaches at national and European levels. In 2015, the European Parliament's Written Declaration on Autism (European Parliament, 2015) called on the EU and its Member States to adopt a European Strategy on ASD that supports accurate detection and diagnosis across Europe, promotes evidence-based treatment and support services, fosters research and encourages the exchange of best practices (Siniscalco and Gallone, 2016). Precedent for such an approach has been set by the European Strategy for Disability 2010-2020 (European Commission, 2010). While the strategy is still under development, in 2018, key recommendations have been put forward by Autism Europe for a holistic EU autism strategy (Autism Europe, 2017).

The United Kingdom

Estimates from the UK suggest that the prevalence of ASD in children is around 1.6% (Rydzewska, Hughes-McCormack, Gillberg, et al., 2018). Notably, the UK withdrew from the European Union on 31 January 2020. Prior to this, The UK's Autism Act 2009 was one of the first ASD specific legislations to be adopted in Europe. The Act is the legal basis for the strategy for adults with ASD in England titled 'Fulfilling and rewarding lives' (2010) and its updated version titled 'Think Autism' (2014) (Department of Health and Social Care, 2014). The UK are at an advanced stage with the implementation of their ASD strategies with all four countries either publishing subsequent strategies or updated versions of existing strategies since the enactment of the Autism Act 2009 (See Table 3).

(Add Table 3)

Content of Autism strategies

Early detection of ASDs, identification of causes and treatments and the sharing of best practices and knowledge are recognized by the WHO as the main challenges in addressing ASD management to increase the capacity of health and social care systems to provide services for people and families with ASDs (Lavelle *et al.* 2014).

The ASD strategies that were reviewed tend to follow a practical approach based on identifying the specific needs of people with ASD and their families and carers. They support the direction and coordination of services at national and regional levels to enhance their efficiency and address areas that require improvement such as assessment and diagnosis, education and service development.

Where and how does respite care feature?

Respite care provides caregivers and families with support and a break from the demands of caring for people with physical, intellectual or developmental disabilities, or other special needs, including chronic or terminal illnesses (Whitmore, 2016). It can be both formal and informal and can be provided in various settings, including: in-home (Corkin, Price and Gillespie, 2006), community-based (Dawson and Liddicoat, 2019), hospital-based or in a residential facility (Wilke and Barr 2008).

Historically there has been a view that the best way to support individuals with disabilities like ASD was to care for them in residential institutions that are separate from local communities. Over time, there has been a major shift in this thinking that has been driven by the values of equality, the right of people to be integrated into their community to plan for their own lives by making their own choices and to be enabled to access the personal supports they require to optimise their independence (Health Service

Executive, 2011). Deinstitutionalisation is the most significant policy development for people with disabilities in the late 20th century (Tatlow-Golden, Linehan, O'Doherty, et al., 2014) and can be defined as the gradual abandonment of large residential institutions and their replacement by small services to enable people to live in the community (Mansell, Knapp Beadle-Brown and Beecham, 2007). One of the many actions outlined in the WHO resolution on 'Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders' includes the need for member states to systematically shift the focus of care away from long-stay health facilities towards community-based, non-residential services (Lavelle *et al.* 2014).

This review also aimed to explore whether countries that have ASD strategies in place have recognised the importance of respite for some people with ASD and their families by explicitly including respite in their respective strategies. Furthermore, the review aimed to determine the context in which respite features within the overall strategy or plan.

Of the ten countries found to have ASD strategies in place within the scope of this review, seven explicitly referenced the concept of respite and three referenced the need for 'specific or specialised supports' but these did not refer explicitly to respite. Of the seven ASD strategies that referenced the concept of respite, this was mentioned in the context of 'respite care', 'family respite' 'short break', 'residential services/homes' and 'residential and semi-residential assistance' (See Table 4).

(Add Table 4)

Overall, the extent to which respite was referenced throughout the countries which had ASD strategies varied. Some countries have focused on the importance of ensuring that the family needs are met as a whole and not just the individual with ASD in terms of availing of respite where as other countries have focused on building capacity for respite and widening the range and types of respite services. While many of the ASD strategies reviewed in this paper identified the need for providing supports to individuals with ASD and their families, seven out ten strategies explicitly identified respite as one of these supports.

It should be noted, however, that an absence of respite in an ASD specific strategy does not constitute an absence of respite for individuals with ASD. As some countries have opted to include ASD explicitly in their definition of disability at national level, the provision of and access to respite care for individuals with ASD may be included in policies related to disability.

Discussion

Countries across the EU and the UK, for the most part, either have strategies or are making progress in the development of ASD specific strategies in an effort to strengthen national capacities to address ASD. These have ranged from single strategies to revised and updated versions with associated action plans and progress reports. This progress is also evident across other countries internationally such as the United States Interagency Autism Coordinating Committee (IACC, 2020) and Canada (CASDA, 2019). In the absence of ASD specific strategies, some countries have opted to develop and implement ASD specific guidelines. For example, New Zealand do not have an ASD specific strategy but do have an Autism Specific Disorder guideline (Ministries of Health and Education New Zealand, 2016). The guideline, first published in 2008 and updated in 2016, aims to assist informed decision-making to improve the health, educational and social outcomes for individuals with ASD.

Internationally, respite is considered a practical means of supporting people and families with ASD as it can help build resilience and promote health and well-being. However, a lack of respite along with insufficient levels of support and funding and a lack of access to information on available and appropriate respite supports continues to be reported (Gillieatt, Martin, Dorozenko and Munro, 2018). Families also report difficulties when seeking respite such as inflexible supports, delays in provision or long waiting lists, restricted or unreliable services, inequality of respite distribution and lack of home-based respite services (Robertson, Hatton, Wells et al., 2019; Spruin, Abbott and Holt, 2018; Southby, 2018). Research also describes poorly coordinated transitions between child and adult services (Robertson, Hatton, Wells et al., 2019) and emphasises the need for better transitions between respite services.

Access to respite services and associated difficulties encountered by families of people with ASD continues to be reported as significant barriers throughout the literature. It is therefore vital that ASD strategies, plans or guidelines set out the requirements and actions needed to guide and support the planning and development of respite services. This has been set out in ASD specific guidelines in some countries, for example, New Zealand where it is outlined that the provision of respite care and a key worker case management model is likely to lead to the most positive outcomes for parents. The guidelines make specific recommendations around respite service requirements and access to respite care information. Furthermore, the necessity for respite care is clearly articulated in terms of enabling other supports for parents, for example, in order for parent education programmes to be effective, parents may first need support in other

areas, such as respite care to deal with their own emotional and mental health issues. The guideline also specifies the requirements for a range of respite services and the need for systems to be in place to support a crisis response including short break respite (with specific ASD knowledge) and other respite in-home supports for families.

Comparably, NICE guidelines on 'Autism Spectrum Disorder in under 19's: support and management' outline the need to offer short breaks and other respite care to support families and carers (NICE 2013). Similar to New Zealand's guidelines, it specifies the importance of providing families and carers with verbal and written information about their right to short breaks and the types of and potential frequency of respite.

Families have consistently highlighted the need for respite care to be tailored to fit the unique needs of the child and their family (Welch, Collins, Hatton et al., 2014). It is important that policy developments in the form of strategies, plans or guidelines provide clarity, detail and guidance on the requirements for the optimum provision of required supports such as respite care for people with ASD and their families. It is also vital that any proposed planning and designing of respite services for the purpose of national and local policy is done so in consultation with the necessary stakeholders which include experts and individuals with ASD and their families.

Barriers to developing and implementing ASD strategies.

ASD policy has been described as an arena of extraordinary complexity and conflict for those navigating within it alongside a bewilderingly complex arena of actors at work (Skubby, 2017). This conflict can be attributed to the complexities of multiple public policies designed to provide needed services for people with ASD and the potential overlap with ASD policies and disability policies. This review has identified that the pace at which countries are developing ASD strategies varies across countries with some at a more advanced stage than others. One possible explanation for the variance in progress and lack of detail on respite within existing ASD policy could relate to the lack of systematic and reliable data on the prevalence of ASD due to changes in diagnostic criteria, (Lyall, Croen, Daniels et al., 2017) delayed diagnosis and the absence of public registries which has been noted as a challenge for policy makers. Planning for future service provision can be difficult if the required data is not sufficient. Furthermore, the spectrum of ASD conditions is so diverse resulting in a wide range of individual needs and support requirements and therefore it is unlikely that there is 'one fit' approach to respite care models.

Conclusion

Policy making in the form of ASD strategies across Europe and the UK have evolved over the years with countries identifying the requirement to address the needs of people with ASD. Notably this is not without challenges due to changes in diagnostic criteria, delayed diagnosis and lack of systematic and reliable data on the prevalence of ASD. Several countries have developed strategies to raise awareness, promote identification and improve support services regarding the particular needs of people with ASD during their lifetime, whilst at the same time improving their quality of life and that of their families. The extent to which respite was referenced throughout the available ASD strategies varied, with some countries lacking detail in the availability and provision of respite services for people with ASD despite being identified as one of the greatest unmet needs. The absence of respite as a specific support need in national strategies, plans and policies has implications for future respite service development which directly impacts on individuals with ASD and their families. Service development needs to be informed by national and local plans and service providers need guidance and direction for future respite service planning and provision.

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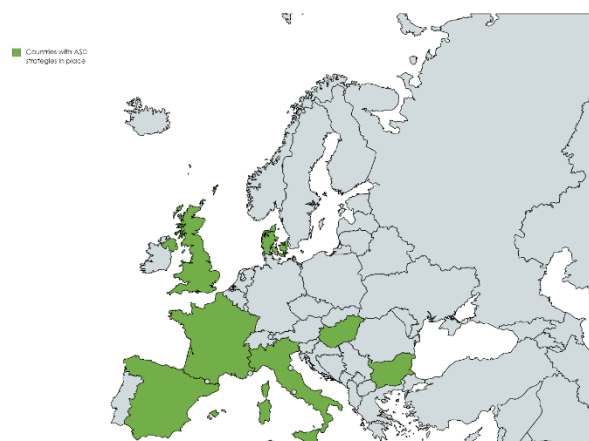
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Figure

Fig 1 Countries with ASD specific strategies currently in place.



Tables

Table 1: EU countries reviewed to determine if ASD specific strategies are in place.

1.	Austria	No	14.	Ireland	No
2.	Belgium	No	15.	Italy*	Yes
3.	Bulgaria	Yes	16.	Lithuania	No
4.	Croatia	No	17.	Luxembourg	No
5.	Cyprus	No	18.	Latvia	No

6.	Czech Republic	No	19.	Malta	No
7.	Denmark	Yes	20.	Netherlands	No
8.	Estonia	No	21.	Poland	No
9.	Finland	No	22.	Portugal	No
10.	France	Yes	23.	Romania	No
11.	Germany	No	24.	Spain	Yes
12.	Greece	No	25.	Sweden	No
13.	Hungary	Yes	26.	Slovenia	No
			27.	Slovakia	No

*While these are noted to be guidelines, Italian literature refers to them as plans (Borgi, Ambrosio and Cordella, 2019)

Appendix 2 Published systematic review of Parents' experiences of accessing respite care for children with Autism Spectrum Disorder at the acute and primary care interface: a systematic review

RESEARCH ARTICLE

Open Access

Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: a systematic review



Emma Cooke*, Valerie Smith and Maria Brenner

Abstract

Background: Population prevalence estimates by the World Health Organisation suggest that 1 in 160 children worldwide has an Autism Spectrum Disorder (ASD). Accessing respite care services for children with an ASD can often be a daunting and exhaustive process, with parents sometimes forced to access acute hospital services as an initial point of contact for respite care or in a crisis situation. To gain an in-depth understanding of accessing respite care for children with an ASD, from the perspectives of parents, a systematic review of the evidence on parent's experiences and views of respite care for children with an ASD at the acute and primary interface was undertaken.

Methods: Pubmed, Embase, CINAHL and PsycINFO were systematically searched. Studies identified as relevant based on predetermined eligibility criteria were selected for inclusion. The search strategy also targeted unpublished studies and grey literature. Qualitative data and qualitative components of mixed method studies that represented the experiences of parents accessing respite care for children with an ASD were eligible for inclusion. A meta-aggregative approach was used during data synthesis.

Results: Database searching elicited 430 records of which 291 studies remained after removal of duplicates. These 291 studies were screened for title and abstract by two reviewers resulting in 31 studies to be screened at full text and assessed for eligibility. Six studies met the inclusion criteria and a further additional study also met the inclusion criteria during a manual search. As a result, 7 studies were selected for the review as set out in Fig. 1.

Conclusion: In the absence of appropriate services and defined pathways to support services such as respite care, overwhelmed parents and community providers of mental health resources may not be in a position to meet the specific needs of children with an ASD and their families which may be contributing to a direct increase in hospitalizations. This systematic review identified a number of barriers to respite care, of which the findings can be used to inform future service development and further research. Knowledge of parental experiences in caring for a child with an ASD is vital in addressing the need and type of respite care required for children with an ASD.

Systematic review registration: PROSPERO CRD42018106629.

Keywords: Autism Spectrum disorder, Autism, Autistic disorder, Respite care, Unscheduled care, Short break, Children, Accessing respite care, Integrated care

* Correspondence: emcooke@tcd.ie
Trinity College Dublin, Dublin, Ireland



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Background

The provision of care closer to home for children with neurodevelopmental needs is being increasingly recognised both nationally and internationally. This is particularly the case for children with and an Autism Spectrum Disorder (ASD). ASD is a lifelong neurological condition characterized by unusual behaviors and impairments in communication skills and social interactions [1]. Population prevalence estimates by the World Health Organisation suggest that 1 in 160 children worldwide has an Autism Spectrum Disorder (ASD) [2]. Parents are, in most cases, the primary caregivers for these children and caring for a child with an ASD can be a full-time job. Consequently, there is a heightened economic, social and political need to address the issue of integrated care and provision of support services such as respite care for a growing population of children with ASD.

The upbringing of a child with an ASD is complex and associated with an important change in family dynamics [3]. There is considerable evidence that raising a child with an ASD can be a source of increased family stress [4–7]. Interestingly, mothers of children with an ASD experience chronic stress comparable to that experienced by combat soldiers [8]. In addition to typical parenting demands, parents of children with an ASD also have extra demands related to caring for their child's often unpredictable behaviour and emotional challenges. Parents can take on complex care tasks such as behaviour and aggression management while balancing all other aspects of family life and work commitments. The adverse effect of this reality is burn-out within a short period of time [9]. Therefore, the complexity of the parental role and well-being of parents caring for children with an ASD is increasingly becoming a public health issue [10–12].

Respite care can be defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to the main carers and their family [13]. Often, despite initial reluctance to use respite services, parents find respite care beneficial [14]. Research reflects the many benefits of respite services for parents such as significant improvement in psychological adjustment, fatigue, mental health and quality of life [15]. In a survey of 122 single mothers of children with autism, 59.8% of mothers accessed respite care and 71% reported that they were satisfied with this care [16]. However, the majority of the respite care was provided informally by family members and friends which could have influenced the high satisfaction rate. Similarly, 88.6% of parents of children with autism reported being satisfied with their care providers which primarily comprised grandparents, babysitters, community agencies and extended family members [17]. Accessing respite care can often be challenging as a

result of complex systems to access services and lack of knowledge about existing services available. There can often be confusion over points of accessing care and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team across acute and primary care services [18]. Consequently, parents may be forced to access acute hospital services as an initial point of contact or in a crisis situation [19–21]. One study found that children with an ASD were nine times more likely to visit an emergency department compared with children who do not have an ASD as a result of psychiatric problems such as physical aggression, disruptive behaviour, running away and hurting oneself [22]. Another study including children with and without an ASD classified about a third of the paediatric emergency room visits by children with ASD as “inappropriate” because the problems could have been handled in an outpatient setting [23]. As a result, parents accessing acute hospital care services as an initial point of access for services such as respite care can be considered a symptom of inadequate service provision for children with an ASD.

There is limited evidence of the actual experience of families seeking access to respite care services for children with an ASD. Furthermore, little is known about the profile and numbers of children with an ASD accessing respite care. Motivating factors for parents attending acute hospitals as a means of seeking respite care for children is multi-factorial and needs to be explored in order to identify and address the current gaps in primary care service provision. In order to improve integrated care services at the acute and primary care interface it is necessary to explore what is currently happening by examining the literature, exploring the pathways to access respite care and exploring the experiences and perspectives of parents accessing respite care for their child with ASD.

This systematic review question is centred around asking what is the available evidence on access to respite care from the perspectives of parents of children with an ASD and what are the key issues, if any, that parents may encounter when accessing respite care for their child.

Methods

A systematic review protocol was developed using the Joanna Briggs Institute Method for Systematic Review Research [24]. The PRISMA checklist was used to guide the reporting of the review [25]. The review protocol was registered on the PROSPERO International prospective register of systematic reviews. (Registration number CRD42018106629).

Eligibility criteria

Eligibility criteria included parents of children with an ASD who had accessed respite care and offered their

views and experiences of the process through qualitative enquiry. The focus on children was influenced by the potential of increasing needs for children with ASDs from childhood through to adolescence which can make them and their parents susceptible to physical and mental health crises because their specific needs are often unmet [26]. There is considerable evidence that the upbringing of a child with an ASD is complex and associated with an important change in family dynamics and family stress is higher in families raising a child with an ASD [4–7]. In addition to typical parenting demands, parents of autistic children also have extra demands related to caring for their child's often unpredictable behaviour and emotional challenges. Consequently, this can lead to a greater need for accessing respite care while the child is growing up and it is likely that parents will start seeking the need for respite as the child begins to get older.

Rationale for focusing on qualitative studies included the need to gain a holistic view of participant lived experiences and the phenomenon under study [27] while also figuring out how meanings are shaped through and in culture [28]. As participants lived experience cannot always be counted and measured through the use of quantitative methods, qualitative studies offered better access to 'how' and 'why' a particular phenomenon, or behaviour, operates as it does in a particular context. Furthermore, qualitative methodology is beneficial where there is limited knowledge on a phenomenon which is applicable in the context of the research topic. Studies that focused on qualitative data including, but not limited to, designs such as phenomenology and grounded theory, were included. Mixed method studies were also included with relevant data related to the qualitative component of the study only, extracted. The age of the child had to be below 18 years. Unpublished studies and 'grey literature' of relevance to the review question were also considered.

Search strategy

A broad search strategy was applied to maximise the potential for capturing all relevant data and to minimize the potential for non-retrieval of relevant studies. The following keywords and search terms derived broadly from a combination of the review's population and exposure inclusion criteria were used; Autism Spectrum Disorder, Autism, Autistic Disorder, Respite care, unscheduled care, short break, Children, Accessing Respite Care, Integrated Care. Databases searched included Cumulative Index to Nursing and Allied Health Literature (CINAHL+) (via EBSCOhost), PsycINFO (via EBSCOhost), PubMed and Embase, with the same search strategy used in each database. All databases were searched from their date of inception to the date of the search.

However, no limitation was placed on the age of the data. The first known paper on autism was published by Kanner in 1943 [29]. To meet the aims of a broad exploratory systematic review, studies published in English, during any publication period were accepted. A manual search of the reference list of all articles included at full text level was also conducted to identify potential studies that may not have been captured by searching the databases. The search strategy also targeted unpublished studies and 'grey literature' to help minimize the risk of missing unpublished studies. Numerical search results were reported using the PRISMA flow diagram [25]. Covidence was used to record citations, abstracts and full texts and to identify duplicates. The search was first conducted in May 2018 and repeated again in August 2018. The search was repeated again in December 2019 and found no new studies matching the inclusion criteria.

Study selection

Study selection was performed using a two-stage process; i) screening of title and abstracts only, excluding studies ineligible at this stage based on predefined inclusion criteria, and forwarding those that appeared relevant or where uncertainty existed around their relevance, for review of their full-texts; ii) retrieval and assessment of full-texts for inclusion in the review. Two reviewers independently screened titles and abstracts of all citations retrieved during the search, after removal of duplicate citations, for eligibility. Disagreements that arose between the reviewers were resolved through discussion and consensus.

Appraisal of study quality

All included studies were formally assessed for methodological rigor, using a critical appraisal tool from Brunton et al., [30], by the author and a second independent reviewer assessed approximately 50% of the selected studies. Issues considered during the appraisal process included rigor, credibility and relevance of studies selected to the systematic review question. As part of the quality appraisal process, studies were summarized in table form, showing the study and reference, aim/objectives, sampling and recruitment, characteristics of participants, socio-economic status, validity and reliability of data collection methods, tools and relevance to the systematic review. The overall quality of each included study was reported as high, moderate or low based on the results of the critical appraisal process.

Results

Database searching elicited 430 records of which 291 studies remained after removal of duplicates (139). These 291 studies were screened for title and abstract by

two reviewers resulting in 31 studies. Of these 31 studies, 25 were excluded after full text review for the following reasons; wrong study design (15), wrong exposure (3), wrong patient population (3), duplication (2), not in English (1), unable to obtain full text (1). Communication was made with the author of the one study that could not be obtained, however, there was no response. This resulted in six studies meeting the inclusion criteria and were included in the final review. At this stage the reference lists of identified papers were searched manually to identify possible omitted studies. One additional study that met the inclusion criteria was sourced during the manual search. As a result, 7 studies were selected for the review as set out in Fig. 1. Interestingly, no single study was found that exclusively explored the views of parents of children with ASD accessing respite care, rather this aspect was a component within the studies.

Seven articles were appraised in total. Six studies were reported as high quality and one study was reported as medium. No studies were found to be of low quality. The author and independent reviewer reached a 97% agreement on the independent quality appraisal assessment of a 50% sample of included studies.

Participants and settings

One study was conducted in Pakistan and India. Two studies were conducted in Ireland and the remaining studies were conducted in Sweden, Kenya, Canada, and

the United States. The profile of participants included a mixture of mothers, parents, families, couples. Six of the studies employed a qualitative design and one study employed a mixed methods design of which the qualitative datum was extracted only for the purpose of this review. The profile of participants from the included studies is detailed in Table 1. The majority of children with ASD were male. Some of the children had been newly diagnosed with autism [31] and other children, in addition to their autism were described as having either a learning disability or an intellectual disability characterized by limitations in intellectual functioning (e.g. learning, reasoning, problem solving skills) and/or adaptive behaviour (conceptual, social and practical skills) which was classified as moderate to profound within some studies. Table 1 outlines the profile of participants from the chosen studies.

Data extraction and synthesis

Details from eligible studies were extracted using a pre-designed data extraction spreadsheet detailing study characteristics such as publication year, study design, country of origin, methodology, sample size, data collection and data analysis procedures, point of access to respite care, type of respite care, conclusion, key findings. This also allowed for synthesis of methodologies and methods. A meta-aggregative approach was used during data synthesis. The meta-aggregative method is aligned

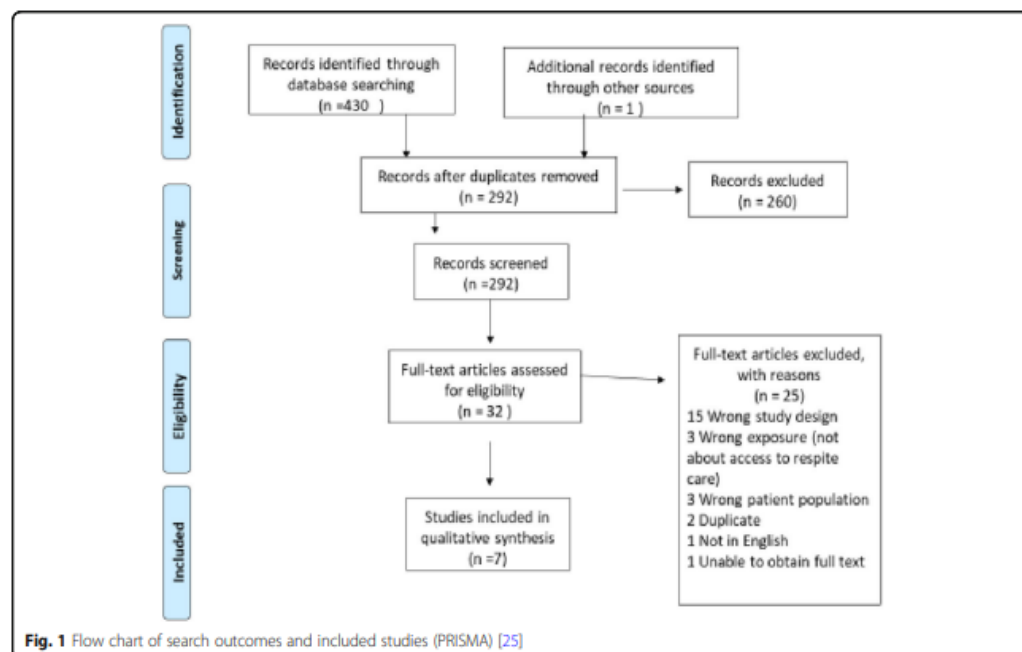


Table 1 Profile of participants from included studies

Author and Year	Number of Parents	Profile of Parents mother/father	Number of Children	Gender of child	Age of Children	Disability	Characteristics
Benderix et al., 2007	5 couples	Not specified	5	Not specified	10-11 years	Learning disability moderate x1 severe x3 bprofound x 1	Delayed verbal/absent language, lacked spontaneous seeking of enjoyment, little or no interest in other persons, hyperactivity, short attention span, self-injurious behaviour, high pain threshold, disorders of sleep.
Gona et al., 2016	103 parents (& HCP's)	Not specified	Not specified	Not specified	Not specified	Not specified	Not specified
Hartley 2003	1	mother	1	female	8 years	Intellectual regression	Rett Syndrome, scoliosis, anti-social, constipation, reflux, teeth grinding
Hodgetts et al. 2013	9	mothers (8) father (1)	7 children (under the age of 19) (2 aged 19&29)	Male	6-10 years	All had moderate to severe intellectual disability.	3 had some functional language, 2 did not have functional language. 4 individuals were diagnosed with Asperger syndrome, had mild or no intellectual impairment, and demonstrated conversational language skills.
Mann 2013	13	13 mothers	13	Male (11) Female (2)	4-17 yrs	Disability not specified. Autism described as Moderate (4), mild (3), severe and ADHD (2) Mild to mod (1)	*as reported by mothers
Minhas et al. 2015	15	mothers (11) fathers (4)	Not specified	Male (12) Female (3)	Not specified	Not specified	Not specified
Keenan 2007	95 parents and carers	87 (female = 4 grandmothers and 3 mothers) 8 (male)	100	Male (80) Female (20)	mean age 8 years 30 (1-6 yrs) 56 (7-12 yrs) 11 (13-15 yrs) 3 (16 yrs)	Intellectual disability: 56 with learning disability ranging from mild, moderate and severe	ASD (80) Aspergers (7) PDD (2) Unknown (1)

with the philosophy of Hannes and Lockwood [32] where the meaning is connected to the idea of practical usefulness and pragmatism and supports the pragmatic approach to this systematic review. Furthermore, the mega-aggregative method has been developed in order to deliver usable synthesized findings to inform decision making at the clinical or policy level. Therefore, this approach was considered helpful when attempting to explore current practice on accessing respite care from the perspectives of parents of children with autism.

The results synthesized during meta-aggregation were the qualitative findings related to parents of children with an ASD and views/experiences of access to respite care. The aim of meta-synthesis by meta-aggregation was to assemble findings from qualitative research, categorize those findings into groups on the basis of similarity in meaning and aggregate these to generate a set of statements that adequately represent that aggregation. Meta-aggregation was achieved using NVivo software through the following three step approach;

1. Extraction of all findings from all included studies related to views/experiences of access to respite care only.
2. Developing categories for findings with at least two findings per category.
3. Developing one or more synthesized findings from at least two categories.

Categorization involved repeated, detailed examination of the extracted findings. The author identified groups of findings on the basis of similarity in meaning to create categories. A category is the combination of a brief description of a key concept arising from the aggregation of two or more similar findings. This description is accompanied by an explanatory statement that conveys the whole inclusive meaning of a group of similar findings.

The results are presented based on the synthesised findings that emerged. Validation of data extracted, and themes identified from all studies was carried out by two reviewers together. Synthesis of the included studies data identified three prominent themes that reflected the perspectives of parents of children with an ASD on accessing respite care. These include (1) The journey to getting and maintaining respite care, (2) The role of healthcare professionals in supporting parents to access services including respite care, and (3) Facilitating factors and barriers to accessing respite services.

The journey to accessing and maintaining respite care

Parents' experience of accessing respite care was described as a relentless journey. A total of four stages emerged from the synthesis as part of the process of accessing and maintaining respite care services for

children with an ASD. Although these stages were not necessarily sequential, each stage featured within the overall journey to accessing respite care. The stages included; identifying the need for/motivating factors for seeking respite care, accessing and maintaining respite care services, parental concerns about respite care services, and alternative options to respite care.

One of the motivating factors for seeking respite was associated with an inability to manage behavioural problems which directly caused increased stress levels amongst parents [31, 33]. Parents reported that as the child grew stronger, they became more difficult to manage [34]. Parents began to seek help outside the home when the secondary behavioural problems associated with an ASD became visible and disrupted family life. 'We thought he would grow out of it, but he has become worse. Now if he gets upset he bites himself, bangs his head on the wall and if somebody goes near him he gets even more upset. No one comes near him' (father of an 8-year-old boy, urban Rawalpindi) [35].

One study found that the strongest predictor of stress for parents was associated with the existence of aggression in a child with ASD [36]. Consequently, high levels of stress emerged as the greatest motivator for accessing respite care [31, 33–35, 37]. However, finding and accessing respite care was equally identified as a stressor [36]. Findings identified a relationship between parents' ability to have respite care services and their stress levels. For example, in one study, mothers frequently described high levels of stress because of the lack of any respite. 'I can't think of a time when I enjoyed a social occasion ... she is getting worse, and it has started to affect my health' (mother of a 5-year-old girl, urban Rawalpindi) [35]. 'How can I look after her when I have so much to do, sometimes I just leave her on her own ... then I feel guilty ... I don't know what to do' (mother of a 6-year-old girl, rural Rawalpindi) [35].

A number of studies outlined how family members were the main source of respite care for parents [34, 35, 37]. In the absence of any external support, parents described how spouses, siblings, grandparents and extended family members provided the main respite for the mothers and often families moved closer together so that the extended family could provide the support [33, 35]. Two studies reported that state-provided respite care was non-existent [31, 35]. Those availing of respite care services were receiving some respite care via supported housing [36] residential/group home/supported housing, [37] and boarding school [37]. One study described the various types of respite services available to participants including out-of-home respite, in-home respite, home-to-home scheme, holiday club and after school club [37]. Other families were in receipt of direct payments to choose from different respite care options

for their child [33]. In the absence of any formalised support system or state funded respite care, traditional healers were cited in one study as being the first port of call for both rural and urban parents in the context of being a source of guidance and relief for carers [35]. These were identified as religious, traditional healers or herbal practitioners and others involved in magic or sorcery.

Accessing respite care services in rural areas was described as a challenge for parents [31, 35]. The most commonly cited reason was that services were located mainly in major cities which were at a distance and parents could not afford the financial or time costs [31, 35]. Overall, parents outlined a significant requirement for respite care but could not access this. Some parents described how they had attempted for many years through the government to obtain adequate home based respite care services for their children in order to be able to manage the family situation but had not succeeded and resorted to arranging a specialised group home in a building that the government made available [34]. Parents also described alternative methods used to find respite care such as online advertisements, newspapers, posting at local universities, grocery stores and word a mouth.

For parents that had accessed and were receiving respite care, the outcome or the impact was described in terms of both the child getting respite and the family [38].

Some parents felt that respite services placed too much emphasis on the medical model and valued a more social care model delivered by healthcare professionals [34]. For example, parents reported wanting a stronger educational orientation and less nursing and for the children to be given more training [34] as parents hoped their child would become more independent and receive lifelong school training or a meaningful daily occupation. Parents also valued non-pharmacological behaviour management strategies recommended by healthcare professionals such as psychologists, behaviourists and occupational therapists [36].

The benefits of respite care were described and reported in all studies. However, parents in one study described how they were not satisfied with their form of respite care, which was provided through a group home, as they felt that their child did not get enough of the activities they needed. The group home was described as a specialized group home made available by the municipality for children with autism and learning disabilities in which the parents could leave their child for respite care ranging from weeks to days [34].

Equally parents acknowledged that no longer having control over their child caused stress and anxiety [34]. The child refusing to return to respite care also caused

stress and anxiety and would prevent the parent from sending their child back [34]. Despite experiencing positive outcomes as a result of availing of respite, parents still expressed ambivalent feels towards leaving their child. Strong attachments to their children rooted in their child's dependency made availing of respite care and the associated short term removal of their child difficult and led to a sense of guilt [34].

The role of healthcare professionals in seeking respite care services and additional supports

With the exception of one [38], all studies mentioned the role of healthcare professionals in the context of seeking support services including respite care or the impact of healthcare professionals on the child and family while in receipt of respite care services [31, 33–37]. Parents in one study described how they were made to feel inferior by healthcare professionals when deciding to seek home and family respite support for their children and families [33]. Healthcare professionals' refusing access to respite care was also cited by some parents as their child did not meet predefined criteria [33]. Families also reported that professionals they met did not appreciate what they went through on a daily basis [33]. Almost half the parents in one study had not been informed by statutory services about home and respite supports available to their family [33]. Parents felt not knowing the questions to ask healthcare professionals prevented them from accessing the appropriate support services [33].

Parents reported that the medical profession had only limited information or knowledge about ASD and a lack of understanding about the condition [35, 36] which often impacted on their ability to provide appropriate supports such as respite care. Parents spoke about how doctors sometimes focused on providing medication as a primary source of intervention [35] and did not consider alternative options. Parents in receipt of respite services for their child valued continuity with staff [35] but also reported that a lack of experienced staff in respite centres was a concern to them [36].

Facilitating factors and barriers to accessing respite care services for children with autism

Perceived barriers to respite care were described at a systems level such as lack of information to assist parents and a lack of general support services for children with an ASD [31, 33, 37]. The uncertainty of the autism condition and lack of adequate information from medical professionals was also described as a barrier to accessing respite care.

Parents wanted a shift from the medical model to a more social model of care within respite care services [34]. Seeing their child pleased was reassuring for

parents but knowing that their child is being taken care of properly enabled parents to have confidence in the respite care service. Noticing an improvement in their child indicated that their child was happy in respite care which had a positive impact on the parents [34].

Discussion

Children with an ASD primarily live with their families and research has shown that parenting a child with an ASD can produce stress in the family. All the studies in the systematic review described the stress associated with caring for a child with an ASD. Stress caused by the child's aggression and an inability to cope with challenging behaviour was found to be one of the greatest motivating factors for parents seeking respite care.

Respite care is an important support service for parents of children with an ASD. In the current review, there was a reported lack of respite care for children with an ASD. It is clear that the sociocultural, demographic, economic and health systems context is quite different from high income countries, where most interventions for such conditions are researched and developed. Parents and families have demonstrated great resilience when faced with challenges accessing respite care services for their children with an ASD. Overall, this review found that families were the biggest providers of respite care for parents of children with an ASD. This reflects research findings throughout the literature.

The point at which parents began to seek respite care services for a child with an ASD was an important finding in this review, with the need for respite care services often increasing as children with an ASD enter adolescence and coincides with increased physical size and strength. A critical need for both behavioural and crises intervention has also been identified. Better access to behavioural health services designed for children with an ASD, such as specialized care coordination and respite care is needed to reduce the burden on acute services and prevent parents from seeing acute services as their only source of meaningful help and access to support services. This is supported by Mandell et al. who examined the use of respite care of over 28,000 children and young adults (through age 21) in the United States with an autism diagnosis and found that based on procedure costs, each \$1000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization [39]. Liu et al. examined the profile on emergency department utilization in adolescents with autism and found that over 20% of children were accessing emergency services as a result of behavioural problems [40]. Overall, further research of service utilization before and after emergency department visits for children with autism is needed to develop a more

effective intervention for children and parents in need of access to support services such as respite care.

An immense need for, but an inability to access respite care was a prominent finding of this systematic review. Similarly, the limitations of respite care reported in the literature are primarily associated with accessing respite care and can be attributed to the level of information about the availability of respite services [41], inflexibility in services, a lack of choice of services [42] and geographical location [43]. Pickard and Ingersoll also identify similar barriers to accessing respite care, such as finances, access to information, transportation and waiting lists [44]. Identified principles in best practice for the provision of respite suggest that there be a single point of access to respite care services in a given administrative area. National and international reports share a common need which centres around a range of appropriate options and supports to meet the diversity of need amongst people with an ASD and to ensure that service provision is responsive, accessible, integrated, co-ordinated, seamless and delivered in partnership with service users and families [45]. However, availability and range of services can often depend on the priority given to respite care by health and social service authorities and these limitations are often a consequence of a lack of resources.

Disparities with accessing respite services in rural areas was also a finding of this review which is shared nationally and internationally. Dew et al. reported that caregivers of individuals with autism living outside of metropolitan centres in Australia noted a lack of autism expertise in healthcare providers in rural and remote areas of the country [41]. Similarly, Thomas et al. (2012) found that caregivers of children with autism who lived in rural communities in the United States reported significantly less access to special summer camps and respite care [46]. In Ireland, the Slainte Healthcare Report [47] outlined that there remained significant geographic differences in access to respite care services in the general sense. Furthermore, the report suggests that based on the evidence, there are often long wait times to access rationed services without choice of service provider and that they also end up paying out of pocket for such services [47]. The financial burden of caring for a child with an ASD was also reported by parents in five out of the seven included studies in this systematic review [31, 33, 35–37]. Parents in receipt of direct payments to access respite support services or respite care grants found this approach very beneficial [33].

Research suggests that respite care services need to be accessible, affordable, in a location that is convenient, provided at the right time, in the right duration and in the right frequency [21, 48–50]. One study referenced how their child's multidisciplinary home-based supports

were discontinued because of their son's aggression [36]. This finding is significant as while parents in general throughout the selected studies found that respite care was hard to access, parents in this particular study found it more difficult to maintain because of their child's aggression. This was attributed to both a lack of appropriate care givers and a perceived lack of adequate funding by the government. Therefore, respite care services also need to be responsive and adaptive to changes in a child's behaviour with an ASD. Having the capacity and capability to meet a family and child's changing needs should also be a criterion for delivering effective respite care services by enabling the family and child to maintain services rather than remove services.

The benefits of respite care were described and reported throughout the studies in this review. Research supports the need for respite care to be more than just the physical separation of a caregiver from their child [21, 50]. The findings from this review suggest that the quality of respite care should be equally as important as the quantity of respite care and this should be considered when improving access to respite care services for children with an ASD. Furthermore, respite programs should be evaluated based on quality and satisfaction and subjected to an accreditation process to ensure providers of respite care are adequately trained to provide for the complex needs of children with an ASD.

The diagnosis and treatment of ASD occurs in multiple settings and is provided by variety of health professionals including family physicians, pediatricians, neurologists, psychiatrists, psychologists and speech & language therapists. As a result, healthcare professionals play a fundamental role in supporting parents to access support services including respite care for their child with an ASD. A significant finding that emerged from the synthesis of data were parental feelings that professionals either lacked knowledge surrounding ASDs or had limited understanding as to what resources they should refer for parents and caregivers. A survey of autism knowledge and attitudes among healthcare professionals found that current professionals in the field have an unbalanced understanding of autism due to presence of several misconceptions regarding many of the common features of autism including developmental, cognitive and emotional features [51]. The study found that more than a quarter of study participants were not likely to endorse the need for vital support and intervention services. This can have significant implications as a lack of awareness of services required for children with an ASD may also suggest that healthcare professionals could be less likely to advocate for much needed services for children with ASDs such as respite care services.

A study found that caregivers of children and adolescents with autism report they are more likely to access

acute services for healthcare when they perceived their healthcare providers do not listen to their concerns, display cultural insensitivity, do not supply needed information, and do not involve caregivers in decision making [40]. This reflects the findings of this review which identified how some parents were made to feel inferior by healthcare professionals when deciding to seek home and family respite support for their children and families. In addition, healthcare professionals refusing access to respite care was also identified. Consequently, parents of children with an ASD may be less inclined to access their primary care physicians when seeking access to respite care as a result of having less assurance for help with acute, emergent, or complex behavioural or health issues [52]. These findings emphasize the importance of professionals to be connected and up to date with resources, services, and trainings to help parents feel better supported.

Implications for health services

Service providers and funding agencies need to better plan and provide respite services to families with children who have an ASD. Healthcare professional education could include the development and provision of continuing education courses aimed at increasing the awareness of the problems associated with parenting a child with an ASD. Respite care services should centre around a range of appropriate options and supports to meet the diversity of need amongst children with an ASD. Furthermore, respite care services for children with autism should be responsive, accessible, integrated, co-ordinated, seamless and delivered in partnership with service users and families. Access to information on respite care services for children with an ASD needs to be transparent and made available to parents and caregivers throughout their engagements with healthcare professionals.

Research implications

Further research is needed concerning implied outcomes and cost of supplying respite care to parents of children with an ASD. There appears to be little research on effective models of respite care for children with an ASD. In addition, further exploration on the benefits of respite care on outcomes for individuals is warranted. The findings from this research could also be enhanced by more quantitative or mixed methods research aimed at investigating the child perspectives or evaluating the impact of interventions such as increasing respite care staff training in challenging behaviour or building workforce capacity. Further research is also needed to examine the effectiveness of respite care services and the economic benefits of an accessible, flexible and integrated system of services.

Strengths and limitations of the review

This review identified and included seven published studies only, of which none exclusively explored the issue of access to respite care, thus the data informing the meta-synthesis and the overall review's findings, while narratively rich, were limited. Respite care has been identified as a challenge for systematic reviewers, particularly regarding how best to identify appropriate evidence for inclusion [53]. The variety of need, type of breaks and range of impacts leads to difficulties when attempting to evaluate outcomes and effectiveness of services provided. A lack of thorough evaluation around the benefits of respite care has been attributed to concerns around existing research methodologies, ethical issues, sample sizes and the use of inappropriate outcome measures. A significant strength of this review, however, is that included studies were assessed as methodologically robust (high quality), which adds weight to, and increases confidence in the validity and reliability of the findings for informing care, practice and policy. However, it must be noted that not all children with an ASD require the same needs as respite care. While a number of studies did indicate the severity level of children with an ASD, others did not. Therefore, not all the results obtained in the reviewed studies are necessarily comparable to all families of children with an ASD.

A possible limitation to the methodology of this review is that inter-reliability checks were not carried out after validation of extracted data and identified themes.

Conclusion

This systematic review synthesized the available evidence on access to respite care from the perspectives of parents of children with an ASD and reported on the quality of the findings.

Respite care was viewed by parents as a vital resource to assist in the management of their child with an ASD, however, access to respite services is a significant challenge, and parents are prepared to go to extreme lengths to obtain appropriate respite services for their children. Findings highlighted that the provision of respite care may not be solely sufficient to alleviate care giver burden. One way of alleviating this is to consider the impact and benefit of providing respite within the home to reduce some of the distress experienced by parents and potential separation guilt often associated with respite care services. However, such a particular continuity of delivery would pose a challenge to services and warrants further consideration.

In the absence of appropriate services and defined pathways to support services such as respite care, overwhelmed parents and community providers of mental health resources may not be in a position to meet the specific needs of children with an ASD and families

which may be contributing to a direct increase in hospitalizations. This review discovered several barriers to respite care, all of which could be addressed in future service provision and research. Knowledge of parental experiences in caring for a child with autism is vital in addressing the need and type of respite care required for children with an ASD.

Abbreviations

CINAHL: Cumulative Index of Nursing and Allied Health Literature; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; ASD: Autism Spectrum Disorder SCIE; WHO: World Health Organization

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Declarations

All authors contributed in the design of the protocol and provided discussion and feedback during all stages of the systematic review before approving the full manuscript.

Authors' contributions

All authors contributed to the development of the research protocol and systematic review. VS provided specialist input for the review methods. MB and VS offered guidance on terminology and presentation and provided discussion and feedback during all stages of protocol development and systematic review findings. All authors have read and approved the manuscript.

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Availability of data and materials

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Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Appendix 3 Letter/email to gatekeepers of autism support groups

Date:

Re: Research Project: To explore access to respite care through the acute care services from the perspectives of parents of autistic children.

Dear XXXX

My name is Emma Cooke and I am contacting you in relation to the above named research project that is funded by the Health Service Executive and being carried out in part fulfilment of a PhD with Trinity College Dublin.

The aim of the study is to explore access to respite care through the acute care services from the perspectives of parents of autistic children. Key objectives of the study include:

- Developing an understanding on how parents access respite services through the acute hospitals
- Identifying any issues parents experience with accessing respite care
- Determining the preferred pathway to respite care by exploring their motivation for accessing respite care for their child through a particular pathway.

I am hoping to recruit participants from existing autism support groups and at this stage I am looking to set up a point of contact with all the support groups so I can communicate with them as to how best I can reach out to parents of autistic children who have experience of accessing respite care for their child through the acute care services/ hospitals.

The intention will be to meet with parent/s either face to face or over the phone and facilitate them to tell me about their experience.

I have posters, information leaflets, consent forms etc as part of recruitment pack that I will circulate at a closer time but for now, I am just looking to establish a point of contact within each support group. The research project is closely supervised by academic supervisors in Trinity College Dublin.

Please can you confirm if your support group would be willing to support the research project and if you could assign a point of contact who I can communicate with when recruitment starts and throughout the study.

If you have any further questions, please do not hesitate to contact me on emcooke@tcd.ie

I look forward to hearing from you and congratulations on all the amazing work that you do for autistic children and their families.

Kind Regards

Emma Cooke

PhD student

Appendix 4 Participant Information Leaflet (PIL)



IS THE STUDY **CONFIDENTIAL?**

All information will be recorded in confidence using a tape recorder and your personal information will be protected so that your identity is not revealed. Participant's names will not be used. A copy of your interview will be written out for you and you will be given the opportunity to review the information provided following the interview process.

WHAT ARE THE BENEFITS OF BEING INVOLVED IN THIS RESEARCH?

You will assist the researcher in identifying frontline challenges/issues related to accessing respite care services for children with Autism Spectrum Disorders.

There are no known direct disadvantages for you. It is noted that you will be dedicating some of your personal time to this study. Therefore, the researcher is committed to arranging a time and location that best suits your needs when carrying out interviews.

Findings may help to identify a requirement for a range of respite service to be developed in a coordinated and structured way to meet the complex needs of children with Autism Spectrum Disorders.



IS THERE ANY OTHER INFORMATION I SHOULD KNOW?

The researcher would like to strongly emphasize that partaking in this study does not prioritize the right to receive respite services nor will it enable quicker access. The information you provide will contribute towards the understanding of the current situation for accessing respite care in Ireland and may inform future models and service planning in the area of accessing respite care in Ireland.



HOW CAN I APPLY?



+353 87 0551190



EMCOOKE@TCD.IE



AM I A POTENTIAL PARTICIPANT?

If you meet the following criteria you may be eligible to take part in this study____

Parent or parents(s)/legal guardians of a child diagnosed with an Autism Spectrum Disorder who have previously accessed or are currently accessing respite care through acute care services.

DO I HAVE TO TAKE PART?

The study is entirely voluntary and participants are free to withdraw at any time, without giving a reason. Information provided during the study will not be used should you choose to withdraw at any stage.

WHAT WILL HAPPEN IF I PARTICIPATE?

You will be asked to chat with the researcher about your experience of accessing respite care through hospitals at a time and location that is most convenient to you. **Interviews can take place remotely using an encrypted version of zoom if you would prefer this option rather than meeting face to face.** You will be given time to ask the researcher any questions you may have before part.



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ARE YOU CARING
FOR A CHILD WITH
AN **AUTISM**
SPECTRUM
DISORDER?

Would you like to share your experiences on accessing respite care through hospitals/acute care services?

If so, here is a chance to talk about your experience.

Appendix 5 Invite letter to participants

Date:

Dear XXX

My name is Emma Cooke, I am a PhD research student at the Nursing and Midwifery Faculty in Trinity College Dublin. For my research study I have chosen a study which aims ***'To explore access to respite care through hospitals/acute care services from the perspectives of families of autistic children.'***

I am inviting you to participate in this study that focuses on identifying the pathways currently used by families of children with Autism Spectrum Disorders to access respite care. Information provided in this study will help to inform how pathways could be put in place to ensure access to respite care services is appropriate and to avoid unnecessary use of acute emergency departments.

This study has the potential to identify a requirement for a range of respite service to be developed in a co-ordinated and structured way to meet the complex needs of children with Autism Spectrum Disorders.

If you would like to participate in this study you will be required to give consent. It is my intention is to carry out interviews with either one or both parents if desired to discuss your experiences of accessing respite care through hospitals/ acute care services. This can be organised at a time and location that is convenient to you and can be facilitated via zoom also. The interview will be audio taped and all information will be confidential. No identifiable information will be included in the study. Also, your right to withdraw from the study at any stage is guaranteed.

If you would like to participate in the study, please contact me (Emma Cooke) and suitable arrangements will be made to carry out the interview. Please find attached a participant information leaflet outlining some questions that you may have. You will be given further opportunity to ask any questions on the day of the interview prior to taking consent.

If I do not hear from you I will assume that you do not want to participate and I will not contact you again.

If you have any questions before making a decision, please feel free to contact me at 0870551190 or via email at emcooke@tcd.ie

Yours sincerely,

Emma Cooke

Appendix 6 Consent form



Participant's consent form

I _____ (insert parent's name), parent of _____ (insert child's name) have read and understand the participant information leaflet to take part in the research study: 'To explore access to respite care through acute care services from the perspectives of parents of autistic children'.

Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General Information and Data Processing	Tick box
I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not have any impact on me and my child.	
I am aware that only the researcher and their corresponding academic supervisors will have access to the information provided.	
I understand that all information will be kept private and confidential and that my name and my child's name will be anonymised and not be disclosed.	

I am aware that confidentiality may have to be breached if the researcher becomes aware that an individual may be at risk.	
I understand that I will not be paid for taking part in this study.	
I am aware that participating in this research will not entitle me to support services for my child.	
I agree to being contacted by researchers by [email/phone] as part of this research study. I know how to contact the research team if I need to.	
I agree to allow my anonymised information to be shared with third parties including; national and international hospitals, and academic research institutions for the purpose of the research.	

I have received adequate information regarding the nature of the study and understand what will be requested of me.

I agree to take part in this research study having been fully informed of the risks, benefits and alternatives.

Participants Signature: _____

Contact Number: _____

Date: _____

Researchers Signature: _____

Date: _____

Appendix 7 School of Nursing and Midwifery Ethics Application Form.

School of Nursing and Midwifery Ethics Application Form

Applicant NAME:	Emma Cooke	
Supervisor NAME:	Professor Maria Brenner, Professor Valerie Smith, Dr.	
Working title of proposed study:	To Explore Access to Respite Care through Acute Care Services from the Perspectives of Families of Children with Autism Spectrum Disorders (ASDs)	
To be reviewed at which ethics committee meeting? (Please indicate the month)	May 2020	
Please tick which of the following ap-	An element of a taught postgraduate course	
	A full time postgraduate research project	✓
	Staff research project	
Type of application	Committee application	✓
	Fast-track Chair application	

ETHICS APPLICATION CHECKLIST

Forms without the checklist completed will not be processed.

Please tick the appropriate box	YES	NO
1. Is this a level 1 application?	✓	
2. Is this a level 2 application?		

Information on criteria for level 1 and 2 committees at <https://nursing-midwifery.tcd.ie/research/ethics/ethics-more.php>

Please answer all questions yes, no or not applicable (as appropriate) to all of the following questions. If you answer no to any question, please explain why and insert the relevant question number in the comment box at the end of the form.

Please tick the appropriate box	YES	NO	NA
1. Are you undertaking the proposed research study in your capacity as a staff member of the School of Nursing and Midwifery?		✓	
2. Are you undertaking the proposed research study in your capacity as a student of the School of Nursing and Midwifery?	✓		
3. If you are a student, has your supervisor read, approved and signed the completed form?	✓		
4. Have you signed the application form?	✓		
5. Have you checked that your application meets the criteria for this research ethics committee?	✓		
6. Are you recruiting participants for this study?	✓		
7. Are the participants purposefully recruited from a vulnerable group?		✓	
8. Is this a health research study?	✓		
9. Does the study include a health intervention?		✓	
10. Are you collecting personal or sensitive data?	✓		
11. Have you completed and included a risk assessment (for data) for this study: https://www.tcd.ie/info_compliance/data-protection/dnias/	✓		
12. Do you require a Data Protection impact assessment?		✓	
13. If applicable (i.e. you have answered yes to Q8 above), have you completed a Data Protection Impact Assessment for this proposed research? https://www.tcd.ie/info_compliance/data-protection/dnias/			✓
14. If accessing personal or sensitive data have you successfully completed Trinity GDPR online course? https://www.tcd.ie/info_compliance/data-protection/training/	✓		

Please tick the appropriate box	YES	NO
15. If accessing collecting personal or sensitive data, and you are an undergraduate or master's student, has your supervisor successfully completed Trinity GDPR online course? https://www.tcd.ie/info_compliance/data-protection/training/	✓	
16. If accessing collecting personal or sensitive data, have all Trinity members of the research team listed, successfully completed Trinity GDPR online course? https://www.tcd.ie/info_compliance/data-protection/training/	✓	
17. Have you included a copy of the questionnaire, interview template, data extraction list?	✓	
18. Are you collecting samples, no matter how small, that could be used for genetic testing?		✓
19. If applicable, have you included the consent form and participation information leaflet?		
20. If applicable, have you included all relevant letters of permission /access from external agencies/organizations/ schools/ industry /clinical site hosting the study, from the appropriate responsible persons/committees including access to databases?		
21. If applicable, have you included the letter of introduction to the participants?		
22. If applicable, have you included any posters/other material used to advertise the study?		
23. If collecting personal or sensitive data, have you included detailed information on how you will implement security measures to protect the personal data in all its forms and all types e.g. encryption?	✓	
24. Have you included any other documents that are needed for your study i.e. Garda clearance, debrief documentation?	✓	
25. If you are collecting personal or sensitive data do you agree to only use the minimum data necessary to carry out the research?	✓	
26. Have you ensured all the necessary security arrangements required to collect, process store and destroy any personal or sensitive data required for this study are in place?	✓	
27. Are there any contractual arrangements required in order to carry out this study?	✓	
28. Have you read and will you abide by the requirements regarding research reporting, data storage and reporting of adverse events?	✓	

If you have answered NO to any of the above questions (except 1,2, 6, 23) please explain:

Q7. The population in question are parents of children with Autism Spectrum Disorders. Children will not be interviewed as part of this research project.

Q9. There is no health intervention included in this study. The aim is to explore parents' experience of accessing respite care for their child with ASD through acute care services and gain a better understanding of the process.

Q12. A research risk assessment was completed for this study and reviewed by the data protection officer and approved (Appendix I). The data protection officer also advised that a data protection impact assessment was not required.

Q18. This study does not involve collecting samples for genetic testing.

Data Protection Checklist for Health Research

If your project relates to health research, then in order to comply with the requirements of the Health Research Regulations 2018, you must carry out the following:

Please mark with an X to indicate the steps have been completed and indicate the relevant section number in the application form.	YES – Section No	NO	N/A
1. Identify and document the data controllers and data processors.	Yes, section		
2. Ensure relevant contractual arrangements are in place.	Yes		
3. Identify and document funding bodies of any kind including commercial entities	Yes, section 5		
4. Identify third parties with whom data will be shared even if pseudonymised.	Yes section 3		
5. Ensure all members of the research team who will access to personal data have completed data protection training.	Yes		
6. a. Please confirm you have undertaken a risk assessment of your study using the TCD Risk Assessment document at the following link: https://www.tcd.ie/info_compliance/data-protection/dpias/	Yes		
b. Please carry out a Data Protection Impact Assessment (DPIA) if the risk assessment indicates this is required or the research is a high risk to individuals or participants and involves the use of genetic data, monitoring of behaviours, large scale processing of sensitive data, use of the data for new purposes or the linking of several datasets. https://www.tcd.ie/info_compliance/data-protection/gdpr/			✓
c. If a DPIA is needed you may need to apply to Level 2 Faculty of Health Sciences Research Ethics Committee. https://www.tcd.ie/healthsciences/research/ethics.php . Please contact snm.ethics.com@tcd.ie for further information.			✓

7. Ensure you only use the minimum data necessary to carry out the research.	Yes, see		
8. Implement controls to ensure the integrity and accuracy of data and determine when the data has been altered, disclosed or erased and by whom.	Yes, see Appendix IX		
9. Implement security measures to protect the personal data e.g. device encryption.	Yes, see		
10. Ensure the data is archived, anonymised or destroyed when the research is completed.	Yes, see Appendix VI		
11. Ensure that participants are provided with sufficient information about the use of their personal data via participant information leaflets	Yes, see Appendix VIII		
12. Obtain explicit consent for the processing of personal data for the research including the screening of individuals for research purposes.			N/A for anonymous

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School of Nursing and Midwifery Research Ethics Committee CONFIDENTIAL

Please complete all information relevant to your application

SECTION 1 – APPLICANTS’ DETAILS

1.1 Name, qualification and position of each person associated with this research project.

List details of all personnel involved with the research (excluding participants)

Investigator Title / First name / Surname	Title of Study	Postal Address	Email address	Tel No Work/Home	Role in research	Primary Employer (Hospital / University/ Other)	Current Occupation
Emma Cooke	To Explore Access to Respite Care through Acute Care Services from the Perspectives of Families of Children with Autism	30 Ashington Rise	emcooke @tcd.ie	0870551190	Principal Investigator	Health Information and Quality Authority (HIQA)	Healthcare Inspector
Supervisor (if investigator is a		Postal Address	Email address	Tel No Work Home	Role in research	Primary Employer	Current Occupation
Professor Maria Brenner. Supervisors: Prof	To Explore Access to Respite Care through Acute Care Services from the Perspectives of Families of Children with Autism	Trinity College Dublin	brennerm @tcd.ie smithv1@t	01) 896 1000	Primary Supervisor and	Trinity College Dublin	Professor in Children's N

SECTION 2 – DETAILS OF RESEARCH STUDY AND PARTICIPANT SELECTION

2.1 Working title of proposed study

To Explore Access to Respite Care through Acute Care Services from the Perspectives of Families of Children with Autism Spectrum Disorders (ASDs).

2.2 Dates and Duration of Study

Proposed start date for data collection: Q2- Proposed end date: 2021
Q3 2020

2.3 What are the primary location(s) for data collection? (e.g. classroom, participant's home, hospital/clinic, laboratory, place of convenience for participant). Please state here if the Lone Researcher Policy is applicable and how it is applied.

Participants will be recruited from identified Autism Support Groups (Appendix II) and will be asked to pick a place that is of convenience to them. It is anticipated that this place could be within a private room during the parent and child's attendance at the Autism Support Group and this setting/location will be encouraged by the principal investigator. However, if this is not convenient, the principal investigator will facilitate a location that is convenient to the participant. This could be the participant's home or a local café/coffee shop. The Lone Researcher's Policy (Appendix III) is applicable to all these locations and will be applied as follows:

-For interview appointments located at Autism Support Groups or cafes/coffee shops, these will be carried out during the working hours of 9-5pm where possible. If these interviews occur after working hours or at weekends, one of my supervisors will be notified and necessary arrangements will be put in place to ensure my location and expected times for arrival and completion are known at all times.

-In the case of a home visit, a supervisor will be informed of the details of the home visit including time and location and will be informed when the visit has been completed. Both my supervisor and I will ensure that we are contactable by phone for the duration of the visit. Additional steps as set out under the section 'Process for monitoring visits' in the TCD Lone Researchers Policy (Appendix III) will also be followed.

2.4 State research aim(s) and objective(s), research question or hypothesis (as appropriate).

Research Aim

The overall aim of the study is to explore access to respite care through the acute care services from the perspectives of parents of children with Autism Spectrum Disorders (ASDs) within an Irish healthcare context.

Research Objectives

1. To systematically review the evidence on access to respite care for children with an autism spectrum disorder at the acute and primary care interface.
2. To develop an understanding on how parents access respite services through the acute hospitals.
3. To identify any issues they experience with accessing respite care.
4. To determine the preferred pathway to respite care by exploring their motivation for accessing respite care for their child through a particular pathway.

- 2.5 Provide brief outline of the project (maximum 400 words). This must include the background, research approach, study design and data collection methods. Please indicate the method of sampling you intend to use, the population size (or approximation) and sample size.

Background: Population prevalence estimates by the World Health Organisation suggest that 1 in 160 children worldwide has an Autism Spectrum Disorder (ASD) (WHO 2017). Parents are, in most cases, the primary caregivers for children with ASD which can often be a complex job as parents deal with challenging behaviours, while balancing all other aspects of family life and work commitments. Consequently, the complexity of the parental role and well-being of these parents is increasingly becoming a public health issue (Kuhlthau et al. 2010, Nicholl & Begley 2012, Smith et al. 2015). The adverse effects of this reality is burn-out within a short period of time (Woodgate et al. 2015). Respite care has been identified as one of the biggest unmet needs of parents caring for a child with ASD (Whitmore & Snethen 2018). Having access to respite care can potentially reduce stress among parents (Whitmore 2017) and assist parents to cope with the hidden burden associated with raising a child with ASD. However, accessing respite care services for children with an ASD can often be a daunting and exhaustive process, with parents sometimes forced to access acute hospital services as an initial point of contact for respite care or in a crisis situation.

Methodology: This study is a qualitative design using an interpretive phenomenological approach. The study will use a non-probability purposive method of sampling as it contributes to an understanding of phenomena (Cresswell & Plano Clark 2011) and involves the deliberate selection of participants with certain characteristics about a particular topic (Doody & Noonan 2013). One to one semi-structured interviews will be carried out in a manner most convenient for the participant. It is anticipated that 32 research participants will be recruited for the study (30 for study and 2 for pilot study). The concept of data saturation and data sufficiency will be applied for guiding decisions related to enacting closure on the information provided by research participant. Data saturation will be reached when further collection of evidence provides little in terms of further themes, insights, perspectives or information gained during interviews. To test that data saturation has been achieved, the guiding principles of data sufficiency as outlined by Paterson et al. (2001) will be applied to guide the sample size of the data interpretation. The principles of data sufficiency suggest that the data should be sufficient to permit comparisons among selected dimensions and that the data should be sufficient to answer the research question.

- 2.6 Describe exactly how participants will be recruited and what steps you will take to access the sample.

The population of interest in the study are parents of children with Autism Spectrum Disorder. Participants will be recruited via gatekeepers from a number identified Autism Support Groups (Appendix II). A letter (Appendix IV) requesting permission to conduct the study will be sent to the identified gatekeepers within the Autism Support Groups outlining the aims and objectives of the study. Posters (Appendix V) about the study will be displayed at the Autism Support Groups and circulated to members' emails/ support group networks or social media. Participant information leaflets (PILs) (Appendix VI) will also be circulated by gatekeepers and the principal investigator at group meetings along with posters.

Interested participants will be encouraged to contact the primary researcher to ask any further questions and to determine if they meet the inclusion criteria. If the criteria is met by the participant, a letter of invite (Appendix VII) will be sent to the participant outlining the next steps of contacting the researcher to make suitable arrangements and to gain consent from the participant.

- 2.7 Who is the gatekeeper(s) for this study (if applicable)? What is the relationship, if any, between the gatekeeper and the prospective participants?

Gatekeepers have been identified in a number of Autism Support Groups. These are essentially individuals who have responsibility for co-ordinating and running the Autism Support Groups. Potential participants will be familiar with these gatekeepers, however, the role of the gatekeeper will be in assisting the principal investigator in identifying participants and circulating recruitment material only.

- 2.8 List your exclusion/ inclusion criteria for participant selection:

Inclusion criteria:

-Parents/legal guardians of a child with an Autism Spectrum Disorder who have previously accessed or currently accessing respite care through acute care services.

Exclusion criteria:

-Parent(s)/legal guardians who are caring for a child < than 2 years old with signs of an Autism Spectrum Disorder.

-Parent(s)/legal guardian of a child with an Autism Spectrum Disorder who have no experience accessing respite care.

SECTION 3a – CONSENT (Please amend if using an anonymous survey)

3a.1 How will you ensure explicit consent is obtained from the research participants?

Give details of who will take consent and how it will be done in full.

Please attach a copy of the invitation letter, consent form and the participant information leaflet (PIL).

Explicit consent: Informed consent that is documented. (You must maintain evidence that it has been recorded). See guidelines on how to prepare these documents: https://www.tcd.ie/info_compliance/data-protection/health-research/ and adapt examples accordingly to suit your study and participants. Please note that explicit consent (freely given, specific, informed and unambiguous) is now mandatory under the General Data Protection Guidelines (GDPR) and the Health Research Regulations (Data Protection Law) unless data are irreversibly anonymized (no key held) or a consent declaration has been obtained from the Health Research Consent Declaration Committee (HRCDC). See [here](#) for further information.

The principal investigator identifies that obtaining unambiguous, affirmative and informed consent is an ethical and legal requirement for research involving human participants. Obtaining informed consent for this research will involve informing the participant about the purpose of the study, procedures to be undertaken if they wish to take part, potential risks and benefits of participation, expected duration of study, an explanation of how personal data will be processed, purpose of processing, intended retention, confidentiality and anonymity of data gathered and that participation is entirely voluntary. This will be achieved by the following;

-When the participant has expressed their interest in the study and following their review of the participant information leaflet (Appendix VI) and accepting the letter of invite (Appendix VII), suitable arrangements will be made to carry out the interview. Prior to commencing the interview, the participant will be afforded time to ask any more questions and following this a consent form (Appendix VIII) will be signed by the participant(s). Issues relating to data protection and processes in place to support any data breaches will be outlined verbally and confirmation that the participant has received this information will be documented in the consent form. Assurance around the confidentiality of data is outlined in the participant information leaflet (Appendix VI).

-Sufficient information and answers to questions will be provided to participants in a language which is easily understood by him/her, so that he/she can make the voluntary decision regarding their participation in the research study.

-Participants will be informed of their entitlement to withdraw from the study at any time and that all identifiable data will then be destroyed. This will be outlined at various stages, for example, this will be covered in the participant information sheet, letter of invite and consent form and again at the outset of the interview.

N. B. Please indicate if you have modified the consent form and/or the participant information leaflet included in the link above?

Yes

☒

No

☐

N/A

☐

If yes please highlight the changes made and why these were necessary.

Please note that both the consent form and the PIL have been reviewed and approved by the Data Protection Officer (DPO) as set out in Appendix I.

Consent Form: Changes made in the overall presentation of the PIL, however the content remains the same.

PIL: Changes made in the overall presentation of the PIL, however the content remains the same.

N.B: If the template is changed substantially this will need to be reviewed by the Deputy DPO for Research and permission to use the modified forms must be attached to your application.
Email: researchDPO@tcd.ie

N.B: For anonymous surveys please indicate where in the process the participant indicates consent and ensure they can withdraw their data prior to submission (please see Code of practice at <https://nursing-midwifery.tcd.ie/research/ethics/ethics-more.php>)

Participants will be informed of their entitlement to withdraw from the study at any time and that all identifiable data will then be destroyed. This will be outlined at various stages, for example, this will be covered in the participant information sheet, letter of invite and consent form, at interview and following interview

3a.2 What is the time interval between giving information and seeking consent?

During this time prospective participants should receive a letter of invitation, a Participant Information Leaflet (PIL) and a Consent Form to consider. It is recommended that a period of seven days be provided for reflection. If less than this, please justify.

Participants will receive the participant information leaflet at least 2-3 weeks before consent will be sought to allow time to make a decision and contact the researcher to seek further information.

3a.3 Data Subject Rights

Describe here how participants will be informed of what data will be collected (and why) and how they can exercise their rights?

These include:

- right of access;
- right to rectification;
- right to erasure;
- right to object to processing based on legitimate or public interest;

- right to data portability;
- right to object to profiling or making decisions about individuals by automated means?

What measures will be put in place to ensure compliance with this obligation? ? How will you deal with any data subjects rights? Do you have a procedure in place if a data subject wishes to withdraw from the study for example?

Participants will be informed about the purpose of the study, procedures to be undertaken if they wish to take part, potential risks and benefits of participation, expected duration of study, an explanation of how personal data will be processed, purpose of processing, intended retention, confidentiality and anonymity of data gathered and that participation is entirely voluntary.

The researcher will adhere to the fundamental data subject rights in line with GDPR. This will include the following;

-Participants will have the right to access their personal data that is processed by the researcher. This request will be responded to in one month and facilitated by the principal investigator.

-Participants will have the right to request rectification of their personal data, including the correction of errors and the updating of incomplete information. This will be achieved through member checking which will provide each research participant an opportunity to review their transcripts and data for factual accuracy purposes. Once they have approved their transcripts and are happy, a copy of their final transcript will be giving to them to keep.

-Participants will be afforded the right to erasure by stopping all processing of their data and agreeing to erase their personal data.

-Participants will be afforded the right to restrict the processing of some of their personal data if they wish. For example, if they choose to not answer some of the questions in the questionnaire.

-Participants will be informed about the uses of their personal data in a clear manner at the outset and prior to consent being obtained. Participants will also be informed about the actions that can be taken if they feel their rights are breached.

-Participants will be afforded the right to data portability whereby their request to send their personal data file electronically to a third party will be facilitated.

How to Make an Access Request

Participants will be encouraged to contact the principal investigator if they wish to make a request to access their data again after member checking has been completed and while final transcripts are being processed. Participants will be given final copies of their transcripts.

The principal investigator will have overall responsibility for the data and will have independent oversight of data access and sharing. The decision to show and share data to those identified in the study will be done only when it is considered necessary and appropriate and for academic guidance from my supervisors.

Any data security breaches will be reported to the information complaints officer immediately by the researcher in line relevant Data Protection Policies and Trinity College Dublin's Policy on Good Research Practice (XVII). These include but are not limited to:

- Loss/theft of mobile computing equipment
- Unauthorised access to data
- Unauthorised copies taken of data
- Unauthorised removal of data from College premises

After reporting the incident the principal investigator will complete the Personal Data Security Breach Report form and email it to the Information Compliance Officer as soon as possible. Following this, the information complaints officer in conjunction with any appropriate members of staff, will take the necessary steps (in line with policy) when responding to the breach.

N.B: For anonymous surveys please indicate in the Participant Information Leaflet (in addition to the usual information) specifically how a participant can withdraw (up to what point), voluntariness, that personal information is not being held by the research team, all data are non-identifiable and what will happen to the data. Please refer to the SNMREC Code of Practice at <https://nursing-midwifery.tcd.ie/research/eth-ics/application-process.php>)

Appendix VI (Participant Information Leaflet) outlines the participant's right to withdraw and how personal information will not be used.

SECTION 3b – CONFIDENTIALITY, DATA PROTECTION, DATA PROCESSING AND DATA STORAGE

3b.1 Does the study involve collecting, using, accessing or sharing personal data¹?

Yes ☒ No ☐

If yes please give details of the personal data to be collected (Participant identities, contact details, consent forms, code keys that link personal data to other data).

Please specify details for all that apply and likewise for all media forms utilised (online, hard copy, audio etc.). Under the Data Protection Law, the collection of personal data is to be kept to a minimum. Please indicate how the personal data being collected relate to the aims and objectives of the study.

¹ Personal data is information which can identify a person – in particular: a name, address, email, telephone number, an identification number, location data, an online identifier, or and IP address

Data Collected	Justification	Processing Activity
Participant names	Identification, so that we can apply matching codes across data sets.	Excel database. See attached Appendix IX 'Data Management Plan under '3.1 Managing, storing and curating data.
Written consent	Legal basis for processing.	Paper forms, stored in locked filing cabinet. See attached Appendix IX 'Data Management Plan under '3.1 Managing, storing and curating data. Access restricted to principal investigator only.
Code keys		Paper forms initially and processed into an excel database. See attached Appendix IX 'Data Management Plan under '3.1 Managing, storing and curating data. Access restricted to principal investigator only.

3b.2 Does the study involve collecting, using, accessing or sharing sensitive data²?

☐

Yes

☒

No

If yes please give details of the sensitive data collected. Please indicate how collecting such data is relevant to the aims and objectives of the study.

Data Collected	Justification	Processing Activity
Demographic Questionnaire (Appendix XV)	Legitimate interest of the data controller. To support further analysis and evaluation of the research's objectives. This will only be collected and processed after receiving the	Paper forms initially and processed into excel database. See attached Appendix IX 'Data Management Plan under '3.1 Managing, storing and curating data. Access restricted to principal investigator only.

² Sensitive personal data means genetic, biometric and health data, as well as personal data revealing racial and ethnic origin, political opinions, religious or ideological convictions or trade union membership.

- 3b.3 Who will control i.e. determine the purpose and way in which the personal and sensitive data is used and be responsible for this use? (i.e. data controller(s), this will most likely be an institution).

Trinity College Dublin is the data controller for this research project.

- 3b.4 Specify the name/s of any personnel who will have access to the personal and sensitive data?

Please identify the affinities and roles of those individuals who are not employees or students of Trinity or their affiliated hospitals or institutes. For other personnel such as data inputters and transcribers see 3b.5. (Insert multiple lines for more individuals).

Personnel names	Data access to	Format available to these
Prof Maria Brenner, Prof Valerie Smith, Dr. Colman Noctor	Anonymised Interviews and demographic questionnaires from participants	Excel spreadsheets and interview transcriptions. Note: The principal investigator will have overall responsibility for the data and will have independent oversight of data access and sharing. The decision to show and share data to those identified in the study will be done only when it is considered necessary and appropriate and for academic guidance from my supervisors.

- 3b.5 Specify the name/s of any service providers such as transcribers, third party's carrying out analysis, data collection etc.? Indicate below the format in which they will receive the data

i.e. original, anonymised, non-anonymised or pseudonymised. Please confirm and attach the agreement that is in place with the provider of this service.

Personnel names	Data access to	Format available to these
<i>EXAMPLE: Transcriber's name</i>	<i>EXAMPLE: Participant names</i>	<i>Original, anonymised, non-anonymised or pseudonymised.</i>
<i>EXAMPLE: Statistician's name</i>	<i>EXAMPLE: Written consent</i>	
<i>EXAMPLE: Data collector name</i> <i>i.e. hired personnel or</i>	<i>EXAMPLE : Participant names and contract details, written con- sent</i>	

- 3b.6 During and after the study, what steps will you take to protect the confidentiality of personal or sensitive personal data collected as part of the project? (e.g. Participant identities, contact details, consent forms, code keys that link personal or sensitive personal data to other data, data collected from patient/client records). Please specify details for all that apply and likewise for all media forms utilised (online, hard copy, audio etc.)

Please note: Double encryption is required on all computers, laptops and mobiles devices. Personal data should not be stored on portable devices unless absolutely necessary and it should be stated here if this is necessary and why. Cloud storage of personal data require secure clouds as recommended by TCD and if cloud storage is used it should be indicated here

Personal/sensitive data type and	Format	Comments on protection
Personal Data-Participant Names	Original, anonymised, non- anonymised or pseudonymised. original and anonymised	(paper forms, excel databases) See attached appendix 'Data Management Plan' under '3.1 Managing, storing and curating data' Confidential research data and records will be stored securely in lockable filing cabinets or a lockable room with controlled access within allocated desk and storage at Trinity College Dublin

Written Consent	Original Hard copy Hard Copy	See attached appendix 'Data Management Plan' under '3.1 Managing, storing and curating data'
Sensitive data	Original Hard copy	See attached appendix 'Data Management Plan' under '3.1 Managing, storing and curating data'

- 3b.7 Please specify that you have a log and controls in place to record who accesses, changes, discloses or erases all personal data collected.

A log of any person who has accessed the data and any necessary changes that have been made will be maintained for the purpose of an audit trail. This will be centrally co-ordinated and controlled by the principal investigator.

- 3b.8 The provision of training in data protection for anyone carrying out health research is mandatory. All researchers and students are expected to have completed the GDPR and Health Research Training to enable them to have permission to assess personal and sensitive data. Please provide details of the training undertaken by those named in 3b.4.

The Principal Investigator completed the TCD Online General Data Protection Training Module in March 2020

- 3b.9 Indicate clearly when processing (i.e. pseudoanonymisation, anonymisation, deletion) will occur and where. Please indicate who will be responsible for these processes and who will retain the key code if applicable

Data collected in this study is anonymous and coded – each participant will be assigned a unique numerical identifier. The principal investigator will retain the 'key' to the coded data to re-identify the data.

The principal investigator intends to audio record the interview as it will provide an accurate account of the responses and can be replayed for analytic and memory purposes. Interviews will then be transcribed by the principal investigator soon after the interviews have occurred onto a Microsoft Word document stored on a password protected, encrypted laptop. Audio recordings will be downloaded to the laptop after each interview and the original will be deleted from the digital voice recorder. These audio recordings will also be password protected known only by the principal investigator. Access will only be granted to supervisors for academic guidance only. Data analysis will primarily take place by the principal investigator either in Trinity College Dublin or in a secure lockable home office.

At times, data will be brought from the supervisor's home to the principal investigator's supervisor(s) in Trinity College for review and academic guidance. This occurrence will be kept to a minimal to avoid any unnecessary transfer of data. In this case, data will be kept with the principal investigator at all times and never left unattended. The data will be kept on an encrypted laptop with access codes known only to the principal investigator. This will only occur once all data has been anonymised.

3b.10 Are there any potential confidentiality issues through identification of the study site?

Yes ☒ No ☐

If yes, please expand.

Confidentiality will be maintained by avoiding attributing information in the findings which would identify the participants and will be achieved by conducting interviews in a private room. Participants will receive a numerical code and their names will not be used. Furthermore, confidentiality will be maintained through the processes put in place to maintain data security for the information generated during interviews as outlined in the data management plan. If a possibility arises where it may become necessary to breach confidentiality (i.e. child protection concerns), participants will be informed about this as consent is being taken. When obtaining consent parents will be informed that the principal investigator is legally obliged to report any thing which is deemed to put a child at risk. Evidence that this has been discussed and the parent understands this requirement will be documented and verified on the consent form (Appendix VIII).

3b.11 Accepted best practice recommends secure retention of personal non-anonymised (of all the types listed previously) for seven years. If there is any reason to apply for a variation from these guidelines, please give details and provide a justification.

Consent forms must be kept for seven years. In the case of students these must therefore be retained by the supervisor. The Participant Information Leaflet must include information regarding the anonymisation and destruction of personal and sensitive data and the implications of this i.e. once anonymised cannot be withdrawn.

Personal/sensitive data type and media format	Format	Retention time, when it will be destroyed
Participants Names	original, anonymised and pseudonymised.	7 years (See section 3.2 of Data management Plan)

Consent	Hard copy forms	7 years (See section 3.2 of Data management Plan)

3b.12 If identifiable data or pseudoanonymised data or material (photographs etc.) will be retained after the study is completed, is it stated on the informed consent form that this will

be done and that material will not be used in future unrelated studies without further specific permission being obtained? N/A

☐ Yes

☐ No

3b.13 Researchers must allow the participant access to their data and transcript, if they so wish.

Please give details of these arrangements also in the PIL.

Yes, participants will be given the opportunity to review transcripts based on audio recordings for factual accuracy purposes.

Participants will have the right to access their personal data that is processed by the principal investigator. This request will be responded to in one month.

-Participants will have the right to request rectification of their personal data, including the correction of errors and the updating of incomplete information. This will be achieved through member checking which will provide each research participant an opportunity to review their transcripts and data for factual accuracy purposes. Once they have approved their transcripts and are happy, a copy of their final transcript will be giving to them to keep.

-Participants will be afforded the right to erasure by stopping all processing of their data and agreeing to erase their personal data.

-Participants will be afforded the right to restrict the processing of some of their personal data if they wish. For example, if they choose to not answer some of the questions in the questionnaire. Participants will be informed

3b.14 Are there any elements of genetic testing involved in the proposed project?

☐ Yes

☒ No

✓

If yes, please explain and note that you must contact researchDPO@tcd.ie and conduct a DPIA, see [here](#).

SECTION 4 - RISK, BENEFIT AND HARM

4.1 Are there ethical issues or problems which may arise with the proposed study and what steps will be taken to address these?

The Nursing and Midwifery Board of Ireland (NMBI) states that nurses must be aware of the ethical principles when undertaking or participating in research (Ethical conduct in research: Professional Guidance, NMBI, 2015.)

Justice or fair treatment of participants will be achieved by ensuring that all information given to potential participant will be in such a manner that affords each potential participant equal opportunities to participate in the study (Houser, 2013). Respect for persons/autonomy refers to a person's right to self-determination and the right to full disclosure (NMBI 2015). Parents will have the freedom to choose to participate in the research. A letter of invitation (Appendix VII) and a participant information leaflet (Appendix VI), will explicitly inform potential participants that this study is voluntary. Full disclosure will be ensured by detailing the purpose and significance of the study and describing its benefits and drawbacks (NMBI 2015, Bryman 2012).

Participants will be protected from harm by the principles of beneficence and non-maleficence. Non-maleficence relates to protecting the participants from harm including the appropriate storage of data which has been addressed throughout this application process. A fundamental ethical principle in research is beneficence, which involves the promotion of good for others. Research should benefit participants and society at large (Parahoo 2014). It is anticipated that findings from this research can be used to inform healthcare policy and contribute to a body of knowledge on access to respite care for children with ASD.

It is the principal investigator's responsibility to balance the potential benefits against the potential risks of participating in a study and to minimise potential risks as best as possible. Support structures will be in place for parents to access if necessary (Appendix X) Fidelity, which refers to the trust between researchers and participants will be achieved through veracity. Anonymity and confidentiality will be affirmed through the use of code names for participants and by de-identifying transcripts. The principal investigator will acknowledge that complete anonymity cannot always be guaranteed in social research. The principal investigator is bound to confidentiality, and adheres to the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (Nursing and Midwifery Board of Ireland 2014).

Justice and fairness will be upheld through the equal opportunity for all eligible participants regardless of nationality, language and age. Additionally, justice will be upheld by ensuring that all findings and results presented will be that of actual facts stated in the interviews. All participants' experiences and perceptions will be portrayed as they have done so in the interviews, no false information or accusations will be included in the final report

Disclosure of Child Protection Concerns

The principal investigator has a duty to safeguard participants and to protect their rights. Should a participant disclose information that a child is being/has been harmed or is at risk, the principal investigator must communicate and escalate these concerns via the appropriate channels. The principal investigator will advise the participant that they have concerns and will need to report these concerns. Confidentiality can never be promised to a person making a disclosure subject to the provisions of the Data Protection Acts. Furthermore, it will be clearly stated on the information leaflet that if the principal investigator suspects that a child is at risk throughout the research process, it will be their legal obligation to report these concerns. 4.24.2 Is there potential for an adverse outcome (for example, illness, pain, discomfort, distress, inconvenience) for research participants? NOTE: for the protection of both the investigator and the participant, this list must be comprehensive and must also appear in full in the Participant Information Leaflet.

There is no known immediate potential for an adverse outcome, however, risk to participants is present in all research (Stahlke 2018). Support structures will be in place for parents to access if necessary (Appendix X) and the principal investigator will discuss any concerns with supervisors. The principal investigator acknowledges that participants will be dedicating some of their personal time to take part in the study which may cause some inconvenience.

Adverse events, although unlikely, that may occur will be reported to the School of Nursing and Midwifery Research Ethics committee.

Please note that any substantive adverse events must be reported to the School of Nursing and Midwifery Research Ethics Committee: snm.ethics.com@tcd.ie

4.2 Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting?

☐ Yes ☒ No

If Yes, give details of procedures in place to deal with these issues. Give specific names of counselling or other support services that might be offered to participants.

Acknowledging the stress associated with caring for a child with ASD, it is possible a parent may become upset during interview when reflecting on their situation and personal circumstances. A list of potential supports for parents has been developed (Appendix X) and the principal investigator will encourage the use of other support services such as a participants' General Practitioner depending on the situation. The Autism Support Groups also offer parents additional supports that the principal investigator can link the parent with if required.

4.3 Is it possible that criminal or other disclosures could be made during the study that would require action (e.g. during interviews/group discussions, or use of screening tests for drugs, during evaluation of work)?

☐ Yes ☒ No

If yes, please provide specific detailed procedures in place to deal with these issues and who will be informed if disclosures occur. Please list below details of any support services to be offered to participants (if applicable). This information needed to be also included in the Participant Information Leaflet.

Disclosure of Child Protection Concerns

The principal investigator has a duty to safeguard participants and to protect their rights. Should a participant disclose information that a child is being/has been harmed or is at risk, the principal investigator must follow national child protection guidelines and protocols by communicating and escalating these concerns via the appropriate channels. The principal investigator will advise the participant that they have concerns and will need to report these concerns. Confidentiality can never be promised to a person making a disclosure subject to the provisions of the Data Protection Acts. Furthermore, at the beginning of the interview, the principal investigator will inform the participant that it is their legal obligation to report any child protection concerns if the principal investigator suspects that a child is at risk throughout the research process.

- 4.4 Is there any potential benefit to research participants through taking part? Please outline only direct benefits.

There are no direct benefits to research participants taking part in the research study. Participants will be explicitly informed that partaking in the study will not entitle them to any access or quicker access to support services that they may require. However, the study's endpoint has the potential to identify a requirement for a range of respite service to be developed in a co-ordinated, integrated and structured way to meet the complex needs of children with ASD.

SECTION 5 - FUNDING AND PAYMENT

- 5.1 Outline sources of funding for the study if applicable and how you will manage any possible conflict between the funders of the study and the aims and results of the study.

This research study is funded by the HSE Integrated Clinical Care Programme for Paediatrics. Payment has been provided in the form of funding towards academic registration fees and tuition. Funds and potential conflicts will be managed by the terms of the contract signed by both HSE and Trinity College Dublin.

- 5.2 Will the results of the study will be used or disclosed for commercial purposes? If yes please also

indicate in the Participant Information Leaflet and indicate that the participant will not commercially benefit. In the case of commercial based research you must contact research-DPO@tcd.ie

Yes ☐

No ☐ ✓

- 5.3 Will payment be made to research participants?

YES	NONE OTHER THAN MINIMAL EXPENSES TO COVER TRAVEL COSTS ETC	NO
		X

5.4 If you answered yes to question 5.3, please specify for what purpose the payment will be made and the amount per participant. N/A

SECTION 6 – ETHICAL APPROVAL FROM OTHER COMMITTEES

Ethical approval from the School of Nursing and Midwifery Research Ethics Committee, if granted, does not supersede any requirements external sites may have that similar applications be made to local ethical approval bodies in advance of the study commencing.

6.1 Has ethical approval been sought from any other organisation(s) in which the study will place?

YES	☒	(If you answer YES go to question 6.2)
NO	☐	(If you answer NO go to question 6.3)
N/A	☐	(If N/A please explain why below)

Please note that ethical approval was granted by ethics committees outlined below for this study.

Trinity School of Nursing and Midwifery Ethics- chair approval letter attached (Appendix XI)

CHI at Crumlin- approval letter attached (Appendix XII)

CHI at Temple Street- approval letter attached (Appendix XIII)

CHI at Tallaght (Appendix XIV)

All aspects of the study in terms of aims, objectives, study design, methods, methodology, data collection and analysis remain the same, however, there is a change in where the population are being recruited from. It was intended to originally recruit participants from the three paediatric hospitals all of which granted ethical approval. However, a collective decision was made to recruit from Autism Support Groups and as the original granting ethics committee was CHI at Crumlin Hospital, they could not support recruitment of participants outside the hospital setting. TCD ethics committee had originally granted chair approval only. Following notification of this change in recruitment to the Trinity Ethics Committee, it was advised to re-apply to Trinity Ethics for Committee Approval.

6.2 If you have answered YES to question 6.1, from where has approval been sought and has ethical approval been granted? Please give the name of committee, the application reference number, date of application and approval and any amendments that were requested by the granting committee. If a DPIA was required for this application please insert as an appendix to this application.

YES	Awaiting Reply	NO	If No, please explain why.

- 6.3 If you have answered NO to question 6.1, is it your intention to seek ethical approval from the organisation(s) in which the study will take place?

YES	NO	IF NO, PLEASE EXPLAIN WHY

SECTION 7 - DECLARATION OF APPROVAL AND SIGNATURES

- 7.1 If applicable please state briefly what preparatory work you will need to undertake to become competent in your chosen method of data collection (e.g. training in the use of a standardised schedule/test, clinical procedures, or practice in conducting an interview)

Preparatory Work

NVivo Training-to be arranged.

GDPR training-completed March 2020

Advanced Training in Excel-completed and certified 2019

Child Protection Training -completed and certified 2018

- 7.2 LEAD INVESTIGATOR DECLARATION

I confirm that the information provided in this protocol is correct, that I am not aware of any other ethical issue not addressed within this form and that I understand the obligations to and the rights of participants (particularly concerning their safety and welfare, the obligation to provide information sufficient to give informed consent, the obligation to respect confidentiality and all the obligations as set out in the Declaration of Helsinki (appendix attached) governing the conduct of research involving human participants) and/or other relevant guidelines including the GRPR regulations and the Health Research regulations 2018. I undertake to provide an annual report within twelve months of the date of approval, yearly thereafter and a final project report within 6 months of the completion of the study to the School of Nursing and Midwifery Research Ethics Committee with details of the number of participants recruited and the number who have completed the study.

If relevant please provide a report outlining any adverse events or complaints that have arisen related to the study. The final project report must also include information on where the data are to be stored and who will be responsible for its destruction. Any serious adverse effects will be reported immediately to the School of Nursing and Midwifery Research Ethics Committee. snm.ethics.com@tcd.ie.

	Emma Cooke
STAFF / STUDENT I.D. No.	16343471
	School of Nursing and Midwifery, Doctor in Philosophy in Nursing

COURSE OF STUDY:	Doctor in Philosophy in Nursing and Midwifery (PRNM-GNUR-2P) 283	YEAR	2020

Professor
in
Children's
Nursing

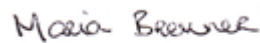
SIGNATURE:		DATE:	4 th May 2020

Head of Discipline for Children's Nursing

School of Nursing and Midwifery,

7.3 RESEARCH SUPERVISOR

State the educational value of this research: This study has the potential to identify a requirement for a range of respite services to be developed in a co-ordinated and structured way to meet the complex needs of children with ASD. By exploring parents' experiences of accessing respite care through acute care services, the potential findings from this study can underpin the development and planning of an integrative and responsive respite service for children with ASD.



Signature of the Supervisor:

Professor in Children's Nursing Trinity College Dublin, the University of Dublin

Appendix 8 Ethics approval letter



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Emma Cooke
30 Ashington Risem
Navan Road
Dublin 7

Date: June 2nd 2020

Application Ref: COM_20_19/20

Study title: To Explore Access to Respite Care through Acute Care Services from the Perspectives of Families of Children with Autism Spectrum Disorders (ASDs).

Dear Emma Cooke,

I am pleased to inform you that your ethics application has been granted approval.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Joan Lalor'.

Prof Joan Lalor
Chair of SNMREC

Scoil an Altranais agus an Chnáimhseachais

Dámh na nEolaíochtaí Sláinte,
Coláiste na Tríonóide, Baile Átha Cliath,
Ollscoil Átha Cliath,
24 Sráid D'Olier,
Baile Átha Cliath 2, Éire.

School of Nursing and Midwifery

Faculty of Health Sciences,
Trinity College Dublin,
The University of Dublin,
24 D'Olier Street,
Dublin 2, Ireland.

+353 1 896 2692
nursing.midwifery@tcd.ie
www.nursing.midwifery.tcd.ie

Appendix 9: Interview guide

Each interview will begin with a welcome greeting and an overview of the research study. Each participant will be provided with assurance of confidentiality and anonymity at the outset of each interview. Participants will also be reassured around their choice to terminate the interview at any time without obligation to provide a reason. The following biographical and socio-demographic details will be collected as follows at the beginning of the interview. While the principal investigator is setting up for the interview, the participant will be asked to complete a brief questionnaire (Addendum I).

1. Socio-demographic Details

Biographical Details	
Participant Identification Number	
Date of Interview	
Location of Interview	
Socio-demographical details	
Age and sex of parent	Age: yrs Sex: M ☐ F ☐ Other ☐
Age and sex of autistic child	Age: yrs Sex: M ☐ F ☐ Other ☐
Relationship to autistic child (mother/father)	

2. Interview Questions

Each interview will begin with an invitation to the parent(s) to describe their experience of being a parent of an autistic child.

- **General introductory question:** Could you tell me what it means to be a parent caring for an autistic child?
- Could you tell me about your experience accessing respite care for your child?
- Were there any key changes for you after accessing respite care through the acute care services? If so, why do think they occurred?
- Has the current COVID-19 situation impacted on your access to respite care? If so how?

Prompts

- Tell me more
- Talk me through that.
- Can you elaborate on what you mean by?
- Could you give more detail on that?
- Do you have any examples of that?
- Do you mean that..?
- Is it correct that...?
- **Close out question:** Is there any other information that you would feel would be of benefit to this study?

Thank you for taking part in the interview (Remind about confidentiality)

Addendum I: Questionnaire to be completed by participants

Participant Identification Number	
Total number of children in the family	
Age of child at diagnosis	
Public or Private diagnosis?	
Age of child when respite services were initially sought	
Type of respite care currently in receipt of (e.g. residential/long stay, short stay)	
How many of hours of respite do you and your child receive (e.g. hours/days)	
Current County Residing In	

Appendix 10 Excerpt from reflective diary.

Q. What is my identity as the researcher in this study?

'I have considered my identity as the researcher in this study and how it may impact on the research process. I am a qualified paediatric nurse and have worked in a tertiary referral paediatric hospital for a number of years and have been actively involved in the care and management of autistic children in the acute care setting. In addition, I have a young family relation with autism which has provided me with a consistent awareness and insight into the lives of autistic children and the many challenges parents can experience on a daily basis when caring for an autistic child. However, I am equally aware that while I have some experience of caring for an autistic child in an acute care setting, this is in a professional capacity and is very much 'my' experience and the need for a more holistic understanding of what parents' experiences are in terms of accessing respite care services for their child requires more exploration and understanding.

I chose to research this topic as it is an area which is not well researched but anecdotally requires significant improvement. My exposure to caring for autistic children in the acute care setting and hearing about the challenges some parents encounter when seeking respite care for their child left me questioning how and why there has been little research carried out on the area considering the rising prevalence in autism globally. In Ireland, there appears to be a gap in the provision of respite care for autistic children with a lack of clarity in terms of the pathways to respite care for autistic children. A review of the literature indicates that this is also shared internationally. National and international policies and strategies appear to lack detail on specific models of respite care and pathways to respite care for autistic. For me, this highlighted the need to explore parental experiences of accessing respite care through the acute care services for their autistic child so that potential barriers or challenges could be identified.

I feel having this professional and personal experience of caring for an autistic child will enable me to establish a rapport with participants during the recruitment and data collection stages of this research. In addition, I believe that my educational, and professional background will enable me to develop sensitivity to issues related to families that have autistic children. My experience will also be an advantage when it comes to the language and terms often used by those involved in the care of autistic language as specific language or terminology can easily be understood by someone

with experience of autism. Notwithstanding this I also recognise that my previous experiences could lend itself to the potential for research bias. Therefore, by using the same guiding framework for all interviews and engaging in reflexivity throughout my study, I am hoping to reduce the potential for any researcher bias. As part of my research journey I anticipate that I will develop an in-depth knowledge of parents' experience of accessing respite care for their child with ASD through the acute care services.'

Excerpts from reflective diary throughout various stages of this study.

'Ethical approval has been granted, happy days'

'Recruitment is proving to be so difficult and I can see why as many of these parents have lost access to their services. How am I going to tackle this as time is moving on'.

'Interviewing parents is a lot harder than I expected. Their lives are consumed with fighting for the needs of their child and a lot of parents have become very upset sharing their experiences.'

"Just transcribed a recorded interview. It was so long and took four hours, I don't know how I am going to do them all, There has to be an easier way!"

'What kind of analysis is best? Do I just stick to thematic analysis as I have done this before? I need more clarification about how to analyse data I want to make sure I am doing the right analysis and I am actually capturing the meaning of parents experiences rather than describing their experiences'

Data Analysis

Phase 1: Familiarizing yourself with the data

- Parents feel that autism is such a spectrum and the more severe forms do not get as much focus or attention as they are hidden away in society-sense of isolation or minority population.
- Idea that autism is somewhat criminalised in Ireland as parents told to contact the guards
- Parents became visibly upset when talking about their time accessing acute care services and having to phone the guards and watch their child been taking away.
- Mental and physical burden of autistic child on parents and family.

- Acute care services accessed in crises for majority of parents
- A lot of parents 'just got on with it'. Coped by themselves.
- Parents at a loss as to where to go for information, not one point of information- multiple sources with conflicting information
- Parents told to have low expectations/no expectation of getting respite.
- Need for respite increasing with age.
- Parents making a lot of references to private and public service delivery
- Poor planning around transition of services for respite
- Maintaining respite difficult depending on the child's particular needs or challenging behaviours.
- Sense that parents want to have their child at home with them and keep them in the community but need respite support in order to cope.
- COVID-19 had detrimental impact, a lot of parents lost their support services with very little follow up or engagement.
- Accessing respite care as a never-ending journey across the lifespan.

All transcripts read at least 3 times. Firstly, during transcription for those that were transcribed by me. Transcripts were verified against audio recording. Transcripts were then reviewed prior to sending out for member checking. Transcripts further reviewed two times during coding.

Appendix 11 Data analysis; Coding and category formation

Research Objective: Report on the experience of care from the perspective of parents of children with an autism spectrum disorder who access respite services through the acute care services.										
Codes		Categories	Codes	Categories	Codes	Categories	Codes	Categories	Codes	Categories
Multiple state agencies	Being told no services	Poor treatment	Caregiver role	Caring for a child with ASD and impact on family	Criminalising autism	Emotional felt space of accessing respite through acute care services.	When problems started	Time spent seeking respite care	Assessment of need	Things that supported parents to access respite care
Shout the loudest	Being treated badly	Interactions with others	Challenging Behaviours	Physical presence of the child on the situation	Dehumanizing process	Felt space of being in the ED/Hospital	Campaigning	Increasing respite need with age	Pile of forms	Things that described parent's experience of accessing respite care
Multidisciplinary Team	Communication after hospital discharge	Justify the need for respite care	Impact of ASD Child on siblings	Physical presence of others and hospital environment on the situation	Doing the right thing	Acute care service/ED as a space to access respite care	Duration of respite	When acute care services were accessed for respite	waiting list	
Schooling	Culture of Autism in	Feelings associated with	Impact of Covid		Emergency department		Autism more severe with	Good and bad experiences	Social Media	

	Ireland	accessing respite care	
Meeting Criteria	Experience of respite	Reasons for accessing acute care services	Impact on parents work
Unsure of what to ask	feeling alone		Level of supervision required
Need to show how bad it is	Denial		Sacrificing families private life
needing to see what is going on	Feelings of guilt		Financial Impact
Negotiating	Feelings when accessing respite		Need to mind the carer
No follow up	Fight for needs		Caring for a child with ASD
No longer coping	Barriers to respite		Parents health
No respite available	A minority population		Unsafe

Traumatised by the system	
Dressed in clinical language	
hospital environment	
Homecare	
Hospital Episodes	
Institutional Abuse	
Unsafe	
Use of restraint	

age	of accessing respite care		
Time	Attitude towards accessing respite care over time	Parent support group	
moving		Hospital Episode	
Increasing respite need with age			
Transition			
Turning Point			
Changes in respite care needs			
Experience of respite			
Attitude towards getting			

					respite care		
No say	envy of other conditions	Sacrificing families private life	Threatening	Fight for needs			
No step-down facility	family support	People's perceptions	Sense of Danger	Shout the loudest			
Not accepting responsibility	Follow up after hospital	Turning point	Parental feelings during hospitalisation	Parental reflections			
Not being believed	Grief Process	Interaction with emergency services	Medicating	Impact of respite on child			
parental reflections	Keeping relationship open with everybody	Hospital environment	Refusing to go home from hospital	Traumatised by the system			
Parental rights	inaccurate information			Crises Respite			
Parental worries	Giving up parental rights			Emergency Respite			
Parents experience of respite	Not believing services						

parents succumbing to services	Giving up parental rights							
Political Influences	lack of access to education							
Process of getting respite	Lack of communication							
Promise of supports and help	lack of control							
Pushing a certain type of respite	lack of entitlement							
Refused respite	lack of experience amongst HCP							
respite care needs	lack of family support							
Respite expectations	Lack of information							
Respite funding	lack of support							
Respite location	lack of training							

Respite not just for the child	Lack of trust
Interaction with emergency services	Legal Route
Role of healthcare professionals	Limited resources
Role of social media	Need for access to additional supports
Seeking help	Need for change
Staff all changing	need for emotional support
Unsure of what to ask	Need for respite identified
Losing respite	Need to be flagged
Maintaining respite	Counselling

manage by ourselves										
meeting criteria										

Appendix 12 Formation of themes and subthemes

Themes	Subthemes	Analytical memos
Impact of caring for a child with ASD on family	Impact on siblings Impact on parents Impact on day to day living	Financial impact, parent having, to give up job, siblings not being able to have friends over, restrictive environment within the house, parents not being able to spend adequate time with siblings, not being able to go on holidays, parents' relationships breaking down, full time caring job.
Accessing respite care: an ongoing process across the lifespan	Process of accessing respite services Maintaining Respite Services Losing respite services	Constantly having to fight, waiting lists, access based on where you live and services available, need to shout the loudest, taking what you can, having to exaggerate, being told to expect no respite service. Having respite but losing services not able to cope, not meeting needs of child, medical model.
How parent's described the process of accessing respite care through acute care services	Emotional Impact of accessing respite care through this particular pathway. Interactions with emergency services	Dehumanizing process, criminalising, use of restraint, role of emergency services, calling the guards, distressing to see, inappropriate placement
Experience of accessing acute care services: During and after	Rationale and defining moment During and After attending acute care services	Refusing to go home on the second occasion that child presented to hospital of social media
Journey leading up to accessing respite care through acute care services	Factors leading to accessing this type of respite Interactions with multiple agencies and individuals	Lack of communication, information, support, significant event, last resort
What parents Want: Requirements for effective respite care provision	Forward Planning Move away from medical model Choice of Respite Equal access	Need to plan ahead, need for crises/ emergency respite. Choice and location of respite

Appendix 13 Data management plan

Research Title	
To Explore Access To Respite Care Through Acute Care Services From The Perspectives of Families of Children with Autism Spectrum Disorders	
1. Description of the data	
1.1 Type of data, data sets and classifications	The main data generated from this research study will be; • Personal data: Participant contact records • Anonymised data: Data prepared from personal data but from which the person cannot be readily identified. This will be achieved by coding the individual interviews and transcripts • Meta data: Data and documentation containing the methods used to generate the data, analytical and process information. Data will be classified as confidential and restricted. The appropriate handling procedures will be put in place as outlined in Section 3 of this data management plan.
1.2 Format and scale of the data	As a small sample size is being used for this research, the scale of the data generated will be generally small. Data will be obtained from number of participants (approx. 15). The data generated within this study will initially be recorded on a digital device, transcribed and contained within computer software programmes.
1.3 Audience of data produced	The data to be produced will be of interest to researchers within this particular area as well as national and international health policy makers. Nationally, the findings will also inform the work of the Integrated Care Programme in the Clinical Strategy and Programmes Division of the Health Service Executive in identifying the specific needs of this cohort of children.
2. Data collection / generation	
2.1 Methodologies for data collection / generation	The researcher intends to audio record the interview and interviews will then be transcribed by the principal researcher. Data analysis will be performed by the principle investigator and be based on the phenomenological method Van Manen
2.2 Data quality	The quality of the data will be controlled by the following; • Audit trail: This will be maintained to demonstrate how the researcher accounted for all the research decisions and activities to show how the data were collected, recorded and analysed. In order to conduct a thorough audit trail the following documents will

	be kept for crosschecking the inquiry process: raw data, interview and observation notes, documents and records collected from the interview days and location • Transferability: This will be achieved through thick description and purposeful sampling • Thick Description: The researcher will provide a rich and extensive set of details concerning methodology and context by outlining in depth all the research processes, from data collection, context of the study to production of the final report. This allows for comparison of this context to other possible contexts to which transfer might be contemplated • Member Checking: This will provide research participants an opportunity to review their transcripts for factual accuracy purposes. • Peer review of data at Trinity Research Support and education days • Data will be reviewed by academic supervisors throughout the research project.
3. Data management, documentation and curation	
3.1 Managing, storing and curating data.	Confidential research data and records will be stored securely in lockable filing cabinets or a lockable room with controlled access within allocated desk and storage at Trinity College Dublin. The researcher will adhere to a clean desk policy and no confidential data will be left unattended on desks. All mobile computing devices used to store, process, and transmit data will be encrypted at all times. All username and secure passwords used by the researcher will meet the following minimum standards: • Secure passwords will contain at least one symbol or number. • Password will consist of a combination of lower- and upper-case letters (i.e. IsDIMs and consist of seven or more numbers/letters or symbols. Good Password Security will be maintained by: • Using different passwords on each accounts required by the researcher • Changing password regularly throughout the study • Never writing passwords down • Entering passwords only when prompted by applications and not storing passwords within applications. All devices used to store, process or store data will be running up-to-date anti-virus software and the researcher is linked with the Trinity IT department for maintaining this and for support with any security issues. The use of public cloud services such as Dropbox, google docs etc are

	not permitted by the college for the backup/storage of project data and therefore the researcher will not use any of these.
3.2 Data Retention and Destruction https://www.tcd.ie/Graduate_Studies/assets/pdfs/TCD%20Good%20Research%20Practice.pdf	Data generated in the course of research will be kept as appropriate to the task and the type of research undertaken and will be retained securely in paper and electronic form. Data already collected for a specific purpose will not be subject to further processing that is not compatible with the original purpose. As per policy, Trinity College requires such data to be securely held for a period of ten years after the completion of a research project. The researcher is responsible for destroying any hard and electronic data as well as back up files in line with the college's relevant data destruction policy at the applicable time.
4. Data security and confidentiality of potentially disclosive information	

4.1 Main risks to data security	The researcher maintains a progress/risk register for the entire project and this is reviewed on a regular basis. Data management risks and controls feature on this progress/risk register and are subject to ongoing evaluation. The following risks have been identified for data management; <table border="1"> <tr> <td data-bbox="624 528 831 624">Risk</td><td data-bbox="831 528 1481 624">Breach of confidential information</td></tr> <tr> <td data-bbox="624 624 831 723">Controls:</td><td data-bbox="831 624 1481 723">As per 3.1 above</td></tr> <tr> <td data-bbox="624 723 831 869">Evaluation of risk:</td><td data-bbox="831 723 1481 869">This will be ongoing throughout the research</td></tr> </table> <table border="1"> <tr> <td data-bbox="624 869 831 965">Risk</td><td data-bbox="831 869 1481 965">Breach of confidential information</td></tr> <tr> <td data-bbox="624 965 831 1064">Controls:</td><td data-bbox="831 965 1481 1064">Cyber hacking of computer software</td></tr> <tr> <td data-bbox="624 1064 831 1301">Evaluation of risk:</td><td data-bbox="831 1064 1481 1301">Established link with Trinity IT department to ensure computer is well protected and appropriate measures in place. Established plan in place in the event that this will happen as per TCD policy.</td></tr> </table>	Risk	Breach of confidential information	Controls:	As per 3.1 above	Evaluation of risk:	This will be ongoing throughout the research	Risk	Breach of confidential information	Controls:	Cyber hacking of computer software	Evaluation of risk:	Established link with Trinity IT department to ensure computer is well protected and appropriate measures in place. Established plan in place in the event that this will happen as per TCD policy.
Risk	Breach of confidential information												
Controls:	As per 3.1 above												
Evaluation of risk:	This will be ongoing throughout the research												
Risk	Breach of confidential information												
Controls:	Cyber hacking of computer software												
Evaluation of risk:	Established link with Trinity IT department to ensure computer is well protected and appropriate measures in place. Established plan in place in the event that this will happen as per TCD policy.												

4.2 Data Security Breaches As per Trinity College Policy	Any data security breaches will be reported to the information complaints officer immediately by the researcher in line with Trinity College policy. These include but are not limited to: • Loss/theft of mobile computing equipment • Unauthorised access to data • Unauthorised copies taken of data • Unauthorised removal of data from College premises • After reporting the incident the researcher will complete the Personal Data Security Breach Report form and email it to the Information Compliance Officer as soon as possible. Following this, the information complaints in conjunction with any appropriate members of staff, take the necessary steps (in line with policy) when responding to the breach.

5. Data sharing and access

5.1 Governance of access Identify <u>who</u> makes or will make the decision on whether to supply research data to a potential new user.	The researcher will have overall responsibility for the data and will make the decision about who gets to see the data and when they get to see the data. The researcher will have independent oversight of data access and sharing. The decision to show and share data to those identified in the study i.e. will be done only when it is considered necessary and appropriate and for academic guidance as outlined in the body of this application.

6. Responsibilities

Researcher/Principle Investigator	All research data collected as part of this project is owned by the University. The researcher of this project will take responsibility for the collection, management, and sharing of the research data The principal Investigator is responsible for; • compliance with Data Management Policy and other relevant data policies with Trinity College Dublin. • study-wide data management • metadata creation • data security • quality assurance of data. • backup and recovery of all research data • promoting ongoing awareness of data management policy • ensuring the integrity of dataset
Academic Supervisor (s)	• Responsible for compliance with Data Management policy • Responsible for providing guidance on good research practice and associated data management procedures.

7. Relevant institutional, departmental or study policies on data sharing and data security

The following College policies and legislation have been identified as being applicable to data collected, processed and stored throughout the duration of this study

- Data Protection Act <http://dataprotection.ie/docs/Home/4.htm>
- Trinity College Network Code of Conduct
http://www.tcd.ie/about/policies/it_and_network_code_of_conduct.php
- Trinity College IT Security Policies <http://www.tcd.ie/ITSecurity/policies/infosec.php>
- Trinity College [Cloud Computing policy and guidelines](https://www.tcd.ie/about/policies/cloud-policy.php)
<https://www.tcd.ie/about/policies/cloud-policy.php>
- Office of the Data Protection Commissioner and the Information Compliance Officer.
- Trinity College Data Protection Website: http://www.tcd.ie/info_compliance/dp/ Office of the Data Protection Commissioner website: <http://www.dataprotection.ie> Staff Contact Information: http://www.tcd.ie/info_compliance/dp/conta
- [https://www.tcd.ie/about/policies/160713%20Records%20Management%20Policy_Reco rds%20Retention%20Schedule_website.pdf](https://www.tcd.ie/about/policies/160713%20Records%20Management%20Policy_Reco%20rds%20Retention%20Schedule_website.pdf)

8. Author of this Data Management Plan

Emma Cooke

Author and Principal Investigator

PhD student: Trinity College Dublin

emcooke@tcd.ie

PH: 0870551190

Appendix 14 Data protection risk assessment



Data Protection Risk Assessment

Template

Project Name: To explore access to respite care through acute care services from the perspectives of parents of children with an Autism Spectrum Disorder.	Date: February 2020
Project Owner: Emma Cooke Email address: emcooke@tcd.ie	Site: Trinity College Dublin Phone Number: 0870551190

Template Version Control

Reference	Date	Author	Comments
2.0	May 2019	TCD DPO	

Risk Assessment Circulation

Name	Date	Reviewed/Consulted
Emma Cooke	Feb 2020	<i>Consulted</i>
Maria Brenner Valerie Smith	Feb 2020	<i>Consulted</i>
DPO Details	[Insert Date]	<i>Revised/Consulted</i>

Risk Assessment - Objective

In line with the risk-based approach to data processing of the GDPR, carrying out a Data Protection Impact Assessment (DPIA) is not necessary for every processing operation. Instead, a DPIA is only mandatory where a type of processing is *“likely to result in a high risk to the rights and freedoms of natural persons”*.

The Article 29 Working Party, consisting of the representatives from each data protection authority in the EU, has adopted guidelines on DPIAs and whether processing is likely to result in a high risk for the purposes of the GDPR. The guidelines are available [here](#).

The Office of the Data Protection Commission has provided detailed information on DPIAs, available [here](#).

Not all processing activities will require a DPIA to be undertaken. It is recommended therefore that you review the examples listed below and answer the screening questions to determine if a DPIA will be necessary. In cases where it is not clear whether a DPIA is required, the Trinity College Data Protection Unit recommends that a DPIA is carried out, as it is a useful process to determine risks and support compliance with data protection law.

It is important to note that a DPIA is required as standard for research studies conducted at St. James’s Hospital, Tallaght University Hospital and all clinical sites in which Trinity researchers are active.

If you require further assistance or advice you should contact the relevant Data Protection Officer:

Trinity College: dataprotection@tcd.ie

St James’s Hospital: research@stjames.ie

Tallaght University Hospital: dpo@tuh.ie

Instructions

You should complete all of the questions in this template and forward the completed document to the Unit to receive feedback on any risks identified and recommendations on the actions or controls needed to address those risks.

It is the responsibility of the School or Business Unit Project Manager as the ultimate risk owner to ensure that the required controls are put in place and to sign off on any risks arising from the processing.

The Risk Assessment should be updated when appropriate to reflect any material changes to the processing as the Project progresses.

Examples

The following examples should be used to assess whether a particular processing operation requires a DPIA:

Examples of processing	Possible Relevant criteria	DPIA likely to be required?
A hospital processing patients' genetic and health data via the hospital information system.	- Sensitive personal data or data of a highly confidential nature. - Data concerning vulnerable data subjects. - Personal data processed on a large scale.	Yes
Storage for archiving purposes of pseudonymised sensitive personal data concerning vulnerable data subjects involved in research projects or clinical trials.	- Sensitive personal data. - Data concerning vulnerable data subjects. - Possibly prevents data subjects from exercising a right or using a service or a contract.	Yes
An organisation systematically monitoring its employees' activities, including the monitoring of the employees' workstations, Internet activity etc.	- Systematic monitoring of individuals on a large scale. - Potentially excessive or unlawful processing of personal data. - Data concerning vulnerable data subjects.	Yes
The gathering of public Social Media data for generating profiles.	- Evaluation or scoring. - Data processed on a large scale. - Matching or combining of datasets. - Sensitive personal data or data of a confidential nature.	Yes
Processing of personal data from patients or clients by an individual physician, other healthcare professional or solicitor.	- Sensitive personal data or data of a highly personal/confidential nature. - Data concerning vulnerable data subjects.	No

Project Details

Project name	To explore access to respite care through acute care

	services from the perspectives of parents of children with an Autism Spectrum Disorder'
Project owner(s)	Emma Cooke (PI) Maria Brenner (Primary Supervisor) Valerie Smith (Co-supervisor) *Colman Noctor (Co-supervisor as of Feb 2020)
Project start date	2017
Number of individuals whose personal data will be processed	Approximately 15-20 (Exact number unknown at present and dependent on data saturation/data sufficiency)
IT systems used	NVivo, Trinity blackboard, Gmail, Microsoft word and Microsoft Excel
Third parties involved (Provide details including information on the contractual arrangements in place and confirm what due diligence has been carried out)	The National Clinical and Integrated Care Programme within the Health Service Executive (<u>HSE</u>) is funding the research. The researcher is contractually obliged to provide updates in respect of the project and to present the overall findings of the project to the funder.

Description of Project

The aim of this project is to explore access to respite care from the perspectives of parents of children with Autism Spectrum Disorders (ASDs) between the acute and primary care settings within an Irish healthcare context.

A qualitative, phenomenological design has been chosen as the most appropriate methodology to achieve the research objectives which are as follows;

- To systematically review the evidence on access to respite care for children with an autism spectrum disorder at the acute and primary care interface.
- To develop an understanding on how parents access respite services through the acute hospitals.
- To identify any issues they experience with accessing respite care
- To determine the preferred pathway to respite care by exploring their motivation for accessing respite care for their child through a particular pathway.

Inclusion Criteria

Parent(s) of a child with an Autism Spectrum Disorder who have previously accessed or

are currently accessing respite care through acute care services.

Data Collection and Analysis

Data collection will involve one to one semi-structured interviews using open-ended questions. The aim of these interviews is to explore rationale for presenting to the acute hospital services as a means of accessing respite care and to ascertain if other pathways were considered.

Potential Outcome

The study also aims to provide a comprehensive understanding of the lived experience in accessing respite care with additional findings such as;

- Knowledge of pathways of access and why
- Requirements for developing optimal services
- Essential elements of a quality respite care service

The study has the potential to identify a requirement for a range of respite service to be developed in a co-ordinated, integrated and structured way to meet the complex needs of children with ASDs.

Screening Questions

Note: Each screening question should be answered, and you should add any additional, relevant question(s) dependant on the risk and/or processing operation(s) you are assessing. These screening questions will help you to identify if a DPIA is required and provide valuable insight into the processing operation risks and areas to focus on.

Screening Question	Yes	No	N/A	Notes
Does the processing require systematic and/or extensive evaluation (<i>via automated means</i>) of personal aspects of an individual(s)?		✓		
Will decisions be based on such evaluations that are likely to produce legal effects, or equivalent effects concerning the individual(s)		✓		
Is the processing on a large scale and/or does it involve special categories of data (sensitive data)?		✓		See Appendix 1 attached 'Data Management Plan' and section 1-'Description of data'.
Is the processing on a large scale and does it involve data relating to criminal convictions and offences?		✓		

Does the processing involve systematic monitoring of a publicly accessible area on a large scale? (i.e. CCTV)		✓		
Will the project involve the collection of new information about individuals?		✓		
Will the project compel individuals to provide information about themselves?		✓		Participants will only have to provide information that they choose to disclose and can refuse to disclose any information if they wish.
Are you using information about individuals for a purpose it is not currently used for, or in a way it is not currently used?		✓		
Screening Question	Yes	No	N/A	Notes
Is the information about individuals likely to raise high risk privacy concerns or expectations?		✓		
Will information about individuals be disclosed to organisations or people who have not previously had routine access to the information or a third-party without adequate safeguards in place?		✓		
Does the processing involve the use of new technology or systems which might be perceived as being privacy intrusive?		✓		NVivo software will be used to analyse the data.
Could the processing result in decisions being made or action being taken against individual(s), in ways that could have a significant impact on them?		✓		
Will the project require you to contact individuals in ways which they may find intrusive?		✓		Participants will be given the option to be contacted by phone or email.

Will any of the processing activities make it difficult for the data subject(s) to exercise their rights?		✓		
Will the operation involve processing considerable amounts of personal data at regional, national or supranational level, which could affect many data subjects?		✓		
Will the processing involve individuals who are considered 'vulnerable'?		✓		
Does the processing operation involve any significant risk of the personal information being leaked or accessed externally?		✓		

Personal Data

List the types of personal data that will be collected, used, accessed or shared for the purpose of the Project.

Data Collected	Justification	Processing Activity
Participant names	Identification, so that we can apply matching codes across data sets.	Excel database. See attached appendix 'Data Management Plan under '3.1 Managing, storing and curating data.
Written consent	Legal basis for processing.	Paper forms, stored in locked filing cabinet. See attached appendix 'Data Management Plan under '3.1 Managing, storing and curating data. Access restricted to principal investigator only.
Demographic questionnaire	Legitimate interest of the data controller. To support further analysis and evaluation of the research's objectives.	Paper forms initially and processed into an excel database. See attached appendix 'Data Management Plan under '3.1 Managing, storing and curating data. Access restricted to principal investigator only.

Consent	✓
Performance of a contract	
Legal obligation	
Public interest or exercise of official authority	
Vital interests of data subjects	
Legitimate interests	

If using *Consent*, then describe the consent process and attach supporting documentation.

The researcher identifies that obtaining unambiguous, affirmative and informed consent is an ethical and legal requirement for research involving human participants. Obtaining informed consent for this research will involve informing the participant about the purpose of the study, procedures to be undertaken if they wish to take part, potential risks and benefits of participation, expected duration of study, an explanation of how personal data will be processed, purpose of processing, intended retention, confidentiality and anonymity of data gathered and that participation is entirely voluntary. This will be achieved by the following;

- When the participant has expressed their interest in the study and following their review of the participant information leaflet (Appendix II) and accepting the letter of invite (Appendix III), suitable arrangements will be made to carry out the interview. The participant will be afforded time to ask any more questions and following this a consent form (Appendix IV) will be signed. Issues relating to data protection and processes in place to support any data breaches will be outlined verbally and confirmation that the participant has received this information will be documented in the consent form. Assurance around the confidentiality of data is outlined in the participant information leaflet. Consent will be signed by the parent(s) and researcher prior to commencing the interview.
- Sufficient information and answers to questions will be provided to participants in a language which is easily understood by him/her, so that he/she can make the voluntary decision regarding their participation in the research study.
- Participants will be informed of their entitlement to withdraw from the study at any time and that all identifiable data will then be destroyed. This will be outlined at various stages, for example, this will be covered in the participant information sheet, letter of invite and consent form.

Lawful Basis – Sensitive Personal Data

Sensitive personal data is defined as:

- Processing of personal data revealing
 - racial origin
 - ethnic origin
 - political opinions
 - religious beliefs
 - philosophical beliefs
 - trade-union membership
- Processing of genetic data for the purpose of uniquely identifying a natural person
- Processing of biometric data for the purpose of uniquely identifying a natural person
- Data concerning health
- Data concerning a natural person's sex life
- Data concerning a natural person's sexual orientation

If processing sensitive personal data then, in addition to the Article 6 lawful basis, you must also satisfy one of the conditions as set out under [Article 9 GDPR](#):

Explicit Consent	✓
Employment / DSP rights	
Vital Interests of the data subject or another person	
Carried out (internally) by a not-for-profit organisation	
Information that has been already made public by data subject	
Necessary for the establishment, exercise or defence of legal claims	
Necessary for substantial public interest	
Necessary for the provision of medical care/ administration	
Necessary for reasons of public interest in the area of public health	
Archiving purposes in the public interest/ Scientific or Historical Research purposes/ Statistical purposes	

If using *Explicit Consent*, then describe the consent process and attach supporting documentation.

It is not the intention to collect sensitive personal data as per the above definition.

International Data Transfers

Will the data be transferred or stored outside the EEA at any point or placed with Cloud providers that store data outside the EEA? Provide details.

Description of data transfers

No, data will not be transferred or stored outside the EEA.

If you are transferring personal data outside of the EEA have you ensured that suitable conditions for transferring the data are in place? Provide details or state if unsure:

Adequate jurisdiction	n/a
US Privacy Shield	n/a
Standard Contract Clauses	n/a
Binding Corporate Rules	n/a
Authorisation from the Data Protection Commission	n/a
Unsure	n/a

Data Retention

How long will the data be retained for and why? Provide details.

Data retention

Data generated in the course of research will be kept as appropriate to the task and the type of research undertaken and will be retained securely in paper and electronic form. Data already collected for a specific purpose will not be subject to further processing that is not compatible with the original purpose. As per policy, Trinity College requires such data to be securely held for a period of ten years after the completion of a research project. The researcher is responsible for destroying any hard and electronic data as well as back up files in line with the college's relevant data destruction policy at the applicable time.

https://www.tcd.ie/Graduate_Studies/assets/pdfs/TCD%20Good%20Research%20Practice.pdf

Data Subject Rights

What plans are in place for responding to a request from an individual in relation to their data protection rights?

These include:

- right of access;
- right to rectification;
- right to erasure;
- right to object to processing based on legitimate or public interest;
- right to data portability;
- right to object to profiling or making decisions about individuals by automated means.

Data Subject rights requests

The researcher will adhere to the fundamental data subject rights in line with GDPR. This will include the following;

- **Participants will have the right to access their personal data that is processed by the researcher. This request will be responded to in one month.**
- **Participants will have the right to request rectification of their personal data, including the correction of errors and the updating of incomplete information. This will be achieved through member checking which will provide each research participant an opportunity to review their transcripts and data for factual accuracy purposes. Once they have approved their transcripts and are happy, a copy of their final transcript will be given to them to keep.**
- **Participants will be afforded the right to erasure by stopping all processing of their data and agreeing to erase their personal data.**
- **Participants will be afforded the right to restrict the processing of some of their personal data if they wish. For example, if they choose to not answer some of the questions in the questionnaire. Participants will be informed about the uses of their personal data in a clear manner at the outset and prior to consent being obtained. Participants will also be informed about the actions that can be taken if they feel their rights are breached.**
- **Participants will be afforded the right to data portability whereby their request to send their personal data file electronically to a third party will be facilitated.**

How to Make an Access Request

Participants will be encouraged to contact the researcher if they wish to make a request to access their data again after member checking has been completed and while final manuscripts are being processed. Participants will be given final copies of their manuscripts.

The researcher will have overall responsibility for the data and will have independent oversight of data access and sharing. The decision to show and share data to those identified in the study will be done only when it is considered necessary and appropriate and for academic guidance from my supervisors.

Any data security breaches will be reported to the information complaints officer immediately

by the researcher in line with Trinity College policy. These include but are not limited to:

- Loss/theft of mobile computing equipment
- Unauthorised access to data
- Unauthorised copies taken of data
- Unauthorised removal of data from College premises

After reporting the incident the researcher will complete the Personal Data Security Breach Report form and email it to the Information Compliance Officer as soon as possible.

Following this, the information complaints in conjunction with any appropriate members of staff, will take the necessary steps (in line with policy) when responding to the breach.

Training

What guidance and training will be provided to individuals involved in this project or activity to enable them to understand their data protection responsibilities? Provide details.

Data protection training

The principal investigator will undergo data protection training.

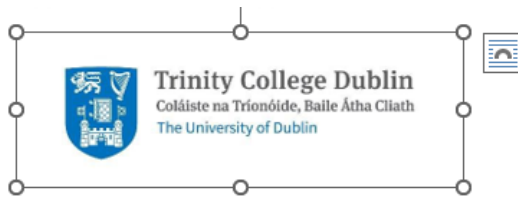
Processing Risks

Describe the source of risk and nature of potential impact on individuals. Include associated Compliance and Corporate risks as necessary.

Risk detail	Risk rating (High, medium, low)	Solutions/Mitigating Actions	Effect	Outcome	Measure approved
Hacking into computers where project data is stored.	Low	Confidential research data and records will be stored securely in lockable filing cabinets or a lockable room with controlled access within allocated desk and storage at Trinity College Dublin. The researcher will adhere to a clean desk policy and no confidential data will be left unattended on desks. All mobile computing devices used to store, process, and transmit data will be encrypted at all times. All username and secure passwords used by the researcher will meet the following minimum standards: - Secure passwords will contain at least one symbol or number. - Password will consist of a combination of lower- and upper-case letters (i.e. IsDIMs and consist of seven or more numbers/letters or symbols. Good Password Security will be maintained by: - Using different passwords on each account required by the researcher - Changing password regularly throughout the study - Never writing	Reduced	Low	Yes/No

		passwords down • Entering passwords only when prompted by applications and not storing passwords within applications. All devices used to store, process or store data will be running up-to-date anti-virus software and the researcher is linked with the Trinity IT department for maintaining this and for support with any security issues. The use of public cloud services such as Dropbox, google docs etc are not permitted by the college for the backup/storage of project data and therefore the researcher will not use any of these. Established link with Trinity IT department to ensure computer is well protected and appropriate measures in place. Established plan in place in the event that this will happen as per TCD policy.			

Appendix 15 Data protection officer approval letter



Study Title – To explore access to respite care through acute care services from the perspectives of parents of children with an Autism Spectrum Disorder

April 15th 2020

Dear Emma

I have reviewed the following documentation in respect of the aforementioned study:

- Research Project Risk Assessment
- Research Data Management Plan
- Participant Information Leaflet
- Invite Letter to Participants
- Participant Consent Form

Upon review of these documents I am satisfied that the intended processing of personal data for the purposes of this study is in compliance with data protection legislation, specifically the EU General Data Protection Regulation (GDPR), Data Protection Acts 1988 - 2018 and Health Research Regulations 2018.

Please note that the completion of a Risk Assessment is not a one-time exercise, but a continual process. If at any stage there are changes to the processing envisaged by this [assessment](#) please contact me.

I wish you the very best of luck with your research.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Eustace", is written over a horizontal line.

John Eustace, Data Protection

The impact of COVID-19 on parents of autistic children with a particular focus on access to respite care.

Abstract

Purpose: To explore how the COVID-19 pandemic has impacted parents of autistic children and their families in Ireland.

Methodology: A qualitative thematic analysis methodology was applied using semi-structured interviews. Parents were asked how the COVID-19 pandemic impacted their autistic child with a particular focus on how it has impacted their access to respite care. Twelve interviews were completed remotely from July 2021 to October 2021.

Findings: Data analysis identified four themes that reflect an adverse pandemic impact. These were; World Gone, Alone and Isolated, Constantly Fighting and Negative and Positive Impact of COVID-19 on child and family. Few parents reported positive outcomes of the pandemic such social distance requirements. Five parents (42%) reported an increase in the amount of respite care received. Three parents (25%) reported a decrease and four (33%) parents reported no change in their access to respite care.

Originality: This study highlights the need for access to respite care for autistic children and for respite services to be responsive to the ongoing needs, in particular the mental health needs, of autistic children and their family, particularly in a crisis situation.

Implications: COVID-19 has turned a spotlight on mental health for politicians, policy makers and the public and provides an opportunity to make mental health a higher public health priority for autistic children and their families.

Key words: Autism, respite Care, mental health needs, emergency respite, COVID-19 pandemic, thematic analysis, qualitative research.

Appendix 16 Paper on the impact of the COVID-19 pandemic on parents of autistic children in Ireland with a particular focus on how the pandemic has impacted their access to respite care.

Introduction

Autism is a neurodevelopmental condition characterised by deficits in social communication and social interaction in addition to restricted and repetitive patterns of behaviour and interests (American Psychiatric Association & Association 2013). Approximately one in every 100 children are diagnosed with autism round the world with prevalence estimates increasing over time (Zeidan *et al.* 2022a).

In March 2020, the World Health Organisation (WHO) classified COVID-19 as a pandemic which saw numerous measures and restrictions being implemented worldwide to curtail the spread of infection. Autistic individuals may be more vulnerable and potentially experience greater adverse effects from the pandemic due to the communication, socialization, and functioning differences that are inherent in the diagnosis (APA 2013) as well as common co-occurring conditions such as intellectual disability (Dekker *et al.* 2022), anxiety and depression (Zeidan *et al.* 2022a). Characteristics of autism place autistic children at greater risk for being negatively impacted by the pandemic as they can experience difficulties with social communication and they often cope better with structured daily routines and predictable environments (Hyman *et al.* 2020). In addition, the lack of routine and associated uncertainty can make autistic children feel more anxious, restless and develop unpleasant feelings (Patel 2020) which can result in significant challenges for an autistic child (Baumer & Spence 2018).

The COVID-19 pandemic has had a significant impact on the lives of individuals across the world including autistic children and young adults and their families (Cassidy *et al.* 2020, Nonweiler *et al.* 2020, Pachner & Aranyi 2021). Measures put in place to limit the spread of COVID-19 such as suspension of in-person education and social activities, closures of essential services such as respite care, social distancing rules, restricted travel movements and the

requirement to stay at home have greatly impacted families of autistic children (Amorim *et al.* 2020, Bellomo *et al.* 2020, Patel 2020). As many essential services and supports closed, the pandemic required parents to take on multiple roles extending their responsibilities while adding increased pressures and causing stress (Dalton *et al.* 2020). Families of autistic children have experienced additional challenges with children presenting with increased behavioural problems for parents to navigate (Colizzi *et al.* 2020, O'Sullivan *et al.* 2021). Emerging evidence suggests that high levels of stress and anxiety in parents, especially during the pandemic, can “spill over” to their autistic children leading to increased behavioural challenges, and decreased mental well-being of these children (Russell *et al.* 2020). Consequently, there is a greater need for access to respite services for these parents as the constant need to monitor aspects of their child's daily care can become increasingly stressful (Eshraghi *et al.* 2022).

Respite care can be defined as the provision of care to children with complex care needs for a specific period of time with the intent of providing temporary relief to the main carers and their family (Brenner *et al.* 2016). Respite care has been cited as one of the greatest unmet needs of families caring for autistic individuals (Dyches *et al.* 2016, Whitmore & Snethen 2018b, Cooke *et al.* 2020). Respite has a positive impact on the well-being of caregivers and is associated with lower levels of stress, reduced levels of depression and anxiety, and more time for rest and rejuvenation (Mc Grath 2019). However, accessing respite can often be difficult and contribute to this stress (Hodgetts *et al.* 2014). Furthermore, respite services available for autistic children may be inappropriate or inadequate (Gadd 2019). Without respite, those caring for autistic individuals are at risk of burnout within a short period of time (Woodgate *et al.* 2015) as they take on complex care tasks such as behaviour and emotional challenges.

Respite care is not without its own challenges with research often citing issues around transitioning of care, which has been described as service-driven rather than person-centred (Ryan *et al.* 2020), lack of choice around the type and frequency of respite received and inadequate capacity to support individuals with complex care needs (Gadd 2019). Research

has found that the lack of access to specialized resources such as respite was perceived as very difficult by Parents during the COVID-19 pandemic (Jacques *et al.* 2021).

Aims

This paper describes how the COVID-19 pandemic has impacted parents of autistic children in Ireland with a particular focus on how the pandemic has impacted their access to respite care. The findings of this paper form part of a wider study that explores access to respite care from the perspectives of parents of autistic children through the acute care services.

Methods

Sampling criteria and recruitment

Parents of autistic children who had accessed respite care through the acute care services were invited to take part in the overall study. In relation to this part of the study, parents were specifically asked how the COVID-19 pandemic impacted their autistic child and their family particularly in the context of their access to respite care. Four phases of recruitment took place between July 2020 and May 2021. Participant information leaflets were circulated on social media platforms and to autism support groups. Potential participants contacted the research team or were contacted directly by the research team after sharing their story on multiple media platforms. Twelve participants were recruited in total. Four potential participants expressed their interest in taking part but did not meet the inclusion criteria and therefore could not be recruited. Those recruited to the study were sent a letter of invite and a consent form in advance of arranging interviews. Participants comprised ten mothers, one father, and one grandfather who participated on behalf of a mother with her consent. Participants were from diverse geographical regions with the majority of parents (n=7) from the capital of Ireland and the remainder of parents (n=5) from the south, west and midland regions of Ireland. The overall median age of the child at time of interview was 17 years. The

average age of the child at time of diagnosis was 2.3 years with ages ranging from 2 to 4 years.

Additional characteristics of the 12 parents are presented in Table I.

(Insert Table I)

Ethics

Ethical approval for the study was granted by the research ethics committee of the project institution. No conflict of interest has been cited.

Data Collection

Data collection comprised semi-structured, audio-recorded remote interviews (via Zoom), field notes (observational notes of non-verbal cues and the environment during interview) and a demographic questionnaire. Interviews followed a phenomenological approach by being purposefully directed to parents' lived experiences. Parents were asked how the COVID-19 pandemic impacted their autistic child and the wider family with a particular focus on how it has impacted their access to respite care. Twelve interviews were completed remotely from July 2021 to October 2021.

Data Analysis

A qualitative thematic analysis methodology was applied. The data, which were coded using NVivo software, were analysed thematically using Braun and Clarke's guidance for thematic analysis (Braun & Clarke 2006, 2013). In this framework, interview transcripts were read first and ideas were noted down in a process of familiarisation. Secondly, line by line coding was conducted to generate the initial codes. This was followed by detailed categorisation which facilitated the identification of themes.

Results

Parents' experiences were largely unanimous resulting in the identification of four main themes that were particularly salient for parents. These are; World Gone, Alone and Isolated, Constantly Fighting and Negative and positive impact of COVID-19 on child and family. The four themes interpreted from the data, each with a number of categories and codes, can be seen in Table II. These themes are discussed in further detail below with a sample of quotations from parents using their unique identifier numbers.

(Insert Table II)

World Gone

Parents described the impact the COVID-19 pandemic had on their child in a way which depicted that their child's whole world had essentially gone. Loss of organised activities, respite, school and other support services had a profound impact on the child and family as their social outlet and daily routines dramatically stopped.

'all of a sudden his whole world.....he wouldn't have a big world but his own world...his day care was gone, his horse riding was gone, his coming home was gone so the behaviours went through the roof'. (Participant 7)

Parents were acutely aware that their child did not fully understand the situation and what was happening which made the situation even more challenging.

'Yeah, there was just nothing for him, he just couldn't understand why his world was torn down'?. (Participant 10)

The theme world gone, while reflective of parents' experiences of how their child's world had been impacted, also reflected how the parents' world and the autonomy that they had as a parent of an autistic child had been significantly impacted by the pandemic. One participant described how they had to obtain a letter from a psychologist just to bring their child out for a

walk in a different location at a time when restrictions prohibited people travelling beyond a five-kilometre radius from their home.

'...the child was crying on his own in his bedroom, non-verbal, sitting there, very placid child, to a child who was nearly depressed looking. And I felt I can't do this. So I got a letter from a psychologist and we drove 10 km and every day we brought him there for a walk., like somewhere different...like different playground'. (Participant 8)

Two sets of parents had children who were in full time residential care before the COVID-19 pandemic. These parents were unable to see their child when restrictions were first introduced at the outset of the pandemic. One parent reported how they were not allowed see their child for a period of ten weeks and were refused permission to take their child home from the respite care facility when asked.

'then Covid hit and we were not allowed to go into the house (respite) anymore'. (Participant 6)

'He stayed in (name of respite) and I wasn't able to see him for ten weeks'. (Participant 7)

The choice to and ability to communicate with their child in a way that parents wanted to and had always done was also lost for one parent as they described the difficulties they encountered when visiting their child in their respite care facility.

'We didn't want to go down the mask wearing route. Because we felt she relies so heavily on our facial expression.....Because the house, the service was demanding mask wearing if we went into the house.' (Participant 6)

Overall, a lack of choice and control over their child's life during the pandemic was difficult for these parents.

Alone and Isolated

Parents reported feeling profoundly alone and isolated during the pandemic. This was described by parents throughout the different stages of the pandemic and in various contexts. For example, at the beginning of the pandemic when everything shut down and lockdown commenced. Parents also experienced these feelings when restrictions started to ease and society began to open up again. Parents also reported feeling alone and isolated for prolonged periods due to the ongoing necessity and desire to isolate their child and family in order to keep their child safe.

The majority of parents narratives were dominated by feelings of being left alone with very little, if any, support.

‘Because the respite during COVID closed down completely, there was nothing, no respite, nothing...we were completely left on our own like.’ (Participant 11)

One parent described how they initially felt alone and isolated at the outset of the pandemic as they became full time caregivers as all the supports that they had once relied on to help them deal with the challenges of caring for an autistic child stopped, coupled with the uncertainty of not knowing how long they would be without such services.

‘Like in the very first lockdown, a year ago, all you kept hearing was, you’ve been asked to sit on a couch. What’s the big deal? Like my god, I was actually been asked to work twenty-four seven without a break, ever.’ (Participant 12)

There were mixed findings in relation to when parents felt most alone and isolated and how long these feelings were experienced for. Three parents spoke about the lack of contact from their child’s support services which added to feelings of being alone and isolated.

‘Nobody rang up to say, “Are you okay in there?”.’ (Participant 4)

Alternatively, some parents described how they chose to isolate their family to protect their child and 'do the right thing' when restrictions began to ease as many of the children within this study had co-morbidities.. However, this isolated them and their child even further.

'Last year we cancelled all services from March until about July.....I was cocooning because of him'. (Participant 8)

Parents also reported feeling alone or left behind as society began to open up yet essential services for their child were either slow to resume or, at the time of interview, had not resumed to pre pandemic levels.

'We had it on a weekly basis, but then they sent me an email and rang me then and said look we have to cut back. They said because of COVID'. (Participant 10)

Three parents were complimentary about their respite services, which, despite having to initially close at the outset of the pandemic, had come up with other ways to support Parents. This in turn made them feel better supported and no longer alone with some parents reporting that they were able to cope better as a result. One parent described how the service their child attends managed to provide some form of respite care in these challenging times.

'So what happened was we did lose it, we did lose it for a few weeks. Then they were able to come and take her for a drive for two hours....So they came to our house and they'd be fully kitted out in masks, and you know temperature checks, the whole lot.... happy days; it gave me two hours of a break'. (Participant 12)

Constantly fighting

While parents accepted and understood, to some extent, the requirement to close essential services at the outset of the pandemic in March 2020, parents also spoke about how services

were slow to recommence with parents themselves having to constantly communicate with services and fight for some respite care.

‘.... I pushed and pushed and pushed. I was making phone calls for about four weeks, before I finally got a day off them’. (Participant 10)

Three parents within this study reported that their access to respite care had yet to return to pre pandemic levels.

Negative and positive impact of COVID-19 on child and family

All parents spoke about the adverse impact of recurring restrictions and multiple lockdowns on their child with many parents noting a regression in their child’s overall behaviour. The reported types of behaviour changes included irritability, obsession, repetitive behaviours, sleep problems, and aggression. Parents also reported changes in their child’s mental health such as depression and anxiety.

‘....he has a number of other issues that have come up now mentally, mental health issues that have come up. And some of it is kind of related to all these lockdowns. It’s not helping him.’ (Participant 9)

While the majority of parents reported negative effects of the Covid-19 pandemic on their child, two parents highlighted how the pandemic and the restrictions that were introduced had some positive aspects for their child. One parent described how their child loved social distancing and the requirement for anyone to be socially distant was a positive aspect of the pandemic. Another parent described how having both parents at home meant more time was spent with the children and that help was not required as parents could cope more by being at home.

Findings in relation to how the COVID-19 pandemic impacted access to respite care.

Overall, the study findings revealed variation in relation to the frequency of respite care received pre COVID-19 pandemic to time of interview as reported by parents. Five parents (42%) reported an increase in their access to respite. Three parents (25%) reported a decrease. Four (33%) parents reported no change in their access to respite. However, findings must be interpreted with caution as there was variation in the type, frequency and timing of parents access to respite.

Although five parents reported an increase in the amount of respite received, the type of and frequency of respite received varied for these parents and their children. At the time of interview, two of these children had since entered full time residential care which had been sought for before the onset of the COVID-19 pandemic. The remaining three children did not access respite services pre pandemic but were now in receipt of respite care. One child had accessed respite care for the first time due to a change in family circumstances but parents had not sought respite prior to this as they reported that they were coping up until this change in family circumstance. This child was in receipt of two nights residential respite care per week. Another child received less than 3 hours key worker support every second Saturday and the final child was in receipt of one to two hours respite care per week in the form of a family support worker.

Three parents reported an overall decrease in the amount of respite their child received. Of these decreases, one parent described how their child was in receipt of respite one week every month but this had now been changed to one week every two months due to the pandemic. Another parent reported how their child's respite went from one night every week to one night every three weeks. Both parents reported that the service cited reasons attributed to the COVID-19 pandemic for the decrease such as the requirement to reduce respite care capacity in order to adhere to COVID-19 restrictions. The third parent reported a reduction in respite from once a week to once every two weeks.

Four parents experienced no change in relation to the amount of respite received.

Discussion

The COVID-19 pandemic has been particularly challenging for many autistic individuals (Cassidy *et al.* 2020, Di Renzo *et al.* 2020, Kim *et al.* 2020, Pfefferbaum & North 2020). In this study, parents reported mostly a negative impact of the COVID-19 pandemic on their child's behaviour, mental health and overall progression. Parents described how the pandemic resulted in increased challenging behaviours for their child, such as more restricted, repetitive behaviours, sleep problems, anxiety, depression and aggression.

Colazzi *et al.* (2020) found that autistic children experiencing behaviour problems pre COVID-19 were twice as likely to experience them more frequently or with higher severity. Findings from this study are similar to that of other recent studies that have explored the impact of the pandemic on autistic people and their families and found increased problematic behaviours and intensity of autistic characteristics in autistic children as well as more emotional and behavioural problems (Colizzi *et al.* 2020, Di Renzo *et al.* 2020, Lee 2020, Nonweiler *et al.* 2020). Research highlights that autistic individuals are experiencing higher levels of psychological distress, anxiety and chronic loneliness compared with the general population during the pandemic (O'Sullivan *et al.* 2021). In this study, feelings of isolation dominated parents' narratives with parents describing how they felt alone and isolated in different ways throughout the pandemic. These feelings were exacerbated as a consequence of having lost access to essential support services such as respite care at the outset of the pandemic with some parents experiencing prolonged isolation as their child's respite did not resume as expected or had yet to return to pre pandemic service levels.

Autistic people demonstrate high rates of service utilization compared to other disabilities (Zerbo *et al.* 2018). During the COVID-19 pandemic, many countries introduced restrictions to contend with the threat of COVID-19 which resulted in the closure of many non-acute

healthcare services. While it was recognised that such extreme measures were required for the safety of everyone, many of these restrictions left autistic people without access to essential services. One of the biggest challenges as reported by parents within this study was the loss of support services, in particular, respite care. The closure of respite care was perceived as very difficult with adverse consequences for the child and family which further added to feelings of isolation. Many parents described taking on physically, mentally and emotionally demanding roles twenty-four hours a day, seven days a week with no additional help resulting in higher levels of stress. Some parents were of the opinion that the closure of their respite services occurred at a time when families with autistic children needed it the most. Notably, some of these families were struggling to access services before the pandemic. These findings are also consistent with several studies reporting the loss of access to essential services during the pandemic for families of autistic individuals (Ameis *et al.* 2020, Eshraghi *et al.* 2020, Jeste *et al.* 2020, Neece *et al.* 2020, Ferguson *et al.* 2021, Manning *et al.* 2021, Wong *et al.* 2021).

A study from the UK found that 86% of parents of autistic children felt a lack of government support during lockdown with 70% reporting that their daily routines were still significantly different since the pandemic began (Pavlopoulou, 2020). While many countries dealt with the pandemic in their own way, there were however criticisms of some countries who did not have adequate representation from mental health experts on COVID-19 advisory panels at the very beginning of the pandemic (Karekla *et al.* 2021, O'Connor *et al.* 2021). Notably, the initial contribution of mental health science was lessened relative to other areas of expertise such as virology and epidemiology, however, as the pandemic continued the mental health implications were becoming increasingly apparent. Historically mental health services in Ireland have been poorly funded receiving approximately 6% of the overall health budget (compared to 12% in New Zealand and United Kingdom) (College of Psychiatrists of Ireland, 2020). Consequently underfunded mental health services have not been able to respond to

the demand for mental health services during COVID-19. Many governments have increased mental health funding in the wake of the pandemic, however more sufficient investment is needed (Latoo *et al.* 2021). Furthermore, research advocates for mental health experts such as psychologists as integral partners in response teams when dealing with problems with a demonstrable behavioural component, either in their emergency or in their intervention phases (Karekla *et al.*, 2021).

In this study, five parents reported an increase in their access to respite since the onset of the pandemic to the time of interview, however, these findings must be interpreted with caution. Parents reported variations in the type and frequency of respite accessed with some parents reporting delays in accessing residential respite because of the pandemic. Some parents who reported an increase in access to respite outlined a requirement for further additional respite or a different type of respite but were grateful to be in receipt of some form of respite considering that other families may not have respite. Most significantly, four parents experienced no change and three parents experienced a decrease in respite services at a time when they needed it the most according to parents. Despite the variations in the type and amount of respite received, there was a consensus among all parents regarding the importance of having access to respite services for all autistic children.

Parents whose children were living in full time residential care before the pandemic reported feelings of isolation and helplessness as their contact with their child was restricted for prolonged periods of time. Research suggests that the COVID-19 outbreak has been extremely difficult for people living in institutions (Danis *et al.* 2020, Schuengel *et al.* 2020) as government measures restricted contact to contain the virus which resulted in visits from family or friends curtailed, access to outdoor spaces restricted and greater powers given to the institutions. There is increasing evidence that individuals living in care homes experienced greater depression and loneliness and demonstrated more behavioural disturbance during the

period that included visitor bans (Liu *et al.* 2021). Consequently, research suggests that a commitment to inclusion means responding to COVID-19 in a way that is sensitive to our most vulnerable communities (Berger *et al.* 2020). While a small number of parents within this study described how their respite service adapted their service to provide some form of respite to the child and parent during the pandemic, findings highlight the need for service providers to devise more innovative respite options that are responsive to the needs of autistic children and their family.

Conclusion

Current research is only beginning to present the impact of the COVID-19 pandemic on autistic individuals. To date, research has highlighted that the pandemic and its subsequent measures have proven to be extremely difficult for autistic individuals living at home and in institutions with research noting that autistic children are a particularly vulnerable population. The present study adds to these findings by providing a qualitative analysis of the lived experiences of the pandemic on parents of autistic children with a particular focus on how the pandemic has impacted their access to respite. Findings have demonstrated that the challenges experienced by many autistic people before the onset of COVID-19 were compounded by an overall lack of support and inadequate access to services, in particular to respite. Prolonged impacts of this pandemic such as loss of or inadequate access to essential services like respite has disproportionately affected autistic people and their families. This study highlights the need to ensure the continuity of autism support services like respite at times when parents need it the most. Respite services need to be better developed, promoted and made accessible to all families of autistic children. Equally, the importance of having access to the right type of respite at the right time was highlighted repeatedly by parents. Another key finding from this study is the requirement to ensure mental health needs of autistic children and their families are addressed as we deal with the impact of the pandemic.

Overall, these findings are consistent with much of the research carried out across Europe and the UK in relation to the impact of the COVID-19 pandemic on autistic individuals and their families. Findings highlight the need for policy makers and service providers to work together to find appropriate ways to meet the needs of autistic children and their families as they continue to live we emerge from the COVID-19 pandemic. To this effect, mental health and autism experts should be included in the decisions concerning service organisation and delivery particularly in the context of respite service provision. In addition, respite services need to be designed in a flexible and way to meet the short term and long term needs of families while ensuring the necessary capacity is available to respond to emergency or unplanned respite requirements.

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