Family relationships and Autism Spectrum Disorder lived experiences of young people with autism and their families

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Trew, S. (2021). Family relationships and Autism Spectrum Disorder lived experiences of young people with autism and their families [PhD Thesis]. Australian Catholic University. https://doi.org/10.26199/acu.8y446

Family Relationships and Autism Spectrum Disorder: Lived Experiences of Young People with Autism and their Families

Submitted by

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A thesis submitted in total fulfilment of the requirements of the degree of

Doctor of Philosophy (PhD)

School of Allied Health

Faculty of Health Sciences

Australian Catholic University

2021

Statement of Authorship and Sources

This thesis contains no material that was extracted in whole or in part from a thesis that I have submitted towards the award of any other degree or diploma in any other tertiary institution. No other person's work was used without due acknowledgment in the main text of this thesis. All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees (where required).

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Sebastian Trew

13 September 2021

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Acknowledgements

The completion of this study and thesis could not have been possible without the expertise, guidance, patience, and support of my supervisors, Associate Professor Parveen Kalliath, Associate Professor Joanna Zubrzycki, and Professor Debbie Plath. There were many others who played a significant role towards this study and thesis, including colleagues at the Australian Catholic University, Emeritus Professor Morag McArthur, colleagues at the Institute of Child Protection Studies, Dr Debbie Noble-Carr, as well as family and friends. A special thank you to my wife Harriet for her constant support and patience. This study could not have been possible without the participation of the young people with an autism spectrum disorder diagnosis and the families who generously offered to be involved in this study. Considerable thanks go to the family advisory group, whose ongoing guidance, support, and encouragement were valued throughout my candidature, from commencement to submission. This thesis was professionally copyedited by Justine McNamara.

Abbreviations

AASW	Australian Association of Social Workers
ACT	Australian Capital Territory
Autism	Autism Spectrum Disorder
NDIS	National Disability Insurance Scheme
TA	Thematic Analysis

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Abstract

There is a developing scholarship in health psychology in investigating family members' perspectives on how autism impacts relationships between family members (e.g., partner/couple/spousal dyad relationships, sibling dyad relationships, parent-child dyad relationships), and the family as a unit. Research into the lived experiences of people with autism and family members remains scant and deserves attention. More notably, there is a dearth of literature of the voices of young people with autism and their lived experiences of family relationships. Without the insights generated from engaging with young people with autism and family members within a qualitative framework, it can be difficult to develop strategies for working effectively with this group.

This thesis reports on a qualitative study which responds to this gap in the literature. The study investigates how autism impacts the relationships between family members, and the family as a unit. It gives a voice to young people with autism and family members, adding greater depth to the quantitative research findings presented in the literature. The study considers the perspectives of twelve mothers, twelve fathers, nine siblings, and eleven young people in families who have an autism diagnosis. A phenomenological approach supports the research in departing from the natural sciences and focuses on the phenomena or lived experience (everyday world) of an individual. The study uses encouragers and open-ended questions to engage the participants in the research and to generate rich data for storytelling from their shared and diverse experiences. Data were collected, analysed, and interpreted using several grounded theory and phenomenological data collection and analysis methods.

The voices of young people with autism and their family members offer insights into how they perceive and experience autism as a way of being in the world, which is often different from others around them, influencing how they think, feel, act, and communicate. Thematic presentation of the findings highlights how family relationships were impacted by physical, emotional, and social behaviours of the young person with autism. Despite the impacts that autism had on the relationships between family members, and the family as a unit, most families in the study navigated these impacts effectively. Families achieved this when all members in the family worked together as a unit. Family members concentrated their efforts to create positive time together. This strengthened the relationships between family members, and the family as a unit.

The findings from this study provide useful insights for family practitioners to structure interventions with families with a member who is a young person with autism. A conceptual framework was generated from the key study findings to indicate how autism impacts on relationships between family members, and the family as a unit. The conceptual framework offers new insights and ways of understanding the factors that have an impact. Suggestions for how the conceptual framework can be translated into practice principles and applied as a practice model for intervention with families are provided. The model can assist practitioners to reflect on the steps they could take to facilitate change in families. The model fills a gap in knowledge by providing an approach to practice for enhancing and strengthening family relationships in families with a member who is a young person with autism, a task thus far not addressed in the literature. The conceptual framework and practice model have direct relevance to practitioners working with young people with autism and their family members in a therapeutic setting. The model and accompanying strategies for practice can be used to inform assessment, case management, group work, and therapeutic work with families as well as with individual family members. It could also be used to develop group work programs, such as groups with fathers, groups with siblings, and groups with adolescents with autism.

Chapter 1: Introduction to the Thesis

Introduction

This chapter provides the background to the research, including a summary of the study population, a description of autism and its core symptoms, and an overview of the known impacts the condition has on families. The line of inquiry the study seeks to address and gaps in knowledge are described. The research question and research aims are provided, and the significance of the study is identified. The chapter concludes with a statement of the foundation of the study and an outline of the thesis.

Language Related to Autism

There is ongoing debate both within the scientific community and among people with autism or autistic people about the appropriate terms to be used related to autism and/or ASD and related terms. While many people with disabilities prefer people first language (i.e., a person with autism), many people on the autism spectrum prefer identity first language (i.e., autistic person). There are recent publications where people on the autism spectrum communicate their preference – and the least offensive terms seems to be autistic person or person on the autism spectrum. This coincides with current Australian research (Burt et al., 2020; Bury et al., 2020; Pellicano et al., 2020) that demonstrates that both person-first and identity-first language are acceptable and preferred amongst adults on the autism spectrum. Some authors (e.g., Botha et al., 2021; Pellicano et al., 2020) have highlighted that within the autism community, identify-first language, such as autistic person is often favoured and considered less stigmatizing than person with autism.

Given the limited knowledge of young people's preferences of the appropriate terms to be used related to autism, young people with an autism diagnosis in the present study were consulted on their preferred language choices. Most of the young people preferred person-first language (i.e., a young person with autism). The young people with autism and their families in the present study, disclosed that they faced stigma and discrimination within their communities with the use of the word *autistic* to negatively describe a person or a person's behaviour. Most of the young people felt they did not belong in their communities when this term was used to describe themselves. This was mainly due to bullying and harassment by peers at school. Given these reasons, throughout this thesis person-first language is adopted. However, when participants themselves have used identity-first language this has been retained in their quotes.

Background to the Study

Prevalence of Autism

Autism Spectrum Disorder (autism) is a lifelong inheritable developmental condition with symptoms and traits present from infancy (Hallmayer, 2011; Lichtenstein et al., 2010; Lundström et al., 2010). Symptoms and behaviours are permanent and include deficits in social communication and interaction and repetitive motor movements that impact on daily functioning (American Psychiatric Association, 2013). In Australia, approximately 1 in 150 people are diagnosed with autism (ABS, 2020). Since 2016, the diagnosis of autism has increased rapidly; whilst there is no certainty about the cause(s) of increased diagnosis, this increase is suggested in part due to a greater awareness of the symptomology of the condition and does not necessarily reflect an increase in the occurrence of autism (ABS, 2016; Walker, 2014). Children and adolescents are the most common cohort to receive a formal diagnosis, with 83% of individuals diagnosed being under the age of 25 (ABS, 2016). Males are more likely to receive a formal autism diagnosis, at four times the rate of females (AIHW, 2019). This is an international trend. In the United States, for example, males have 4.5 times the rate of autism diagnosis of females (Centre for Disease Control and Prevention, 2017).

Autism across age groups varies, and the condition affects individuals differently, with some experiencing a grouping of behaviours that can have an impact on their daily functioning ranging from minimal to intense (ABS, 2016). Most people with autism (88%) also have another disability (ABS, 2016) and many people with an autism diagnosis have comorbid long-term health conditions (lasting 6 months or longer); these include, for example, asthma, attention deficit disorder or hyperactivity, depression, and anxiety (Mattys, 2018). In Australia, amongst children up to 16 years of age living with a disability, persistent and ongoing health conditions are frequently reported for those with autism (Australian Bureau of Statistics [ABS], 2020).

Aetiology of Autism

Recent research suggests that approximately 80% of autism cases are linked to genetic causes; however, a universal and singular “autism gene” has not been identified (Abbeduto, 2019). Psychiatrists in the early 1940s believed the cause of autism to be emotionally unsympathetic parents, particularly mothers lacking in expressions of love towards their children. This view was known as the refrigerator mother hypothesis (Kanner, 1949). The refrigerator mother hypothesis influenced research over a decade, which focused on treatments for what psychiatrists believed were substandard mothers and fathers. It was not until Schopler and Reichler (1971) first studied the effects of parent involvement in the treatment of autism that this view began to change; these authors proposed that parents respond to their child's developmental disorder rather than parental behaviour triggering a manifestation of the disability.

Research during the 1990s and throughout the early to mid-2000s was predominantly focused on investigating the biological causes of autism. Within the last decade, neurobiology research, using neuroimaging and magnetic resonance imaging (MRI) to investigate the autistic brain in vivo, has reported an association between autism and abnormal brain activity that differs across the lifetime and aligns with key developmental stages (Horwitz et al., 2013; Lange et al., 2014; Maximo et al., 2014).

This abnormal brain activity included irregularities in the brain matter in various regions of the brain when compared to that of a typically developed brain (Courchesne, 2002; Lange et al., 2014; Schumann et al., 2010). Abnormalities included distended brain volume of the frontal and temporal lobes in early childhood (Courchesne et al., 2002) followed by stunted growth and a possible decline in volumetric capacity of the brain and thinning of the cortical thickness in various regions after 5–10 years of age (Lange et al., 2014). Furthermore, brain cortex folding in autistic brains has been found to fold and unfold differently than in typically developing brains, affecting brain areas that process sound and spatial information (Kohli, et al., 2018; Libero et al., 2019). These findings suggest that cortical development is curvilinear across the lifespan of autistic brains.

Studies of the physical and chemical structures in autistic brains have played a role in discovering that autism is a combination of complex, individualised genetic anomalies, and environmental factors (Abbeduto, 2019; Hornig et al., 2002). Research into autism as a cognitive and neurological disorder is recent compared with disorders in similar categories (Abbeduto, 2019). This delay is thought to be due, in part, to the varied concepts that were associated with its origins in the early 1940s (Thurm & Swedo, 2012).

Description of Autism

Since the early 1940s, autism research has investigated and understood autism from a medical model of disability. A medical model sees a person disabled by their impairments, which are considered abnormal compared to the general population (Fasciglione, 2015). Under this model, autism is viewed as something that might be cured or fixed. One of the earliest descriptions of autism (Kanner, 1943) attempted to propose nosological bounds on the condition. This approach continues to the present day through continuous redefinitions of diagnostic criteria in various editions of the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM): DSM-III (1980), DSM-IV (1994), and DSM-V (2013). Some authors (Xavier et al., 2015) have suggested that continual redefinitions of the diagnostic criteria for autism have constrained the pervasiveness of the condition and failed to capture its heterogeneity.

Nosological boundaries are applied through either a categorical approach or a developmental approach. The categorical approach is a medical method used in the DSM that works within cut-off points, such as inclusion and exclusion criteria for a disorder (Xavier et al., 2015). The categorical approach of measuring and describing autism is not without limitations, which are evidenced by the need for multiple indicators, including the vast extent of comorbidity and the common application of the “Not Otherwise Specified” diagnosis in the DSM (Xavier et al., 2015). The developmental approach measures autism in individuals along a band of normal and abnormal pathological characteristics, with a concentration on some elements of behaviours across that band (Thurm & Swedo, 2012).

Common practices in neuroscientific studies of autism is to align a hypothesis to the diagnostic criteria in the DSM-V for investigating neurological reasons behind social and interactive deficits and repetitive behaviours in individuals with autism. In recent years, Cheng et al. (2015) isolated distinctions between autistic brains and typically developing brains, which showed that in the brains of people with a diagnosis of autism differences reside in the temporal lobe visual cortex, with a deficit in cortical functional connectivity, an area responsible for processing face expression and social cues. A further reduced functional connectivity with the ventromedial prefrontal cortex is associated with emotion and social communication behaviours (Cheng et al., 2015), aligning with DSM-V diagnostic criteria. Some of these symptoms can be sensory behaviours or needs that affect the person’s physical, emotional, relational and social wellbeing, such as fear, anger, sadness, anxiety and social isolation (Acker et al., 2018; Sibeoni et al., 2022; Spain et al., 2020). These can also include rigidity in behaviour, a need for persistent sameness in routine, anger, and limited social communication skills (Cridland et al., 2014; Schaff et al., 2011; Sibeoni et al., 2022).

Cheng et al. (2015) examined two kinds of functionality—face expression relatedness and self and environment relatedness—which are as significant mechanisms for cognitive processes related to the “theory of mind” (Baron-Cohen, 1991). The “theory of mind” proposed by Baron-Cohen (1991) is an innate skill that involves attributing psychological states to the self and others. The author suggested that this ability is lacking in people diagnosed with autism.

Despite this evidence, physiological studies are yet to identify consistent structural and physical differences between autistic brains and typically developed brains (Gudbrandsen et al., 2020). This suggests that autism is not simply one thing (Nair et al., 2020). Given the ongoing difficulty in determining autism-specific pathophysiologies, the gap between medical science research and clinical practice is widening (Thurm & Swedo, 2012; Verhoeff, 2015; Walker, 2014; Xavier et al., 2015). Autism is mostly considered a “disorder”; however, this is challenged by supporters of the neurodiversity model (Kapp et al., 2013). Some scholars (e.g., Jaswal & Akhtar, 2019) have suggested that understanding and supporting people with autism will involve questioning many of the assumptions made in psychological and medical science about the behaviours and social interests of people with autism, and that this will lead to establishing a more accurate and useful science of autism (Jaswal & Akhtar, 2019).

The neurodiversity model considers autism to be a neurocognitive variant, an inherent aspect of human biodiversity. Through the lens of neurodiversity, disabled people’s subjective experiences tend to be readily acknowledged (Walker, 2014). The subjective experience of people with autism can be described as “…more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable” (Walker, 2014, Definition section, para. 1). The neurodiversity model focuses on the individuality of symptomology expression in individuals and recognises individual’s talents, despite fundamental neurological similarities (Walker, 2014). Also, in this model consideration is given to the impact the environment can have on the individual; as Walker (2014) commented, "…in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree" (para. 4).

In the context of the availability of funding, government and non-government organisations have focused heavily on biological, medical, and genetic investigations into autism. Some researchers (e.g., Gatfield et al., 2016; Milton, 2014; Pellicano et al., 2014) have noted a distrust of this type of research on the part of the autistic community and have called for funding of autism research to shift its primary focus. This call seeks to promote areas of research that improve and enhance the daily lives of individuals with autism and those who care for them, including families (Verhoeff, 2015).

Care and Support of People with Autism

Globally, 85% of people with an autism diagnosis require lifelong care and support, which is provided mostly by family members (Volkmar & Pauls, 2003). This includes physical, social-emotional, and cognitive care and support (ABS, 2015, 2016, 2017; Australian Institute of Health and Welfare [AIHW], 2015, 2017, 2019). Most of the care for children and young people is provided by mothers (88%), followed by fathers (7%) (ABS, 2016; Cridland et al., 2014; World Health Organization, 2011). The range of support that families provide to young people with autism is not fully understood (Bromley et al., 2004).

It is well established in the literature that autism has a significant impact on family members' mental health and physical health (ABS, 2016; Baker- Ericzén et al., 2005; Factor et al., 2019; Krieger et al., 2018). A recent systematic review (Factor et al., 2019) showed that the core symptoms of autism in children impacted on family members' mental health and perceived levels of stress (Davis & Carter, 2008; Tomanik et al., 2004). Some of these symptoms can be sensory behaviours or issues that affect the person's physical, emotional, relational and social wellbeing, such as fear, anger, sadness, anxiety and social isolation (Acker et al., 2018; Sibeoni et al., 2022; Spain et al., 2020). These can also include rigidity in behaviour, a need for persistent sameness in routine, anger, and limited social communication skills (Cridland et al., 2014; Schaff et al., 2011; Sibeoni et al., 2022). These challenges and stressors may have negative impacts on families or result in poor outcomes for family functioning; for example, families may exhibit limited problem-focused or coping strategies or experience increased family conflict and higher levels of emotional distress (Bromley et al., 2004; Cridland et al., 2014; Marshall & Long, 2009; Meadan & Stoner, 2009; Phelps et al., 2009a).

Over the last couple of decades, autism research has tended to examine the impact of the condition on the family as a unit, but with a focus on parent-caregiver outcomes (Abbeduto et al., 2004; Blackledge & Hayes, 2006; Grindle et al., 2008; Rao & Beidel, 2009), and studies have continued to describe and understand these findings quantitively. Most of this research has been conducted with standardised measurement scales to determine the levels of severity of core symptoms presenting in individuals diagnosed with autism.

This gives the reader a measurable understanding of the impacts of autism on these individuals and family members (Wertz et al., 2011) but does not offer a description behind the impacts, such as how and why they are occurring and what these impacts mean for families, or how families make sense of them. Most of these studies have investigated the negative impacts on the family as a unit and have reported on the poor outcomes for family members. This has resulted in an under-reporting of findings on the positive and growth-related outcomes in family members (Bluth et al., 2014). Cosden et al. (2006) have suggested that without this knowledge it is unclear how interventions for families might be designed from a strengths-based approach.

Recommended approaches, design, and methods for intervention with families where a member has an autism diagnosis is varied (e.g., Goepfert, 2015; Helps, 2016; Ramisch, 2013; Solomon, 2012,). Most evidence suggests that social and cognitive-behavioural approaches (Fletcher-Watson et al., 2014; Lang et al., 2010; Spain, 2015; Sukhodolsky et al, 2013) and skills-based approaches for intervention with families (Reichow, 2013; Spain, 2015) are the most effective tools in managing autism core symptoms presenting in the family member to reduce the impact of autism on the wellbeing of the family. Authors Spain et al. (2017) suggest that a drawback of these approaches is they do not target intervention for relationship and communication issues between family members, and do not seek to improve family coping strategies or resilience factors (Spain et al., 2017) or to promote cohesion and connectedness within families (Manzi & Brambilla, 2014; Lee & Robbins, 1998; Tomison, 1999).

Understanding the impact autism has on young people and family members is important. It is also important to understand what intervention might help young people with autism and their family members to reduce the negative impacts and poor outcomes that autism has on family members, and how such an intervention might be designed. Quantitative studies have provided a firm understanding of the measurable impacts that autism has on young people with the condition and on the families that care for a member who is a young person with autism. However, we do not have a good current understanding from a qualitative perspective of how and why autism impacts the relationships between family members, and the family as a unit in families that include a young person with autism.

Gaps in the Literature

Qualitative Studies Exploring Autism and Family Relationships

Few studies within health psychology have qualitatively investigated family members' perspectives on how autism impacts relationships between family members (e.g., partner/couple/spousal/marital dyad relationships, sibling dyad relationships, parent-child dyad relationships), and the family as a unit. This is a limitation in current knowledge because the "What is it like?" question is not answered, and the unsaid and hidden features of human experiences in this group are not revealed, when quantitative measures are used (Wertz et al., 2011). Quantitative measures typically employ observation, surveys, questionnaires, and statistical analysis of data to reach conclusions (Creswell & David, 2018).

The qualitative studies that have investigated relationships in families with a member who is a child with autism have mostly focused on the parent or caregiver and their interactions with the child with autism. Many of these studies report understanding from a maternal perspective (Phelps et al., 2009b; Smith et al., 2010) and limit the consideration of other perspectives or other familial relationships (e.g., sibling or partner relationships). A heavy focus on the maternal perspective might be because mothers are reported to be the primary caregiver of children and young people with autism (e.g., AIHW, 2019; ABS, 2016; Cridland et al., 2014; World Health Organization, 2011).

Although it is crucial to capture the maternal perspective, relying solely on this has limitations, as the maternal perspective may not be reflective of all family members, such as fathers or siblings (Seligman & Darling, 2007) or of young people with autism. Without the perspectives of multiple family members there is limited guidance on how to structure family interventions that could offer mutual benefits and provide positive experiences for the family as a unit in a therapeutic setting, and limited guidance on how to identify issues specific to certain family member groups, such as fathers or siblings (Varghese et al., 2020).

Perspectives and Experiences of Young People with Autism

Recently, Courchesne et al., (2021), highlighted that whilst research on lived experiences of autism has mostly focused on the insights of parents, siblings, teachers, and clinicians, it has not meaningfully or substantially included the first-person perspectives of people with autism (Nicholas et al., 2019; Richards & Crane, 2020; Tesfaye et al., 2019). There is research (e.g., Chown et al., 2017; Le Fletcher-Watson et al., 2019; Frazier, Dawson & Murray, 2018; Galpin et al., 2018; Hurlbutt & Chalmers, 2002; Jones et al., 2003; Lebenhagen, 2019; Pellicano, Dinsmore & Charman, 2014; Pellicano et al., 2018; Scott-Barrett, Cebula & Florian, 2019) to indicate the value in seeking the perspectives of people with autism. For example, how this group perceives and experiences the condition and how it influences their interactions with others, including family members. However, knowledge of this group's experiences is mostly understood from an adult perspective and not from a child or adolescent perspective (Depape & Lindsay, 2016; Kirby et al., 2014; Nicholas et al., 2019;

Richards & Crane, 2020; Tesfaye et al., 2019). Authors Depape and Lindsay (2016) have recognised in their meta-analysis that first-person narratives from children and adolescents with autism are scarce in the recent literature. Some other authors (e.g., Clark & Adams, 2020; Kirby et al., 2014 Pellicano et al., 2018; Saggers et al., 2011; Scott-Barrett et al., 2019) have highlighted that few scholars have recognised the crucial need to research the perspectives of children and young people with autism.

There is valuable, but limited, research incorporating the voices of young people with autism. For example, in a recent study Courchesne et al., (2021) sought to test and develop strategies that may prove potentially effective in capturing the voices of autistic teenagers, and creating inclusive methodologies within disability and autism research. A few studies (Cappadocia et al., 2012; Chen & Schwartz, 2012; Fisher & Tayor, 2015) interviewed adolescents with autism about their experiences of peer victimisation including bullying and teasing and put forward recommendations that schools might use to address this issue. One study (Kirby et al., 2014) using phenomenological interviews explored how children and young people between 4-14 years of age share information about their sensory experiences. The findings showed that these children and young people share information about their sensory experiences through themes of normalising, storytelling, and describing responses. Another study (O'Hagan et al., 2022) included autistic mentees ages 14-21 amongst a larger study sample in focus groups to understand their perspectives of an inclusive peer mentoring program (Teens Engaged as Mentors) for autistic adolescents. The findings showed that autistic mentees enjoyed the mentoring program because of increased socialisation opportunities, which promoted friendships and openness towards others.

However, efforts to engage children and young people with autism in research remain uncommon (Factor et al., 2019). This is a limitation of the current literature, because without the perspectives of young people with autism we will not know if there are other ways to understand the condition and how it might be experienced for this group, and how this might influence their interactions with others, including family members. This has implications for interventions designed for families with a member who is a young person with autism, as without this knowledge it is unclear how the design of an intervention accommodates the young person's perspective or reflect an understanding of issues in the family. Practitioners who have access to this knowledge could develop unique strategies for intervention that are informed by the young person's perspective, or practitioners might identify better ways to structure supports for the young person with autism in the intervention.

The limited inclusion of the voices of young people with autism in research could be attributed to the deficits in social communication and interaction that are the core symptom of the condition (American Psychiatric Association, 2013), which might make it more difficult for them to participate in research interviews. Additionally, due to the nature of autism and its effects on people, it might make it more difficult for some people with autism, particularly those who are minimally verbal or with intellectual disability (Courchesne et al., 2021; Tesfaye et al., 2019) to partake in traditional research interview methods, and for the researcher to engage with them meaningfully. It might also be due to the significant impairment to daily functioning experienced by many individuals with autism, who require the constant support of a parent, carer, or guardian (ABS, 2016), therefore limiting their opportunities to participate in research. Another reason might be that researchers are yet to identify which methodological approaches and methods are best suited to facilitating the inclusion of young people with autism in research aiming to explore their perspectives (Courchesne et al., 2021; Cridland et al., 2014; Depape & Lindsay, 2016; Preece, 2002).

Support and Intervention for Young People with Autism and Their Family Members

Despite the evidence suggesting that some family intervention approaches can be effective for families (Fletcher-Watson et al., 2014; Lang et al., 2010; Reichow, 2013; Spain, 2015; Sukhodolsky et al., 2013), more research is needed to inform and guide interventions for families with a young person (12–19 years of age) with autism as a family member. Current family autism research mostly focuses on caregivers and their young children, from 2 to 12 years of age (Schwartz et al., 2018), as early intervention is the best approach to manage the core symptoms of autism and a critical time to identify and implement supports for families (Factor et al., 2019; McConnell, 2002). Children with autism develop skills in different orders and at different rates when compared with children without an autism diagnosis (Landa & Garrett-Mayer, 2006). Autism can also affect understanding and perspective. Children without autism develop the skills to consider another person's perspective between 3 and 5 years of age. However, children with autism may develop these skills later (Leudar et al., 2004).

Adults and young adults (older than 25 years) with autism have also been included in research-focused interventions (Depape & Lindsay, 2016; Haertl et al., 2013; Hurlbutt & Chalmers, 2002; Nicholas et al., 2017), as it has been recognised that transitioning from adolescence to adulthood is especially challenging for young people with autism (First et al., 2019). In a recent review, authors Spain et al. (2017) concluded there is sufficient evidence to suggest that psychological interventions can reduce stress and mental health morbidity for individuals with autism and their family members. In a more recent systematic review, Factor et al. (2019) found no evidence of targeted interventions for young people with autism aged 14 years and older and their family members.

The authors Spain et al. (2017) have suggested that family (systemic) therapy can be an effective approach for individuals with autism and their family members to enhance communication, relationships, and coping. However, the authors concluded that whilst systemic therapy is tentatively suitable for this group, few studies have examined the effectiveness of such an approach for this group, suggesting further research is needed.

Working with families throughout adolescence is important, as negative behaviours are prevalent in middle adolescence and amongst young adults with autism (Laghi et al., 2018; Mazzoni et al., 2018) and we see increased difficulties in the relationships between the young person with autism and their caregiver and their siblings during adolescence (Desai et al., 2012; Halloran et al., 2013; Nealy et al., 2012; Pottas & Pedro, 2016).

A need for targeted intervention responses for young people with autism and their family members remain. To inform policy for therapeutic practice and intervention for young people with autism and their family members, there is a recognised need for research to focus on the social and environmental factors that sit outside the family as a unit and to understand the influence they have on this group (Factor et al., 2019; Kirby et al., 2016; Kriegar et al., 2018; Simpson, 2018).

Research Question and Aims

In response to the gaps in the literature described above, this study seeks to investigate *how autism impacts the relationships between family members, and the family as a unit*. To do so, it considers the perspectives of mothers, fathers, siblings, and young people in the family who have an autism diagnosis. Three theoretical orientations of childhood studies, family systems theory, and disability studies have been drawn upon as a theoretical framework for the examination of the research question. The purpose of the theoretical framework is to provide direction and guidance to the study. The content of the framework is drawn from the academic literature and provides viewpoints or lenses through which the study participants and data are viewed (Creswell & Poth, 2018; Guba, 1990). In Chapter 3, the application of each theoretical orientation is discussed in terms of where and how the orientation informed or guided the study and what outcomes it produced in the design of interview schedules, data collection methods, and in the analysis of data.

The theoretical orientation of childhood studies includes multiple areas of study that appreciate and recognise childhood as a phenomenon experienced by children, as they participate in the world as social actors (Qvortrup et al. 2011). The lens of childhood studies is fundamental to this study, as it considers childhood to be a concept that is socially constructed and understands children are positioned in a distinct period that is affected and shaped by social and cultural factors (James & James, 2012; Mayall, 1994). Childhood studies supported the participatory methodology of this study, including the use of in-depth interviews and open-ended questions. The framing of childhood studies helped to create an accessible space for children and young people to discuss and make sense of autism and their family experiences and relationships in their own ways. Further details about childhood studies and how it informed the study are provided in Chapter 3. Disability studies considers people with disability as capable social actors and not passive recipients of society and culture. People with disability are acknowledged as people with unique, diverse, and shared experiences. The viewpoint places significant value on the importance of disability rights, agency, and wellbeing, and brings the voice of people with disability to the foreground. Disability studies helped focus the study on the leadership of young people with autism, their families, and the autism community (Hall, 2019). Disability studies supported the inclusion of children and young people in the research processes and provided guidance for foregrounding the voices of young people with autism in the research. Further details about disability studies and how it informed the study are provided in Chapter 3. Family Systems theory places and understands individuals in relation to other people in their family and the inter-relationships between them (Cox & Paley, 1997; Minuchin, 1985). Family systems theory views the family as an emotional unit and examines the bonds and interactions amongst members to describe the complex interactions within it. Individual problems are interpreted as family problems. An issue or problem inherent in an individual is suggested to impact other members in the family and their relationships with one another. Family systems theory played a central role in informing and interpretation of dynamics and interactions within the families, and between the family members, throughout the data analysis phases and in the presentation of the study findings. Further details about family systems theory and how it informed the study are provided in Chapter 3.

A phenomenological approach supports the research in departing from the natural sciences and focuses on the phenomena or lived experience (everyday world) of an individual.

The study seeks to “return to the things themselves” (Moustakas, 1994, p. 26) when speaking with young people with autism and their family members. A phenomenological approach to the study helps the researcher to acquire a deeper understanding of family members’ perspectives and personal experiences.

The study uses encouragers and open-ended questions to engage the participants in the research and to generate rich data for storytelling from their shared and diverse experiences (O’Reilly & Dogra, 2017; Ponizovsky-Bergelson et al., 2019). In-depth semi-structured interviews with the study participants were used to explore the following aims of this study:

1. How do young people with autism perceive and experience their condition within their family?
2. What are family members’ perspectives on how autism impacts relationships between family members, and the family as a unit?
3. What are family members’ perspectives on how external responses to autism impact on their family relationships?

Significance and Contributions of the Study

Based on the review of the literature presented in Chapter 2, a gap in current knowledge on understanding how autism impacts family relationships from the perspectives of young people with autism and their family members is evident. The present study addresses this gap by giving voice to young people with autism and their family members to provide some greater depth to the quantitative findings presented in the literature. Without the new insights generated from engaging with families within a qualitative framework, it can be difficult to develop strategies for working effectively with this group.

Working with families throughout adolescence has been identified as important, as negative behaviours are prevalent in middle adolescence and amongst young adults with autism (Mazzoni et al., 2018) and we see increased difficulties in the relationships between the young person with autism and their caregiver and their siblings during adolescence (Desai et al., 2012; Nealy et al., 2012; Halloran et al., 2013; Pottas & Pedro, 2016). Despite this, in a recent systematic review Factor et al. (2019) found no evidence of targeted interventions for young people with autism aged 14 years and older and their family members. Whilst evidence suggests that some family intervention approaches can be effective for families (Fletcher-Watson et al., 2014; Lang et al., 2010; Reichow, 2013; Spain, 2015; Sukhodolsky et al., 2013), research is needed to inform and guide interventions for families with a young person (12–19 years of age) with autism as a family member.

A need for targeted intervention responses for young people with autism and their family members remains. To inform policy for therapeutic practice and intervention for young people with autism and their family members, there is a recognised need for research to focus on the social and environmental factors that sit outside the family as a unit and to understand the influence they have on this group (Factor et al., 2019; Kirby et al., 2016; Kriegar et al., 2018; Simpson, 2018).The findings from this study addresses this gap by providing useful insights into family experiences of autism which can inform family practitioners in structuring interventions with families with a member who is a young person with autism.

A conceptual framework was generated from the key study findings to indicate how autism impacts on relationships between family members, and the family as a unit. The conceptual framework offers new insights and ways of understanding the factors that have an impact. It is a tentative and indicative framework, providing an outline of ideas that help to make sense of what is happening in families, understood through their experiences. This helps us to better visualise this process, how it functions, and how change might occur from within families. The conceptual framework fills a gap in knowledge, providing a deeper understanding of how autism impacts family relationships than previous research (explored in the literature review in Chapter 2) has provided.

Suggestions for how the conceptual framework can be translated into practice principles and applied as a practice model for intervention with families are provided. The model can assist practitioners to reflect on the steps they could take to facilitate change in families. The model fills a gap by providing an approach to practice for enhancing and strengthening family relationships in families with a member who is a young person with autism, a task thus far not addressed in the literature. The conceptual framework and practice model have direct relevance to practitioners working with young people with autism and their family members in a therapeutic setting. The model and accompanying strategies for practice can be used to inform assessment, case management, group work, and therapeutic work with families as well as with individual family members. It could also be used to develop group work programs, such as groups with fathers, groups with siblings, and groups with adolescents with autism.

Researcher Positionality and Foundation of the Study

There is a substantial body of literature (e.g., Adu-Ampong & Adams, 2020; Bourke, 2014; Carter et al., 2014; Clift et al., 2018; Davis, 2018; Holmes, 2020; Kapinga et al., 2020; Merriam et al., 2001) discussing researcher positionality in qualitative research and its influence on the research process (Ahmad, 2022). As described by Holmes (2020, p.1), "… the term positionality both describes an individual's world view and the position they adopt about a research task". A statement on researcher positionality is generally a reflexive description of the researcher's lenses adopted for the study, such as personal, philosophical, or theoretical beliefs and their viewpoints of the research process; a researcher's influences or possible bias on the research, such as gender, ethnicity, age, career, and education background; and the researcher's position in reference to the participants included in the study, such as the researcher's insider or outsider status (Holmes, 2020). Included in this statement is a justification of the influence of these aspects on the research, such as how they influenced the research and in what ways or where or when throughout the research process (Savin-Baden & Major, 2013). My statement on researcher positionality is provided below, beginning with the foundation of this study, and continued under the subheading, Insider-Outsider Status.

The foundation of this study can be traced back nearly 15 years, to my first job working at an after-school care program at a primary school in Canberra, Australian Capital Territory. It was there that I was first introduced to the term autism and, to my knowledge at the time, I was first introduced to young people with autism. Over the course of my career as a disability support worker, family practitioner, youth worker, and currently as a social researcher, I strive towards a better understanding and knowledge of working with and for young people with autism and their families.

Most recently, working at the Institute of Child Protection Studies (ICPS) at the Australian Catholic University, I began to develop the skills, understanding, and rigour important for connecting with and eliciting the views and experiences of young people and families in research. I began to appreciate how this work can, in turn, inform policy and practice to drive positive social change for the families. These endeavours have been guided by my undergraduate education in history, anthropology, and cultural studies, as well a master's degree in human rights. Together, my work and education are supported by values of ethics, disability rights, and social fairness and the conviction that difference amongst individuals is an element of diversity and not a limitation.

The choice of my PhD topic was deeply influenced by my work with families and young people with autism, including how I approached, conducted, and framed the research. The specific focus of this study was developed through a combination of observations made throughout my career as a disability support worker and family practitioner, my own observations, and reflections of my own family and family relationships, and through detailed reading of research literature on autism and families. Today, I remain in contact with two young people with autism and their families whom I first met and worked for 15 years ago. As well as my work and educational background, being a person who was recently diagnosed with autism also deeply influenced the research and guided the approach taken to the research.

For example, I was aware of various elements in the research process, such as interviews, which might prove challenging or anxiety-inducing for some young people with autism because of the formal and structured way a traditional interview might be conducted. To tune into the potentially diverse experiences of others, I employed strategies in the research to set my own experiences aside. This included a clear articulation of the researcher's "insider member" status and clear delineation of the role and impact this had on the research, demonstrated by the *epoche* statement and the statements of reflexivity throughout the data collection and analysis (Chapter 4) and the inclusive and flexible design and processes (Bergold, 2007). These represent efforts to design inclusive research to account for the diversity of the participant groups in this study. In practice, this meant adapting the research environment, research materials, and research activities to facilitate broad engagement and access to the study for children, young people with autism and young people with intellectual disability (Long & Clarkson, 2017; Tesfaye et al., 2019). These strategies are further elaborated and described in Chapter 4, which focuses on methodology and methods.

Insider-Outsider Status

In this study, as a researcher who identifies as a person with autism, my *insider* member role status influenced my engagement with the research and guided the approach to the study. An insider researcher is a member of "…specified groups and collectivities or occupants of specified social statuses; outsiders are the non-members" (Merton, 1972, p. 21). An insider might share the characteristics and experiences of the group being studied (Dwyer & Buckle, 2009) as opposed to the status of an *outsider* researcher (Chhabra, 2020).

Acknowledgement of researcher membership (i.e., whether the researcher is an insider or outsider) is increasing "…in response to a greater consciousness of situational identities and to the perception of relative power" (Angrosino, 2005, p. 734). This is important in qualitative studies, where the researcher often has a close and ever-present role in the study design and in the collection and analysis of the data (Dwyer & Buckle, 2009). Awareness of the insider-outsider researcher member position is important when conducting research with people with disabilities, due to the group's historical objectification and oppression in research processes (Barnes, 1996; Barnes, 2008; Chhabra, 2020; Dwyer & Buckle, 2009; Oliver, 1990, 2013; Stone & Priestley, 1996).

Some benefits of being an insider researcher can include having the knowledge to better access participants and engage with them (Berger, 2013; Dywer & Buckle, 2009) and knowledge of a group's language, preferred terminology, or shared views. This might assist the researcher to build stronger rapport with participants, potentially resulting in deeper insights or reflections being captured during data collection (Brannick & Coghlan, 2007; Hellawell, 2006). At the same time, these perceived benefits, if not clearly articulated in the research design and processes, could be viewed as the researcher securing privileged access to the group to undertake co-construction of knowledge that might benefit the individual researcher directly (Chaudhry, 2019; Humphrey, 2007).

In this study, a clear articulation of the researcher insider member status and clear delineation of the role and impact this had on the research is evidenced by the epoche statement, the statements of reflexivity throughout the data collection and analysis, and the inclusive and flexible design and processes (Bergold, 2007). These efforts were made to design inclusive research that accounted for the diversity of the groups in this study. This included adapting the research environment, research materials, and research activities in efforts to facilitate broad engagement and access to the study for children, young people with autism, and young people with intellectual disability (Long & Clarkson, 2017; Tesfaye et al., 2019).

Ethically, critical awareness of the researcher insider-outsider member role aligns with the participatory design of this study, informed by the needs, wants, and values of people with autism and their families. This is evident in the research topic, the research design, the articulation of the research question and research aims, and the research methods. These approaches worked together to foreground the voices of people with autism, and to make sure research findings could be translated and applied to settings outside of the research (e.g., to inform policy and practice) (Carrington et al., 2016; Grinker et al., 2015; Parr, 2016; Parsons & Cobb, 2013).

Outline of Remaining Chapters

Chapter 2: Literature Review provides the context to the research, discussing background literature that informed the focus of the study investigation and reviewing the autism and family relationship literature.

Chapter 3: Theoretical Framework presents the theoretical framing of the study and how theoretical and value perspectives have shaped the research design to address the research question and research aims. The theoretical framework ensured the experiences of young people with autism was a central part of the research.

Chapter 4: Methodology and Methods includes a description of the qualitative participatory methodology and the phenomenological approach to this study. This includes how the research approach influenced the methods used for data collection and analysis. The methods section of this chapter describes the procedures used to prepare for and conduct the fieldwork. This includes descriptions of the advertisement for and recruitment of participants, ethics approval, the interview process, and data collection and analysis.

Chapter 5: Findings provides an in-depth presentation of the results. The global themes constructed from the data are examined, and participants perspectives are described in detail.

Chapter 6: Discussion examines the findings in the context of the literature and discusses the key study findings. The key study findings are interpreted to conceptualise how behaviour patterns that appear to occur in families drive underlying social processes (Strauss & Corbin, 1990), disrupting family and social connectedness and impacting on families' relationships.

Chapter 7: Practice Model and Conclusions provides suggested practice principles and a practice model informed by the findings to guide interventions for families with a member who is a young person with autism. The principles can assist practitioners to reflect on what steps they could take to design and structure an intervention. The practice model has the potential to assist practitioners to reflect on what steps they could take to action change in families, with an emphasis on enhancing and strengthening family relationships. The model and its components bring together multiple forms of knowledge to bridge the gaps between theory, research, and practice. The thesis concludes with a reflection on the research design and approach that guided and informed the study, the study strengths, and the study's contributions to research, policy, and practice.

Chapter 2: Review of the Literature on Autism and Family Relationships

Introduction

This chapter presents a comprehensive review of the literature that informed the context of the research and guided the development of the research aims and question. To understand the population from which the study sample was drawn, the chapter builds on the introduction to provide a thematic presentation of the literature on the study topic. A tri-layered approach was adopted to conduct this review of the literature (Fileborn, 2014). This included: a search of autism across multiple fields, such as medicine, psychology, and sociology, and of key authors and family outcome research findings across qualitative and quantitative studies; a search of literature focused on family relationships and autism within databases in the EBSCOhost research platform; and *snowballing*. *Snowballing* as a search method allowed for the discovery of information through other sources. For example, as publications or websites were identified, the reference lists of these publications and links provided on these websites were searched for other sources relevant to this review.

The review of literature begins with an overview of family outcome research findings, followed by literature on supports and assistance available to families. To understand how previous research informed the approach to this study, an overview of inclusion and engagement of young people with disabilities, including autism, in research is provided. The chapter then focuses attention on what is known about family relationships and autism through a detailed search of empirical research related to the current study's line of inquiry, which is to investigate how autism impacts the relationships between family members, and the family as a unit. This is a synthesis of knowledge on the topic of family relationships and autism, which informed the development of the study and research question. The chapter concludes by highlighting gaps in current literature in relation to the research question and describes how the study responds to these gaps.

Search Methods

A targeted desktop search of publications such as journal articles, books, theses, and websites was undertaken to find suitable information for the review. This approach meant *grey* literature from government and non-government sources could be captured. These types of information and publications are unlikely to be sourced through academic peer-reviewed journals or databases (Fileborn, 2014).

The range of sources for the targeted search was informed by the researcher's knowledge of autism and the use of *snowballing* methods to locate information from source to source (Fileborn, 2014). For example, each Australian State and Territory Department of Health and Community Services (or equivalent) website was examined for information on current support services and resources for families with a child or adolescent with autism, and for programs across the early years, school years, and adulthood. Also, the Knowledge Centre of the Cooperative Research Centre for Living with Autism (Autism CRC) was examined for current articles and research publications in the field of autism and related to the topic of the present study. Links to additional resources provided on these and other government and non-government websites were used to locate further sources of information and to identify programs or services through other websites related to autism and families.

Additionally, to cover as much peer-reviewed literature as possible on the topic from a broad selection of related disciplines, a literature search targeting family and relationships and autism was conducted in the EBSCOhost research platform. The details of the search, including search terms, subject headings, and search limiters are provided in Appendix A. Examples of some of the databases selected for searching were CINAHL, PsycInfo, SocINDEX, ERIC, and Medline (Pubmed). Each database dictionary and thesaurus were consulted for subject headings consistent with the research question and aims of the study. The search parameters were limited to English and to academic journals and dissertations, and no limits were specified for study publication date. This approach was designed to capture as much empirical research published on the topic of autism and family relationships as possible.

After data extraction was completed from the studies included for review, the results of the search were thematically sorted and grouped together under family dyad relationship headings: that is, family relationships, partner relationships, parent-child relationships, and sibling relationships. Findings across these studies are discussed below, from page 57 of the Chapter, identifying knowledge about the impacts of autism on family relationships. Discussion of additional studies from a related field are also incorporated.

In addition to this search on family relationships and autism, a search for literature in a related field was conducted. This was a broader search for literature related to disability, chronic mental disorder, or chronic illness and family relationships. The purpose of performing this search was to identify research focused on the study of family relationships in the related disability literature and to compare study results. Some additional relevant literature was identified.

The results of the searching described above are presented thematically in the following subsections.

Search Results

Impacts of Autism on Young People and Family Members

Research (Matty et al., 2018) has found that stress, anxiety, and depression as well as neuroticism (Vazire, 2010) and irritability (Mervielde et al., 2005; Sizoo et al., 2015) are common traits observed in individuals diagnosed with autism. Generalised anxiety, separation anxiety, and social anxiety are commonly reported amongst individuals with an autism diagnosis, with an estimated 40% prevalence rate (Keen et al., 2019; Ozsivadijan et al., 2012; Spiker et al., 2011; Steensel et al., 2011; Wood & Gadow, 2010); these are the most frequently reported mental health difficulties amongst this group (Magiati et al., 2015).

The environment a young person with autism is situated in is thought to play a role in their anxiety and stress levels. This might be due to the unique processing styles, communication, behaviour, and sensory hypersensitivities associated with autism, as parents report their children having wobbly legs, butterflies, and out of control breathing in a range of situations and environments (Ozsivadijan et al., 2012). Parents report that anxiety levels in their children spike at specific “triggers” characteristic of autism symptoms, such as communicating and interacting in social situations (Spiker et al., 2011) and sensory sensitivities to noises, including its level of frequency (Weiss et al., 2013), and obsessions or restricted interests, including repetitive interests and fixations. These all contribute to increased levels of distress for children and their families (Spiker et al., 2011). Parents report their children have difficulty in expressing their concerns verbally, which can mean anxiety is expressed through changes in behaviour (Gatfield et al., 2016; Ozsivadijan et al., 2012).

In addition, people diagnosed with autism find it difficult to identify their own emotions, including having a lack of insight into themselves (Frith & Happé, 1999; Raffman, 1999), limited self-awareness, and a poor introspective faculty (Baron-Cohen, 2003; Baron-Cohen et al., 1985; Frith & Happé, 1999; Lombardo & Baron-Cohen, 2011; Yirmiya, et al., 1998). This is possibly explained by impairments in a specific aspect of functioning (Huang et al., 2017; Zahavi, 2010), such as in the self-system (e.g., Elmose, 2016; Peterson et al., 1984), or impairments in the psychological self (Baron-Cohen, 1995; Baron-Cohen et al., 1993).

Impacts on Parents

Many families who care for a member with autism experience a wide range of impacts on mental health and wellbeing (AIHW, 2019; Baker-Ericzén et al., 2005; Davis & Carter, 2008; Spain et al., 2017; Tomanik et al., 2004). High levels of depression and anxiety are prevalent in families caring for a child with autism (Dababnah & Parish, 2016; Dabrowska & Pisula, 2010; Dale et al., 2006; Davis & Carter, 2008; Estes et al., 2009; Gray, 2003; Ludlow et al., 2011; Sharma et al., 2013; Spain et al., 2017) as well as increased levels of stress (Dumas et al., 1991; Gray, 2006; Gray & Holden, 1992,) and fatigue (e.g., Cadman 2012; Firth & Dryer, 2013; Giallo, 2013; Hoefman et al., 2014).

Mothers, as the primary caregivers of children with autism, report higher levels of depression and stress than fathers (Marshall & Long, 2009). Mothers are reported to have high rates of mental and physical health issues, and to experience social isolation and financial burden (e.g., Hines et al., 2013; Larson, 2010; Pisula & Dorsmann, 2017; Tint & Weiss, 2016). Fathers are reported to have heightened stress levels, and external stressors have a greater contribution to the stress levels of fathers compared to mothers (Davis, 2008; Hartley et al., 2011). Siblings are reported to have small increases in levels of behavioural problems (Hastings & Petalas, 2013) and to display characteristics of anxiety (Shivers et al., 2013).

Parenting a child with autism has been described as difficult due to challenging behaviours such as tantrums, aggression, and violence towards family members, often due to sensory hypersensitivities (e.g., Aylaz et al., 2012, Ballan, 2012; Dickie et al., 2009; Goin-Kochel et al., 2009; Marquenie et al., 2011; Schaaf et al., 2011) Grandparents of a child with autism can also be impacted (Prendiville & Kinsella, 2019) via the observed impact the child with autism has on other children and parents (Hartmann, 2012). Impacts on family life includes fewer familial interactions and less involvement in recreational activities than families that do not include a young person with autism (Boyd, 2002).

Impacts on Siblings

Reported impacts on siblings of a brother or a sister in the family diagnosed with autism include stress and issues with anger (Hartman, 2012; Orsmond & Seltzer, 2007; Petalas et al., 2012). Stress for siblings may result from the frustration associated with their brother or sister's deficits in communication and social interaction (Hartman, 2012). In several studies, communication and interaction deficits have been reported as a disappointment for siblings trying to interact with their brother with an autism diagnosis, as the response in these studies was primarily aggression, violence, and unpredictable and erratic behaviour (Mascha & Boucher, 2006; Petalas et al., 2009; Ross & Cuskelly, 2006). In another study, siblings self-reported feelings of being "driven mad" and worries of "being attacked" by their sibling with an autism diagnosis (Ozsivadijan et al., 2012, p. 115). In a study investigating aggression and sibling interaction for siblings aged 8–15, 84% reported aggression as a key factor in interactions with their sibling with an autism diagnosis (Orsmond & Seltzer, 2007). Sibling relationship quality may be dependent on the level or severity of autism characteristics presenting in the diagnosed child (Petalas et al., 2009, 2012; Rivers & Stoneman, 2003), however quantitative research does not fully investigate the effects of this on these relationships (Spain et al., 2017).

Support and Assistance for People with Autism and Families

Young people with autism usually require ongoing supports from family members throughout their lifetime (Spain et al., 2017). The Australian Bureau of Statistics (ABS, 2020) reported that, in 2018, over half (61%) of all people with an autism diagnosis required high support in daily activities and over one third (39%) required support with emotional and social wellbeing. The 2018 Survey of Disability, Ageing and Carers (SDAC) found that people with an autism diagnosis who needed support (n=170,100) did not receive the support they needed or wanted. More than half (51.7%) indicated they needed greater support than they received. Adults with autism indicated their greatest unmet needs were around cognitive and emotional supports (ABS, 2020).

Researchers (e.g., Read & Schofield, 2010; Roughan et al., 2017) have suggested that many mental health services are failing families with children and young people with autism. Some authors (e.g., Gabovitch & Curtin, 2009; Hodgetts, 2013; Hodgetts et al., 2015; McKenzie et al., 2020; Nicholas et al., 2020; Roughan et al., 2017; Wilson, 2013) are calling for organisations and services to develop innovative interventions to meet the needs of this diverse client group. Parents, as well as service providers, recognise a lack of appropriate family-centred care in services, including limited understanding of what services and supports families are receiving. Parents of children with autism report that current support services are not meeting their needs, which contributes to their feelings of isolation and alienation (Galpin et al., 2018).

An increased need for autism services continue to place demand on an already stretched service system, particularly in regional areas of Australia. Farmer and Reupert (2013) reported that parents in rural settings in Australia "…feel confused, frustrated and overwhelmed" by the impact of autism on the family, and by their own lack of knowledge and understanding of the condition (p. 13). Parents also stated they did not have adequate information and that they felt "lost in the system" (p. 23). Another area of concern for parents is centred on workers and supports not meeting or fulfilling their child's needs, including behavioural, emotional, and developmental needs (Houser et al., 2014). As a result, parents repeatedly and regularly, or exclusively, rely on family members for assistance with care (Houser et al., 2014).

Despite the common occurrence of anxiety, separation anxiety, and social anxiety for individuals with an autism diagnosis (Keen et al., 2019; Ozsivadijan et al., 2012; Spiker et al., 2011; Steensel et al., 2011; Wood & Gadow, 2010), which contributes to the level of care that parents need to provide for their children (Catalano et al., 2018), there are some therapies that demonstrate positive outcomes for anxiety in children with autism, including group therapy and cognitive based therapy (CBT) (Khan et al., 2016). The treatment of anxiety with CBT for young people with autism shows promising results in reducing the symptoms of anxiety (Ung et al., 2014). However, interventions that have shown promising results are time and cost intensive for both patients and practitioners (Ung et al., 2014). A study by Corbett et al. (2015) involving young people with autism in a theatre-based intervention found improvements in social ability and a decrease in trait anxiety accompanying social interaction. A recent and underexplored area of research is the impact and effectiveness of autism-related supports and services for culturally diverse families caring for a child with autism, with recent evidence suggesting large inequalities in delivery, support, access to diagnosis, and outcomes (Chlebowski et al., 2018).

Focus groups and paraprofessional autism networks have been shown to provide meaningful and positive experiences for families, with parents reporting that swapping family stories in an open forum created “meaningful moments,” bringing individuals closer together (Loukas et al., 2015, p. 461). Additionally, networks can increase knowledge, introduce, and teach improved living patterns, increase capacity for heightened coping skills, and help bring desired changes, while helping families to know that they are not alone (Lock et al., 2013). The importance of “place making” has been identified (Loukas et al., 2015, p. 461). This involves creating a safe space for families and parents to talk about their autism life experiences; providing such a safe space has been found to create positive interpersonal changes amongst families and their member with autism (Loukas et al., 2015; Ludlow et al., 2011; McCabe, 2012; Safe et al., 2012; Zhang et al., 2013b). However, many parents regard support groups and social groups as inaccessible, partly because of professionals’ lack of understanding of, and limited involvement in, the unique ways in which each family functions, and because these services are either lacking, or communication about them is inadequate (Khan et al., 2016).

Other research has suggested that modifying services to accommodate families' needs may improve their quality of life and reduce strain on the family system (Hodgetts et al., 2015). Parents have recently called for supports and services to adopt an interpersonal, family-centred approach, one that ensures an understanding of the specific needs of the family as a unit (Gaplin et al., 2018). There is an ongoing call for parents' involvement in family supports and therapy-based interventions (Factor et al., 2019; Kriegar et al., 2018; Spann et al., 2003). Therapeutic interventions from a whole family approach can address the support needs of each family member and help to limit any adverse effects on them throughout the diagnosis process and beyond (Oono et al., 2013). Structuring family therapy processes with diagnostic guidelines may assist in delivering consistent outcomes in family therapy (Pellicano et al., 2018).

Close family involvement can be especially significant when conducting family-based therapies, and interventions such as early intensive behavioural intervention methods (EIBI) may depend critically on intimate family involvement, especially when conducted in the family home (Grindle et al., 2008; Maurice, 1996). There has been limited research on families' experiences of EIBI in the family environment. A recent Cochrane review (Reichow et al., 2018) that systematically reviewed the available evidence prior to and including 2017, for the effectiveness of EIBI in increasing functional behaviours and skills, decreasing autism severity, and improving intelligence and communication skills for young children with autism, showed that one randomised control trial (RCT) conducted in the USA and four nonrandomised control trials conducted in both the USA and UK, totalling 219 children, have produced findings with a low quality of evidence for the effectiveness of EIBI and its use in the family setting. However, positive practical benefits have been reported for both parents and children, such as a reduction in tantrums and increased capacity in toileting and feeding, reducing parenting duties (Grindle et al., 2008).

Increasingly, RCTs are being conducted for early intervention models (Lai et al., 2018). Current trials show intervention models that have progressed from the structured traditional EIBI and Applied Behaviour Analysis, ABA (Weitlauf et al., 2014) towards more *naturalistic* approaches (Prizant & Wetherby, 1998), namely Naturalistic Developmental Behavioural Intervention (NDBI) (Schreibman et al., 2015), those informed by developmental and cognitive science of autism research. A recent systematic review by French and Kennedy (2017) of 48 RCTs (40 published since 2010) found most using an NDBI approach i.e., JASPER (Joint Attention Symbolic Play Engagement and Regulation) are the most tested model by RCTs. However, only 12·5% of RCTs met criteria of low risk of bias with most frequent methodological concerns being a lack of blinding of outcome assessment and no reporting of method of allocation concealment (French & Kennedy, 2017).

Given the findings of the studies discussed here were drawn from either small samples or weak methodological designs, future research including robust RCTs are needed where substantive conclusions can be drawn on, rather than small qualitative studies or RCT's with methodological concerns (Lai et al., 2018).

Inclusion and Engagement of Young People with Disabilities in Research

Globally, children and young people are becoming increasingly acknowledged as active participants in research (James & James, 2012; Mahon et al., 1996; Moore, 2012; Moore et al., 2016; O'Kane, 2008), and there are examples of studies which have successfully gained meaningful insight into their lives (e.g., Bailey et al., 2015; Inglis & Cook, 2011;

Minkes et al., 1995; Nind, 2008; Tesfaye et al., 2019). The fundamental reason and purpose for involving children in research is to provide them with a safe avenue to express their perspectives and understandings, and to contribute to the knowledge of children's lived experiences, reflections, and concerns (Jenkin et al., 2015). Additionally, such involvement can afford children a voice, which is otherwise often silenced or quietened by the unequal power disparities between children and adults. It is widely accepted that when including children and young people in research it is important that researchers are aware of and acknowledge power and status imbalances (Christensen & James, 2008; Mahon et al., 1996; Moore, 2012; Moore et al., 2016; O'Kane, 2008).

The significance of acknowledging and incorporating children and young people's voices in research first gained traction in 1989, when the United Nations Convention on the Rights of the Child was adopted (James et al., 2015; Lewis & Kim, 2009). Parallel to this, an "…original sociology of childhood emerged in which children are viewed as social actors who dynamically shape and respond to their social world" (James et al., 1998, p. 207). Whilst the voices of children and young people in research are now frequently recognised, those labelled with an intellectual or developmental disability have only recently been considered as valued participants in research (Jack & Pelphrey, 2017; Kasari et al., 2013; Lai et al., 2006; Russell et al., 2019). Such participation is particularly important in areas related to their personal lives, including family, peers, parenting, childhood, and intimate relationships (Martino & Schormans, 2018).

People without disability, such as parents, support workers, and professionals, have often spoken on behalf of or for people labelled with intellectual or developmental disability.

As a result, studies reporting the direct experiences of people with disability are lacking when compared to those without (Boxall & Ralph, 2009; Milner & Kelly, 2009; McDonald et al., 2015), and knowledge construction has, until recently, been exclusively built from the perspectives of those without disability (McDonald et al., 2016).

Emphasis has shifted, however, to include collaborative and participatory research methodologies, meaning that people, including children and adolescents, with a diverse range of perspectives and experiences can feel valued as contributors to knowledge production (Andersen & Dolva, 2015; Cavet & Sloper, 2004; McDonald et al., 2016; Stafford 2017). McDonald et al. (2016) argue that including people labelled with intellectual or developmental disability in research "…can spur new thinking about vulnerability and inclusion and resonate with increasing attention to human rights" (p. 205). People labelled with intellectual or developmental disability report positive experiences of their participation in research, appreciating the chance to share their experiences and have their voices heard, particularly with the potential that what they share contributes to improving the worlds of others labelled as intellectually or developmentally disabled (Bigby & Frawley, 2010; Fudge Schormans, 2015; Gustafson & Brunger, 2014; Martino & Schormans, 2018; McDonald et al., 2016; Nind, 2008).

Since the importance of including people with disability in research has been recognised, methodological challenges and issues when including children and young people with intellectual disabilities have been identified. Communication challenges and social interaction differences and difficulties associated with such disabilities partly explain the exclusion of this cohort from qualitative research (Beresford et al., 2004; Courchesne et al., 2021; Cridland et al., 2014; Lewis & Kim, 2009; Tesfaye et al., 2019). Other issues, such as gatekeeper consent, presumed vulnerability, concerns about participants being targets for manipulation, and clinical presumptions around functioning and ability to participate may have contributed to children and young people with autism being neglected as participants in research (Harrington et al., 2013; Lewis & Kim, 2009; Russell et al., 2019).

To combat some of the above issues, methodological suggestions for including children and young people with autism in research have been proposed (e.g., Courchesne et al., 2021; Cridland et al., 2013; Tesfaye et al., 2019). Some of the suggestions by these authors included paying attention to how instructions are written, constructing questions in ways that are appropriate for the processing pathways of children with autism, including concrete and single-faceted sentences in written instructions, and focusing interviews on alternative mediums such as drawing, photographs, or pictures rather than verbal interaction, which, if not appropriately considered, can lead to linguistic confusion.

Whilst the diverse methodological challenges faced by researchers seeking to involve children with autism in studies have not been routinely or widely documented (Courchesne et al., 2021; Cridland et al., 2014; Preece, 2002; Tesfaye et al., 2019), there have been developments in the field over the last decade, although these have had an emphasis on interviewing children with the condition through a clinical lens (e.g., Bölte, 2019; Bölte et al., 2018; Dindar et al., 2017; Gyori et al., 2015; Nair et al., 2014). Therefore, knowledge about approaches that may help to increase the participation of young people with autism in research is limited (Bartlett & Carrington, 2021; Courchesne et al., 2021; Tesfaye et al., 2019).

Given the methodological challenges and issues outlined above, there is a shortage of qualitative research, primarily in health psychology, which purposefully and exclusively draws out the perspectives and experiences of children and young people with autism (Bartlett & Carrington, 2021; Courchesne et al., 2021; Depape & Lindsay, 2016; Harrington et al., 2013; Krieger et al., 2018; Preece & Jordan, 2010; Tesfaye et al., 2019). DePape and Lindsay (2016), in their qualitative meta-synthesis, identified for inclusion in their review a total of 33 studies across a period of three decades that investigated lived experiences from the perspective of people with autism. DePape and Lindsay (2016) concluded that most lived experience research focused on adults (e.g., Hurlbutt & Chalmers, 2002; Müller et al., 2008; Punshon, et al., 2009), and only a very small number of studies included children or young people (e.g., Huws & Jones, 2008; Marks et al., 2000; Penney, 2013; Preece & Jordan, 2010; Saggers et al., 2011; Zukauskas et al., 2009). These research studies included children and young people with autism who were verbal and without an intellectual disability as participants in semi-structured interviews. These studies contributed knowledge from the first-person perspective on issues related to diagnosis and disclosure, perception of self and struggling with their condition, mental health issues, social life and interacting with others, feeling different to others, sensory issues, experiences at school, and isolation and factors related to employment.

Since the publication of DePape and Lindsay's (2016) qualitative meta-synthesis, there have been limited studies that have captured the voices of children and young people on the autism spectrum. Currently, there is limited qualitative participatory autism research, where autism researchers and members of the autistic and autism communities collaborate in the research process (Bartlett & Carrington, 2021). Knowledge of first-person experiences and perceptions of children and young people with autism is largely limited to the challenges they experience in school, including establishing friendships with peers and their experiences of being bullied and excluded and poor wellbeing at school (Calzada et al., 2011; Cappadocia et al., 2012; Chen & Schwartz, 2012; Connor, 2000; Cunningham, 2019; Fisher & Tayor, 2015; Goodall & Mackenzie, 2019; Hill et al., 2016; Hill, 2014; Marks et al., 2000; Preece & Jordon, 2010; Saggers et al., 2011; Warren et al., 2020).

A small number of qualitative studies have investigated how young people with autism form their identity, how they understand belonging and wellbeing, and the challenges young people face when transitioning out of high school and issues related to finding employment (Browning, et al., 2009; Cridland et al., 2015; DePape & Lindsay, 2016; Foley et al., 2012; Gaona et al., 2018; Humphrey & Lewis, 2008). One study (Kirby et al., 2014) used phenomenological interviews with children with autism to gain insight into their sensory experiences. Another study (O'Hagan et al., 2022) included autistic mentors as part of a larger study sample to understand their perspectives of an inclusive peer mentoring program for autistic adolescents. Finally, authors of a few studies (Courchesne et al., 2021; Richards & Crane, 2020; Winstone at al., 2014) sought to test and develop strategies that may prove potentially effective in capturing the voices of autistic teenagers with a broad range of verbal and intellectual abilities and are a step towards creating inclusive methodologies within disability and autism research.

The findings from the literature suggest that there is valuable, but limited, research that incorporates the perspectives and experiences of young people with autism.

Family Relationships

The search generated several studies that reported on impacts on relationships across multiple member relationships in the family (Bayat, 2007; Chan & Goh, 2013; Desai et al., 2012; Halloran et al., 2013; Kuhlthau et al., 2014; Mazzoni et al., 2018; Nealy et al., 2012; Phelps et al., 2009a; Pottas & Pedro, 2016). Most of the studies reviewed were conducted in the US and others were conducted in Singapore, Ireland, South Africa, and Italy. Across the studies, informants were mostly parents, being mothers and some fathers. Methods utilised across studies included semi-structured interviews, focus groups, online surveys, and instruments for collecting and measuring quantitative data. A summary of the findings from across these studies of the impacts of autism on family relationships and some critical evaluation of these studies is provided, below.

In some studies (Desai et al., 2012; Halloran et al., 2013; Mazzoni et al., 2018; Nealy et al., 2012; Pottas & Pedro, 2016), autism resulted in disruptions to family structure and coordination. Due to increased caring requirements for the child with autism, parents in these studies needed to direct additional attention towards this family member, and this impacted the relationships parents had with other family members, mostly children without autism.

Across a few studies (Desai et al., 2012; Halloran et al., 2013; Nealy et al., 2012; Pottas & Pedro, 2016), a desire for greater attention from parents left siblings with feelings of resentment towards their brother or sister with autism. In a couple of studies (Desai et al., 2012; Pottas & Pedro, 2016), attending to the needs and desires of the child with autism was reported as a time-intensive process that impacts the quality of relationships with other family members, resulting in increased difficulties and tense relationships between parents and other children.

Themes in the literature of positive impacts autism had on family relationships family were identified across a few studies (Bayat, 2007; Chan & Goh, 2013; Kuhlthau et al., 2014; Phelps et al., 2009a). Across these studies (Bayat, 2007; Chan & Goh, 2013; Kuhlthau et al., 2014; Phelps et al., 2009a), positive impacts included a stronger, greater, and closer relationship connection amongst members because of shared experiences, working together, and shared hardship. Studies from the broader family relationships literature suggest, that adults with a cognitive or developmental disability living at home with their parents and siblings establish close family relationships (Burbidge & Minnes, 2014; Seltzer et al., 2001; Smith et al., 2013).

All studies reviewed have limitations in that most used small and specific samples of parents, mostly mothers, some fathers, and siblings. No studies included families where the young person with autism had an intellectual disability. Further, the demographic profile of samples across studies were mostly white participants from middle to high socioeconomic status. Some studies reported on limitations to methodological rigor, such as lack of triangulation and member checking in qualitative studies (Bayat, 2007; Nealy et al., 2012), recruitment carried out across different points in the child’s clinical assessments of autism diagnosis and treatments in a quantitative study (Mazzoni et al., 2018) and in a mixed method study (Kuhlthau et al., 2014) biased results from self-selection, that is common in survey research. In addition, none of the studies reported on establishing or consulting with a family advisory group or other stakeholders about the nature, relevance or impact of the research.

Nevertheless, these studies provide some important insights into the experiences of families with a young person with autism and the factors impacting family relationships.

Partner Relationships

Findings in the literature across several studies conducted over the years (Desai, et al., 2012; Hirsch & Paquin, 2019; Hobart, 2008; Gau et al., 2012; Kuhlthau et al., 2014; Marciano et al., 2015; Nagib & Williams, 2018; Nicholas, et al., 2016; Papp et al., 2019; Pottas & Pedro, 2016; Sen & Yurtsever, 2006; Sim et al., 2017; 2019a; Zechella & Raval, 2015) on the impacts of autism on spousal or marital relationship suggest that autism has multiple impacts on this dyad. Most of the studies reviewed were conducted in the USA and others were conducted in Canada, India, Taiwan, China, Turkey, and one study was conducted in Australia. Across the studies, informants were mostly mothers of children with autism and some fathers. Methods utilised across studies included semi-structured interviews, self-reporting surveys or questionaries, online surveys and validated tools/instruments and measures for collecting quantitative data. A summary of the findings from across these studies of the impacts of autism on the partner relationship and some critical evaluation of these studies is provided, below.

Several of these studies identify negative impacts, including strain, difficulties, conflicts, less satisfaction, and increased challenges within the spousal relationship (Desai et al., 2012; Gau et al., 2012; Hobart, 2008; Kuhlthau et al., 2014; Pottas & Pedro, 2016; Sim et al., 2016).

Across a few studies, greater conflict in daily life, diminished “alone time,” and poorer quality of romance and intimacy were found within the dyad (Sen & Yurtsever, 2006; Hirsch

& Paquin, 2019; Papp et al., 2019). In a couple of studies, a decrease in happiness in some marriages was observed, which led in some cases to divorce or risk of divorce for married couples (Desai et al., 2012; Nagib & Williams, 2018).

Several studies (Hobart, 2008; Marciano et al., 2015; Nicholas et al., 2016; Sim et al., 2017; 2019b) reported on positive impacts autism has on the spousal or marital relationship. These included increased camaraderie between couples (Nicholas et al., 2016), couples coming together to work towards the common goal of helping their child with autism (Hobart, 2008), and couples feeling more bonded over the care of their child (Marciano et al., 2015). One study in a related field investigating caring attitudes of parents of children with intellectual and developmental disabilities, including autism, reported that mothers tended to focus on the positive impact having a child with intellectual and developmental disabilities had on their marriage (Zechella & Raval, 2015).

Limitations of most of the studies reviewed include small and specific or convenience samples or purposively recruited samples of parents, mostly mothers and some fathers, creating potential self-selection bias to well-adjusted couples who had the means to participate in the research (Sim et al., 2017) or those recruited through an autism clinic-based sample (Gau et al., 2012) or professional care centres (Desai et al., 2012). Further, most studies did not include partners of the participants and other family members e.g., stepparent were included in just one study (Sim et al., 2017). Just one study (Sim et al., 2017) included families where the young person with autism had an intellectual disability. The demographic profile of samples across most studies were mostly white heterosexual female participants from middle to high socioeconomic status limiting the generalisability of the findings across studies.

Some studies reported on limitations to methodology, such as lack of a comparison group (Marciano et al., 2015), no causal inference (Sim et al., 2017) and the results of all studies are based on one point in time. In addition, like the studies reviewed reporting on impacts to family relationships, none of the studies here reported on establishing or consulting with a family advisory group or other stakeholders about the nature, relevance or impact of the research. Nevertheless, these studies provide some important insights into the experiences of mothers and fathers with a young person with autism and the factors impacting partner relationships.

Parent-child Relationships

The search generated several studies that reported on impacts to the parent-child relationship (Chan & Goh, 2013; Connell et al., 2014; Corman, 2009; Cridland et al., 2016; Griffith et al., 2012b; Hickey et al., 2020; Navot et al., 2017; Potter, 2016; Riany et al., 2017; Shu et al., 2001; Smith et al., 2008; Zechella & Raval, 2015). Most of the studies reviewed were conducted in the US and UK and others were conducted in Canada, Singapore, Ireland, Indonesia, Taiwan, and one study was conducted in Australia. Across the studies, informants were mostly parents, being mothers and fathers, and a few studies included siblings, mostly older sisters of brothers with autism, and just one study included males with autism (Cridland et al., 2016). Methods utilised across studies included semi-structured interviews, validated measures, and self-reported surveys for collecting quantitative data. A summary of the findings from across these studies of the impacts of autism on the parent-child relationship and some critical evaluation of these studies is provided, below.

Negative impacts on the parent-child relationship were identified across several studies (Chan & Goh, 2013; Cridland et al., 2016; Hickey et al., 2020; Navot et al., 2017; Riany et al., 2017; Shu et al., 2001; Zechella & Raval, 2015), including a comparison of mothers' and fathers' perceptions of the quality of the parent-child relationship (Riany et al., 2017). In one study, mothers were more critical about the nature of the relationship than fathers (Hickey et al., 2020). In another study (Griffith et al., 2012b), parents reported that the characteristics associated with autism contributed to their child's interpersonal difficulties and seemed to define the relationship that parents had with their sons with autism.

In one study (Navot et al., 2017) most mothers reported that their expectations for closeness between themselves and their daughter with autism were not fulfilled. The study reported that "…mothers had to form a relationship with their daughters that was very different from their early expectations and were met with a sense of helplessness and incompetence even when they did their best to support and understand their daughters" (p. 6). Authors of another study (Shu et al., 2001) reported that for mothers in the study, the ongoing and continued nurturing of a daughter with autism forced them to rethink their relationship with their child.

In a few studies (Chan & Goh, 2013; Connell et al., 2014; Zechella & Raval, 2015), parents reported the impact autism had on the parent-child relationship with the child without an autism diagnosis. This included parent guilt due to a lack of time spent with their child and low levels of energy to engage meaningfully with them (Chan & Goh, 2013; Zechella & Raval, 2015) but also open and supportive relationships (Connell et al., 2014).

Some studies (Chan & Goh, 2013; Cormon, 2009; Griffith et al., 2012b; Potter, 2016; Smith et al., 2008) reported on positive impacts autism had on the parent-child relationship. The respondents in two of these studies (Griffith et al., 2012b; Potter, 2016) were both mothers and fathers, who reported on complex but close and warm relationships with their child with autism. Fathers in one of these studies (Potter, 2016) reported their relationships as “loving” with their sons with autism. Mothers and typically developing daughters in one of the studies (Griffith et al., 2012b) reported that having a young member in the family with autism led them to make conscious efforts to maintain their relationship with each other, as they recognised the importance of their mother-daughter relationship.

In one study (Chan & Goh, 2013), some mothers had children with autism who were verbal, and some mothers had children with autism who were non-verbal. In this study, the ability of children to communicate verbally was associated with the levels of perceived intimacy mothers had with their child. In another study (Smith et al., 2008) 149 mothers were drawn from a larger, longitudinal study of 406 families of adolescents and adults with autism. Mothers in the current study were co-residing with their adolescent or adult child with autism. The authors highlight that positive aspects of the family environment are linked with autism symptoms and problem behaviours. Findings reported indicate that a high level of relationship quality, warmth, and praise were associated with reductions in internalising and externalising problems as well as reductions in impairments in social reciprocity and repetitive behaviours.

Limitations observed in the studies reporting on parent-child relationships were like those in the studies reporting on family relationships and partner relationships. This is not surprising given the overlap of a few studies (Chan & Goh, 2013; Cridland et al., 2016; Zechella & Ravall, 2015) and that the samples and participant recruitment strategies and design of the studies were similar, including quantitative, qualitative, and mixed methods. The demographic profile of samples across most studies were mostly white heterosexual female and male participants from middle to high socioeconomic status limiting the generalisability of the findings across studies. No studies reported on including families with a child with autism and intellectual disability. Like the studies reviewed reporting on impacts to family relationships and partner relationships, none of the studies here reported on establishing or consulting with a family advisory group or other stakeholders about the nature, relevance, or impact of the research. Nevertheless, these studies provide some important insights into the experiences of parenting a child with autism from the perspectives of mothers and fathers and including the perspectives from some sisters of brothers with autism of the impacts had to the parent-child relationship.

Sibling Relationships

The search generated several studies that report on sibling relationship impacts (Atkin & Tozer, 2014; Chu et al., 2021; Corsano et al., 2017; Cridland et al., 2016; Day et al., 2019; Diener et al., 2015; Gorjy et al., 2017; Hastings & Petalas, 2013; Jones et al., 2019; Kaminsky & Dewey, 2002; Laghi et al., 2018; ; Nuttall et al., 2018; Orsmond & Fulford, 2018; Petalas et al., 2015; Pollard, et al., 2013; Roeyers & Mycke, 1995; Shivers & McGregor, 2019; Thomas et al., 2019; Tomeny et al., 2017; Tsai et al., 2018; Tudor et al., 2018; Walton et al., 2015).

Most of the studies reviewed were conducted in the US and the UK and others were conducted in Canada, Italy, Belgium, Taiwan, and two studies were conducted in Australia.

Across the studies, informants were mostly siblings of brothers with autism, and some parents, mostly mothers. Two studies (Petalas et al., 2015) a qualitative study conducted in the US and a qualitative study (Cridland et al., 2016) conducted in Australia included adolescents with autism as participants. Methods utilised across studies were like those observed across the studies reviewed for family relationship impacts, partner relationship impacts, and parent-child relationship impacts. A summary of the findings from across these studies of the impacts of autism on the sibling relationship and some critical evaluation of these studies is provided, below.

In a qualitative study by Petalas et al., (2015, p.38), that included eleven male adolescents with autism and one female adolescent with autism, the authors found that "…despite the social context reinforcing views that autism impacts the sibling relationship in an atypical way, the overwhelming sense from adolescent participants was of typical sibling relationships." This finding challenges the assumption of atypical relationships in families of children with autism and highlights the importance of including the child or young person with autism in future qualitative studies. When interpreting the findings, it is important to note that all families included in the study were at the time of their interviews engaged in formal support services and that the levels of stress experienced in the home most likely lesser than for example, families not engaged in formal support services.

An obvious strength in this study is the inclusion of adolescents with autism in individual interviews. The authors offered their reflections on the process of interviewing the adolescents with autism and considered how their prompting for information about the young person’s autism spectrum disorder might have influenced their responses. By bringing autism to the attention or focus of the adolescents’ minds, this might have produced information otherwise not volunteered. The authors contrasted this with the more natural or unprompted comments by adolescents with autism during the interviews. The authors raise an important consideration, and which highlights the need for researchers to carefully consider methods for collecting data from children and young people with autism and for determining the meanings that children or young people with autism attach to their experiences.

In the Australian qualitative study (Cridland et al., 2016) three families participated in the research and included three adolescent sisters (ages 16-17), three adolescent brothers with autism (ages 13-15), three mothers and two fathers. A major strength of this study is the inclusion of multiple family members e.g., mothers, fathers, and siblings and presented divergent and conflicting perspectives among family members regarding the roles of adolescent siblings in the family. The study utilised individual semi-structured interviews with participants and whilst discussion was focused on adolescent sisters’ experiences of having a younger brother with autism, the study also reported on several impacts to the family. A couple of sisters of brothers with autism reported cherishing quality time together as a family but also the desire to distance themselves from the family, as time together as a family as a unit was spent mostly focused on the interests of their brothers with autism, which was impacted by their brothers’ moods.

In the studies reviewed, negative outcomes found for the sibling relationship suggest, overall, negative interchanges between siblings and fewer positive sibling relationship attitudes than those where neither sibling has an autism diagnosis, including less involvement, and more avoidance (Laghi et al., 2018; Orsmond & Fulford, 2018; Pollard et al., 2013; Tomeny et al., 2017; Walton et al., 2015).

One study (Tudor et al., 2018) reported findings that suggest the higher the level of autism in the sibling, the greater the positive impact on the sibling relationship. Three studies investigated behaviour and suggested that sibling relationships are at risk of poor outcomes when the brother or sister with autism has significant behavioural problems (Hastings & Petalas, 2013; Jones et al., 2019;).

Siblings without autism across a few studies (Atkin & Tozer, 2014; Chu et al., 2021; Corsano et al., 2017; Day et al., 2019; Gorjy et al., 2017; Tsai et al., 2018) reported on mixed experiences with their sibling with autism. Siblings shared the difficulty they experienced in juggling the changing and developing nature of their relationship with a brother with autism, describing relationships initially mixed with difficulty, sadness, and frustration at communication difficulties and the limited relational exchange, then changing to encompassing love and pride and protectiveness at great personal cost. In one study (Tsai et al., 2018) conducted in both Chinese and Western settings, the findings suggest that cultural context may have a significant impact on the responses of the family members and that culturally aware or sensitive supports might help navigate any differences in attitudes and traditions.

The studies discussed above suggest that, over time, siblings learnt to bond and communicate with their sibling with autism, to appreciate them, and to find positive aspects in the relationship. It is not clear, however, from the reporting in these studies if siblings were supported by either family members or professional services and interventions to bond and communicate with their sibling with autism. Just two studies (Atkin & Tozer, 2014; Chu et al., 2021) reported limitations in that participants recruited for the study were either actively involved in the care of the sibling with autism or in family interventions at the time of their involvement in the research.

A couple of studies (Kaminsky & Dewey, 2002; Shivers & McGregor, 2019) reporting on sibling relationships that included multiple family dyads and multiple family structures—such as those with a child with autism, those with a child with cognitive or developmental disability, and those with children with no disability—highlighted the differences between family members' perceptions of relationships (Shivers & McGregor, 2019). In a study involving mothers and sisters from families with a young person with autism, sisters easily recognised the positive features of their relationships with their brothers, while mothers emphasised the challenging and difficult aspects of the sibling relationship (Kaminsky & Dewey, 2002).

Limitations observed in the studies reporting on sibling relationships were like those in the studies reporting on family relationships and partner relationships and parent-child relationships. This is not surprising given the samples and participant recruitment strategies and design of the studies were similar, including quantitative, qualitative, and mixed methods. The demographic profile of samples across most studies were mostly white heterosexual female and male participants from middle to high socioeconomic status limiting the generalisability of the findings across studies. No studies reported on including families with a child with autism and intellectual disability. Like the studies reviewed reporting on impacts to family relationships and partner relationships, and parent-child relationships none of the studies here reported on establishing or consulting with a family advisory group or other stakeholders about the nature, relevance, or impact of the research. Nevertheless, these studies provide some important insights into the experiences of siblings who have a brother or sister with autism from the perspectives of the siblings themselves and the perspectives of some adolescents with autism.

How Findings from the Literature Inform the Research Question and Aims

The search of the literature found that many studies that report on the impact of autism on relationships in families are informed by parents (mothers and fathers), with mothers making up most participants across all studies (Chan & Goh, 2013; Griffith et al., 2012b; Navot et al., 2017; Potter, 2016; Riany et al., 2017; Shu et al., 2001; Zechella & Raval, 2015). Within the literature search targeting family and relationships and autism, siblings were identified as respondents in nearly half of the studies reviewed. Fathers appeared as respondents in five of the studies, and two studies (Cridland et al., 2016; Petalas et al., 2015) included the perspectives of adolescents with autism. Across the studies reviewed, the age of the child or adolescent with autism in families was between 18 months to 18 years.

The findings of the review suggest that perceptions of young people with autism as a group in the context of the study topic are mostly limited from research literature. This finding from the review aligns with the recognised dearth of research targeting autism in adolescence (Courchesne et al., 2021; Depape & Lindsay, 2016; Krieger et al., 2018; Tesfaye et al., 2019), including the shortage of qualitative studies that explore the perspectives of young people with autism in the context of the study topic or the perspectives of multiple members in the family (Factor et al., 2019).

Including the perspectives of multiple member groups in studies with a qualitative design could help to increase understanding of differences in family members' perceptions of the impact autism has on relationships between members as well as provide insight as to how best support families who are experiencing difficulties within their family relationships.

Most studies investigating the impacts of autism on family relationships report the findings of relationship impact outcomes, such as stress and tension on relationships (Baker-Ericzén et al., 2005; Factor et al., 2019). Further investigation is needed to reach a deeper understanding of *how* autism impacts the relationships between family members and the family as a unit. One approach to this is to explore the perspectives of multiple member groups in the family. This information will be of interest to family practitioners, as it could help to inform the design of an intervention for families with a member who is a young person with autism with a goal of strengthening and enhancing relationships between family members, and the family as a unit.

The search of the literature found a few studies that reported on a theoretical orientation that guided or informed the study in some way (Chan & Goh, 2013; Nicholas et al., 2016; Tudor et al., 2018). Of these studies, one qualitative study (Nicholas et al., 2016) used an ethnographic approach, and reported on the impacts on partner relationships in families with a member who is a young person with autism up to 25 years of age. A second qualitative study (Chan & Goh, 2013) used social relations theory to help explain the impacts autism had on the relationship between the parent and the typically developing child and on the sibling relationship. The third, a quantitative study (Tudor et al., 2018), used the Feinberg sibling relationship model and reported on the impact of autism on the sibling relationship. Given that just these few theoretically based studies emerged from the comprehensive search of the literature suggests a significant gap in the theoretical and methodological approaches that guide and inform studies of family relationships and autism.

The search did not reveal any consideration of methodological issues in studies that included children or young people, including children or young people with autism, or with other disabilities, such as Down syndrome or intellectual disability. This finding might be explained by the current literature's lack of focus on the inclusion of young people in research or the scarcity of research that has included children or young people with autism. It could also suggest that there may be limited knowledge available to inform methods that enable children and young people, including those with disability, to participate in research. The search did, however, reveal one qualitative study (Petalas et al., 2015) where the authors presented critical reflections on the methods and processes used to interview adolescents with autism and to interpret the meaning of their responses.

How the Study Responds to Findings in the Literature

The qualitative study reported in this thesis explores autism and family relationships from the perspectives of young people with autism and their family members, including mothers, fathers, and siblings, and seeks to generate new insights into how autism impacts the relationships between family members, and the family as a unit. This exploratory study is an initial step to address some of the gaps identified in the literature and the study is not without its limitations (see Chapter 7). The study is informed by theoretical orientations to guide the engagement and participation of children and young people with autism in research, as discussed in the next chapter. The formation of a family advisory group (see Chapter 4) provided the expertise needed to guide the approach to the research, and to advise how best to enable young people with autism to participate as fully and as meaningfully as possible in the study.

Chapter Summary

This chapter presented the background literature that guided and informed the conceptualisation of the research and the development of and approach to the study. The findings generated from the literature review assisted with the design of this study and with refining the research question and aims. In Chapter 3, the thesis builds on this basis to explain and justify the theoretical principles and values that have informed the approach to the research.

Chapter 3: Theoretical Framework

Introduction

Chapter 2 comprehensively examined the literature that informs and frames the research question and approaches for this study. A shortage of qualitative insights from young people with autism and their families concerning family relationships was identified. Building on that basis, this chapter outlines the theoretical framework designed to address the research question and research aims of this study. The purpose of the theoretical framework is to provide direction and guidance to the study. The content of the framework is drawn from academic literature and provides viewpoints, or *lenses* through which study participants and data are viewed (Creswell & Poth, 2018; Guba, 1990). Creswell and Poth (2018, p. 18) note that a theoretical framework includes the "…researcher's view of reality (ontology); how the researcher understands reality (epistemology); the value-stance taken by the researcher (axiology)," as well as the theories selected to guide and inform the study (theoretical orientations).

This chapter discusses why social constructivism is a suitable epistemological stance for this investigation. It explains how a social constructivist view relates to the three theoretical orientations of childhood studies, disability studies, and systems theory that have informed the study. The three areas of work discussed here have a wider set of ideas, concepts and understandings than discussed here, but those aspects are relevant to the research, particularly for the methodological approach undertaken. Together, these support the use of a phenomenological approach to this participatory qualitative study and highlight the value and purpose of conducting the research using this approach.

Ontology: Multiple Realities

An ontological issue considers the question, “What is the nature of reality and its characteristics?” (Creswell, 2012, p. 20). Two contrasting ontological traditions divide Western thought; these are a Heraclitan ontology of *becoming* (changing and emergent world) and a Parmenidean ontology of *being* (permanent and unchanging reality) (Creswell, 2014). The Parmenidean ontology of being dominates Western philosophy, and reality is perceived as distinctly created entities with perceptible properties (Gray, 2009). Three positions have emerged from the ontology of being: objectivism, constructivism, and subjectivism. Constructivism suggests that “…others hold a different worldview” (Creswell, 2014, p. 8); in this position, “…truth and meaning do not exist in some external world but are created with the subject’s interactions with the world” (Gray, 2009, p. 18). A constructivist worldview, a perspective naturally associated with qualitative research, is evident in this study through its focus on participants’ descriptions of their experiences of autism and family relationships (Moustakas, 1994).

Epistemology: Constructivism

This study needed an epistemological stance that acknowledged the diverse experiences that are shaped by varied contexts and dynamics in participants’ lives. The study is appropriately aligned with social constructivism, which asserts the position that “…individuals seek understanding of the world in which they live” and “develop subjective meanings of their experiences” (Creswell, 2014, p. 8). This worldview also supports the inclusion of the person-in-environment social perspective (Bishop-Fitzpatrick & Rubenstein, 2019; Creswell, 2009; Healy, 2005; Oktay, 2012).

Adhering to the social constructivist view that personal construction of meaning is socially situated, experienced, and influenced by an individual's interactions with others and their surrounding context (Arends, 1998; McKingley, 2015). This study has not sought to produce a uniform or generalised representation of families, but rather has aimed to recognise and bring out the diversity within families' shared experiences of relationships and autism. Being open to and aware of variability and complexity is essential for a social constructivist (Oktay, 2012), and is important practice for researchers when engaging with vulnerable populations (Charmaz, 2006).

In this study, the perspectives, and experiences of young people with autism and siblings, fathers, and mothers are understood as a construction, influenced by both the microenvironment (e.g., the interactions and relationships between family members) and the wider social and cultural setting (e.g., ideals such as identity and expectations about the purpose and role of family). Social constructivism is beneficial for probing facets of Australian culture that affect and influence young people with autism and their families, and their capacity to form, establish, manage, and strengthen their relationships. Interview data are interpreted within this context, and the impact of stresses and strains on families from schools and service providers, and the impact of wider social ideals including individualism (Crotty, 1998) and community attitudes towards people with a disability (Thompson et al., 2012), are considered.

Axiology: Values and Bias

Researchers working from a social constructivist approach typically rely on participant perspectives and do not generalise to a group or population. Reflexivity as a component of practice is important, so that researchers acknowledge their experiences of, connection with, and bias towards the topic. A researcher's presence in a study may be woven into the text throughout. Researchers should recognise and state that interpretation of the stories voiced in a study are influenced by the author's profile, background, and views, and by the study participants (Denzin, 1989). Researchers may provide demographic information or information about their characteristics, which could include their gender, age, ethnicity, place of birth, or where they live. They could also provide some details about personal experiences that are related to the study, or express their political and professional views (Berger, 2015).

As the researcher, I was committed in this study to recognising children, including those with disability, as active research participants. I have advocated for this throughout the last three years of my research training and early career experience as a Research Officer at the Institute of Child Protection Studies. Recognising autism as part of human variation, more recently referred to as neurodiversity (Kapp et al., 2013), is something I have incorporated into my profession as a disability youth worker for many years and in my more recent experience as an early career researcher. This view is supported by a more recent trend towards the participation of young people with autism in qualitative research, after decades of studies on, and not with or including, people with autism.

Childhood studies, disability studies, and social research emphasise the use of reflexive methods and processes which highlight and focus on the role and position of the researcher (Bishop-Fitzpatrick & Rubenstein, 2019; Oktay, 2012; James & Prout, 2015; Wasserman, 2018). This study has adopted a phenomenological approach, aligned with its qualitative methodology. Phenomenology seeks to understand the world from the participant's view, and the researcher must “bracket out” their own preconceptions to manage the prejudices and bias of the researcher and ensure they do not impact the data and limit the “new” or “fuller” meaning (Gray, 2009, p. 22).

To limit bias, I adopted a reflexive stance to critically reflect on my influence on the research process (Attia & Edge, 2017; Gray, 2009). This includes describing my own background, experiences, and perspective and ensuring my role as the researcher is captured as honestly as possible (Rice & Ezzy, 2007). When the role and position of the researcher are recognised and acknowledged, reflexivity is strengthened (Whittemore et al., 2001). Throughout the research process I used six main methods for reflexive practice: (1) journaling, (2) critiquing interviews, (3) recording and written memos, (4) debriefing and supervision, (5) reflexive questioning during data analysis, and (6) epoche. An explanation of how these six main methods informed my research practice is provided in Chapter 4, Methodology and Methods.

Epoche is a phenomenological concept and process that encourages the researcher to self-examine and self-reflect on their relationship or connection with the study and topic (Moustakas, 1994). In this thesis, reflecting on and recounting my experiences of autism and family relationships is described throughout the epoche, in Chapter 4. In this study, the practice of epoche helped me recognise any assumptions I had about my experiences and understandings of autism and family relationships, and to explore these further. This continual self-reflection process helped me remain aware of any significant bearing or weight that my personal experiences or perceptions might have had on the research (Moustakas, 1994).

Theoretical Orientations

A review of family relationship theories was conducted to ensure that the theoretical orientations adopted for the study were aligned with the phenomenological approach and complemented the participatory methods used to conduct the research with young people with autism and their family members. The process of review and selection of a theoretical orientation is considered an integral part of research design and practice (Creswell & Poth, 2018). The purpose of selecting a theory in the design of a research study is to provide a clearly articulated signpost or lens for how the researcher will process new knowledge. This is often referred to as the *theoretical frame* (Collins & Stockton, 2018). In addition, the researcher must consider the fit and alignment of the theoretical orientation with the theoretical framework adopted.

This section of the chapter describes the three theoretical orientations—childhood studies, disability studies and systems theory—selected for this study. Each orientation is discussed in detail, including the justification for its inclusion in this study, how it contributes to the theoretical framework of this study, and how it aligns with the epistemological stance of constructivism. The application of each theoretical orientation to the study is detailed, including how each aligns with the phenomenological approach.

The application of each theoretical orientation is discussed in terms of where and how the orientation informed or guided this study and what outcomes this produced, such as throughout data analysis or in the design of interview schedules and data collection methods. The childhood studies orientation is presented first, followed by disability studies, and finally with systems theory.

Childhood Studies

The theoretical orientation of childhood studies includes multiple areas of study that appreciate and recognise childhood as a phenomenon experienced by children, as they participate in the world as social actors (Qvortrup et al. 2011). Aligned with a social constructivist assumption that "…others hold a different worldview" in which "truth and meaning do not exist in some external world but are created with the subject's interactions with the world" (Creswell, 2014, p. 8; Gray, 2009, p. 18), the childhood studies perspective supports the constructivist interpretivist worldview of this study that children have different worldviews to adults (Garlen, 2019).

The lens of childhood studies is fundamental to this study, as it considers childhood to be a concept that is socially constructed and understands children are positioned in a distinct period that is affected and shaped by social and cultural factors (James & James, 2012; Mayall, 1994). Furthermore, childhood studies are grounded in social constructivism, where childhood is not considered to be a universal experience, and there is no fixed and unified meaning of what childhood involves (James & James, 2012).

The childhood studies perspective understands child development as a flexible experience, distinct from a developmental lens (Mason & Watson, 2014; Moore, 2012). Childhood studies challenges the assumption that adolescence is a fixed universal experience (Leonard, 2016; Woodhead, 2008), but recognises children's biological development. In childhood studies it is understood that societies, systems and structures, culture, community, and groups that children inhabit and exist in are all considered a significant influential force on their development, behaviours, identities, and roles, parallel to that of their biological development (Leonard, 2016).

As researchers study children's agency and their participation as social actors (Qvortrup et al., 2011), children are increasingly being recognised as holding unique perspectives and insights, making active and significant contributions to society, to their communities, and to their own lives (James & James, 2012; James et al., 2015). Childhood studies appreciates and recognises that childhood is experienced by children and can be considered a "complex social phenomenon" (James & James, 2012, p. 9). Childhood studies highlights the diverse experiences of children, sees childhood as variable, and places significant value and importance on child rights, agency, voice, and wellbeing (Graham & Fitzgerald, 2010; Woodhead, 2008).

Application of Childhood Studies

Childhood studies supported the participatory methodology of this study, including the use of in-depth interviews and open-ended questions. The framing of childhood studies helped to create an accessible space for children and young people to discuss and make sense of autism and their family experiences and relationships in their own ways.

Childhood studies recognises that adult views and child views can be different from one another, and that adults and children can differ in their interpretations and understandings of the world. This encouraged the researcher in this study to seek the expertise and advice of children and young people throughout the various stages of research. This influenced the design of the study, including approaches and strategies applied to conducting interviews and the incorporation of strategies to feature and emphasise children and young people's voices.

This meant remaining alert to the importance of keeping power balances in check, to ground the generation and development of themes in the narratives of young people with autism, and to observe and scrutinise the impact of the adult researcher perspective.

Disability Studies

As with childhood studies, the disability studies approach supports the constructivist interpretivist worldview of this study. Disability studies, alongside the disability rights movement, works towards highlighting the "…rigidity, faultiness, deficits, and pathological structures" in society (Linton, 2005, p. 518). This involves shifting the focus away from an intervention to fit people with disabilities into society, to one that emphasises that the challenges faced by people with disability relate to a misalliance between their characteristics, their needs, and the physical and social environment (Scotch & Schriner, 1997). It is the setting of the physical or social environment which turns the variation of disability into a source of vulnerability or disadvantage (Erevelles & Kafer, 2010; Wasserman, 2018). However, with a setting or environment that is aligned with their characteristics and their needs, people with disabilities and their families are active and capable social actors (Li et al., 2019).

Recognition of the value and significance of talking to children and young people with disabilities about their experiences is continuing to develop in Australian and international research (Hall et al., 2019; Jenkin, 2015; Lai et al., 2006; Martino & Schormans, 2018). These viewpoints suggest that people with disability may be less capable than people without a disability, and these perspectives often define people with disabilities based on the ways in which they act or learn. Disability studies considers people with disability as capable social actors and not passive recipients of society and culture. People with disability are acknowledged as people with unique, diverse, and shared experiences. The viewpoint places significant value on the importance of disability rights, agency, and wellbeing, and brings the voice of people with disability to the foreground.

As a practical approach, the disability studies field is directed and led by people with disability, who investigate and scrutinise the ongoing and changing social conditions which control their capacity, oppress their autonomy and agency, define their limitations, shape their experiences, and govern their needs (Hall, 2019; Siebers, 2008). From this perspective, observations of a person with disability are not absolute, but rather are relative to the observer's perspective, as "…a person is not born a disabled person, one is observed to be one" (Michailakis, 2003, p. 2019).

The value and significance of talking with people with disabilities about their experiences is being further developed in an Australian policy context, highlighted by the recent policy shifts related to the Australian Government's National Disability Insurance Scheme [NDIS], designed to promote a more active role for people with disabilities. The NDIS funds costs associated with disability. The NDIS is seeking the guidance of people with disabilities in efforts to increase the contribution of those registered with the scheme and their families, including their influence on decisions and scheme design, with the aim of positively impacting their experiences of service and supports obtained through the NDIS. These policy shifts, whilst encouraging, are initial steps towards greater direction and leadership by people with disabilities and their families for a scheme legislated to provide individualised support for people with disability, their families, and carers and with the reasonable and necessary supports they need to live an ordinary life (NDIS, 2020).

As steps towards change are being driven by both people with disabilities and their communities on a research, policy, and practice level, there is increased encouragement and potential for sociological understandings of children and young people with disabilities to contribute towards better understanding of, and responses to, this cohort and their families.

Application of Disability Studies

Whilst both childhood studies and disability studies informed the selection of the research approach and guided the selection of methods for this study, disability studies focused the study on the leadership of young people with autism, their families, and the autism community (Hall, 2019). This was supported by an awareness of the "…nothing about us without us" principle, which considers and acknowledges the ethics of outsider research and the relationships between the "…researcher and the researched" (Bridges, 2001, p. 1). Part of this process of consideration meant taking steps to check that the research topic and the processes of the research were reflective of study participants and the broader community, as well as seeking the guidance and direction of families with lived experience of autism (Cooperative Research Centre for Living with Autism, 2016). These were all part of helping to ensure that the research and its processes were performed "with, rather than on" individuals and groups (Christensen & James, 2008, p. 1). Some examples of how this approach was applied in this study are provided below.

Disability studies, alongside the childhood studies approach, supported this study's inclusion of children and young people in the research processes, and provided guidance for foregrounding the voices of young people with autism in the research. Working to keep the viewpoints of the young people with autism at the foreground of the study included clarifying their responses during interviews and ensuring that the development of themes from the data was grounded in their responses. This helped to capture divergent viewpoints and experiences, not just the dominant ones. Using direct quotes in the presentation of the data helped to limit the interpretation of the insights of young people with autism through my adult perspective. In addition, this helped limit the interpretation of the perspectives of participants who did not have autism through my perspective as a person with autism. These processes were in place to ensure that participants' voices were correctly reported and to check that the outcomes of the research were relevant to their lives.

A family advisory group of young people with autism and their family members provided guidance and advice on the appropriateness and relevance of the topic after an initial literature review. Group members also offered their expertise in the development of the research question and research aims and the development of the interview schedules, provided input into the recruitment approach, and suggested strategies to make sure young people with autism felt comfortable and supported throughout the interviews. The family advisory group also assisted with approaches to managing power dynamics, so that the balance was not tipped towards the researcher. Using direct quotes, identifying, and presenting divergent viewpoints and experiences, and having a family advisory group are examples of how a disability theory approach was applied in this study.

Disability studies supported the involvement in this study of both children and young people with autism and those without by informing the practical components of the research and how the research was conducted with young people with autism and their families. In addition, asking young people with autism to define autism by asking what autism meant to them, without imposing any fixed descriptions or diagnostic labels of autism, such as those in the DSM-V (American Psychiatric Association, 2013), helped to stay focused on the perspectives of the individual young person. This also helped to prioritise the individual over the label of autism and lessen the stereotypes or misconceptions associated with the label.

Smith-Merry (2017), in their review of current practice in inclusive disability research, argue that participants benefit most from research that is not designed with a strict, rigid, specific model, but which allows for the development of a flexible model to mould to the needs of a study and its participants. To contribute to removing some of the barriers that can obstruct young people's involvement in research, this study adapted part of the recognised body of knowledge and methods that exist in children's research (e.g., Christensen & James, 2008; Johnson et al., 2014; Mahon et al., 1996; Moore, 2012; Moore et al., 2016; Noble-Carr & Woodman, 2018; O'Kane, 2008), and apply these to young people with autism. In the current study, young people with autism and their families confirmed that these methods were appropriate; for example, the methods accommodated for the unique behavioural, sensory, and communicative differences of people with autism. Providing the necessary supports to allow young people's participation in research is one strategy to help reduce power dynamics between the researcher and young people (Jenkin et al., 2015).

Systems Theory

Systems theories are the study of systems as they connect and interact with each other. The main concept of systems theory is that "…the whole is more than the sum of its parts"

(Bertalanffy, 1975, p. 16) and the characteristics of the whole are emergent i.e., a system is an entity made up of interrelated/interdependent parts that are not explained in isolation (Adams, 2013). In the social sciences, a complex system is considered a large, whole system comprised of individual smaller systems. An expression of a complex system is evident in the socio-ecological model (Bronfenbrenner, 1972). Constructivist researchers frequently investigate the processes of social interaction between individuals and the social structure in which social processes occur. As a theory of human behaviour, systems theory, of which ecological systems theory and family systems theory are a form of systems theory, focuses on how persons interact with their environment and how the family system affects the individual. Regardless of the focus, all systems perspectives adhere to the concept of related elements as part of a whole reacting to and affecting each other (Cridland et al., 2014). Application of a systems perspective to family relationships can help to explain the influences of and interactions between various systems levels and the connections within subsystems in a family.

Ecological Systems Theory

An ecological systems perspective recognises the interconnectedness between people and their environments, such as an individual’s relationship with their communities, with the broader society, and with their family (Bronfenbrenner, 1979, 1989). This perspective can be appropriately applied to families, in that it highlights the significance of understanding actions, conditions, and people situated in their system and not separated (Cridland et al., 2014), viewing individuals “as interconnected parts of a system that cannot be understood in isolation from one another but as embedded within their family" (Gardiner & Iarocci, 2012, p. 2178).

Ecological systems theory suggests that individuals interact in and across five environmental system levels: the microsystem (family, school, peers, community); the mesosystem (the interactions between microsystems, such as disability support services and the family); the exosystem (links between settings outside of the individual, such as experiences at home being potentially influenced by a partner's experiences at work); the macrosystem (the culture the individual lives in); and the chronosystem (environmental events and transitions over the course of an individual's life, including social and historical settings).

An ecological systems perspective has been applied to a variety of social issues to understand more about people and their interactions and connectedness with their environments. For example, it has been applied to health care systems, family relationships, income and housing, mental health, the law and justice systems, unemployment, and education (Algood et al., 2013; Hepworth et al., 2017).

Family Systems Theory

Family Systems theory places and understands individuals in relation to other people in their family and the inter-relationships between them (Cox & Paley, 1997; Minuchin, 1985). Family system theory is rooted in a functionalist perspective and originated from systems theory, a broad umbrella term, described above which applies the principle of understanding the interconnectedness and reliance an individual component has on another. Systems theory has applications to families in that it highlights the significance of understanding actions, conditions and people situated in their system, and not separated

(Cridland et al., 2014). A system is described as a contained group of interconnected elements displaying consistent behaviour (Constantine, 1986). The system can be considered as dynamic, changing, and adaptable to external and internal events and is particularly susceptible to periods of transition (McGoldrick et al 2016).

Applying the concepts of systems theory to families offers four fundamental principles to understand family structure and interactions: "…the whole is greater than the sum of its parts", (Bornstein & Sawyer, 2008, p. 382) the family functions as a whole unit; change or disruption to one member affects the other members, and members in a family are causally related (Gardiner & Iarocci, 2012); roles and boundaries are largely dictated by the parents to the children, that is the structure of the family is hierarchical (Gardiner & Iarocci, 2012); and families are not static, they are fluent and can work to rearrange in times of interruption or interference to the system (Gardiner & Iarocci, 2012). Relationships within the family are examined via a microscopic approach, focusing on paternal, maternal, sibling and partner subsystems (Cridland et al 2013).

From a functionalist viewpoint of human behaviour, family systems theory views the family as an emotional unit and examines the bonds and interactions amongst members to describe the complex interactions within it. Individual problems are interpreted as family problems. An issue or problem inherent in an individual is suggested to impact other members in the family and their relationships with one another. In addition, the family system acknowledges members' various roles, including those that may cross multiple boundaries. For example, an individual in the family may function as the child, sibling, and caregiver (Gardiner & Iarocci, 2012). If a member of the family has a disability, such as a child or sibling, supplementary risks and stressors are considered, as other family members roles and relationships may be constantly renegotiated during times of intense stress (McGoldrick et al., 2016).

Family systems theory has made a significant contribution to family research and clinical approaches to working with families in the areas of chronic health issues and traumatic events, substance abuse and treatment, and intergenerational kinship networks (Anderson & Sabatelli, 1999; Goldner, 1989; Steinglass, 1987; Minuchin 1974; Finkelhor, 1984). Well known models and associated techniques include Bowen theory family therapy which prioritises intergenerational issues and family triangles, a three-person relationship typically made up of two parents (mother and father) and their child (Bowen, 1966). Family systems approach has applications to family therapy and intervention as it accounts for all members of the family and characteristics of the family's functioning (Altiere & von Kluge 2009). As family systems theory views family relationships as inextricably connected, practitioners working with families focus on individual members whilst simultaneously consider subsystems in the family, such as the parent-child relationship and the sibling relationship.

Application of Systems Perspectives

In this study, a systems perspective, including ecological systems theory and family systems theory, was used to consider how the connection between the five environmental systems levels impacts family members and their family relationships. This perspective informed the approach and design of the study, recognising that family experiences are shaped and influenced by a range of environmental systems levels, including interactions among family members, and interactions with community, school, peers, other families, and workplaces, and with the service provision sector. This perspective helped to provide a contextual understanding of the presentation and analysis of the data and informed the interpretation of the findings. The perspective underpinned the consideration of the contextual circumstances in which families are positioned when developing and framing the implications of the research.

The systems theory perspective informed and guided this study's recruitment methods, which involved connecting with families via the various systems they interact with, such as recruiting through schools, disability support agencies, and advertisement within the community. This study recognised the various systems families are engaged in, and efforts were made to ensure that the recruitment methods aligned with families' usual environments and were not external to their daily routines or unfamiliar to them. This was deemed an important component of the research process, and the literature review confirmed that families are involved in many systems and that routine and structure for families is important for the management and planning of daily activities (Guralnick, 2000; McGoldrick et al., 2016; Minnes, 1998).

Family relationships are influenced by a range of factors across and within systems levels (Factor et al., 2019). This knowledge informed the approach to data collection and analysis for this study. During interviews with participants, external system interactions that might affect or influence interactions with family members were explored in depth. Interview transcripts were also read and re-read, with particular attention paid to systems outside of the family that may have influenced subsystems (parent-child, sibling, and partner) within the family. Recognising and applying elements of a systems approach contributed to the overall rigour of this study.

A criticism of the systems perspective is that inequality, power dynamics, and victimisation are not addressed, or are overlooked or understated (Goldner, 1988; Spronck & Compernolle, 1997; Yllo, 1993). Childhood studies and disability studies were used to offset some of these limitations by highlighting and focusing on children and young people's individual experiences, paying close attention when sorting and analysing the data and writing the findings up to the importance of recognising and highlighting the perspectives of young people with autism, and referring to these throughout the research wherever possible.

Asking families for their own definitions of "family" and "relationships" without setting a predetermined definition of family also helped to reduce concerns that systems perspectives emphasise or assume traditional gender roles, hierarchical structures in families, and functionalist perspectives of family as either functional or dysfunctional (Goldner, 1988; Yllo, 1993). In addition, the phenomenological approach that guided the thematic grounded theory analysis of the data buffers concerns about the impractical nature of utilising systems-based interventions in practice; this approach was able to present the complex and divergent experiences of families in a credible way, adding depth to the findings and to the practice model for families (Healy, 2005).

Investigations into families from a macroscopic approach consider how families engage with and relate to external systems; for example, school, the community, and social networks, including other families (Cridland et al., 2014). Relationships within the family are examined via a microscopic approach, focusing on paternal, maternal, sibling, and partner subsystems (Cridland et al., 2014). Family systems theory played a central role in informing and interpretation of dynamics and interactions within the families, between the members. Although this study predominantly focused on a micro-level system, the family system, it is important to acknowledge and situate families and their internal relationships in the broader context of their social and environmental circumstances. The study incorporates an understanding that the external environment in which families are positioned can influence the family system, including the dynamics, interactions, and behaviours within the family, and impact the relationships of family members (Healy, 2005).

Together, childhood studies, disability studies and a systems perspective inform a robust theoretical framework that supported the purpose of this research, guided the methodology, and enhanced the analysis and interpretation of the findings in this study.

Childhood studies supported the participatory methodology of this study, including the use of in-depth interviews and open-ended questions. The framing of childhood studies helped to create an accessible space for children and young people to discuss and make sense of autism and their family experiences and relationships in their own ways and influenced the design of the study, including approaches and strategies applied to conducting interviews and the incorporation of strategies to feature and emphasise children and young people’s voices.

Disability studies focused the study on the leadership of young people with autism, their families, and the autism community (Hall, 2019). This meant taking steps to check that the research topic and the processes of the research were reflective of study participants and the broader community, as well as seeking the guidance and direction of families with lived experience of autism (Cooperative Research Centre for Living with Autism, 2016). Disability studies assisted to keep the viewpoints of the young people with autism at the foreground of the study included clarifying their responses during interviews and ensuring that the development of themes from the data was grounded in their responses. This helped to capture divergent viewpoints and experiences, not just the dominant ones. Using direct quotes in the presentation of the data helped to limit the interpretation of the insights of young people with autism through my adult perspective. In addition, this helped limit the interpretation of the perspectives of participants who did not have autism through my perspective as a person with autism.

Systems perspective, including ecological systems theory and family systems theory, was used to consider how the connection between the five environmental systems levels impacts family members and their family relationships. A systems perspective informed the approach and design of the study, recognising that family experiences are shaped and influenced by a range of environmental systems levels, including interactions among family members, and interactions with community, school, peers, other families, and workplaces, and with the service provision sector. This perspective helped to provide a contextual understanding of the presentation and analysis of the data and informed the interpretation of the findings. The perspective underpinned the consideration of the contextual circumstances in which families are positioned when developing and framing the implications of the research.

Chapter Summary

This chapter outlined the theoretical framework of the study. The components of the research framework were pieced together to bring both a central focus on the perspectives of young people with autism and their family members and to draw attention to broader social factors that impact on families. Guided by a social constructivist epistemology, this study did not seek out a specific or definitive account of family relationships; instead, there was an expectation that study participants would have varied perspectives and understandings and that their viewpoints might diverge from those presented in the existing literature.

The chapter justified the selection of the theoretical orientations of childhood studies, disability studies, and systems perspectives to guide and inform this study. This theoretical framework guided the data collection methods, data analysis, and interpretation of findings in this study. Each theoretical orientation within the framework complements and balances the others to create a research space that allows a diverse group of people, including young people with autism, to communicate openly and freely about their experiences. The intersection of theory supported the study in recognising, acknowledging, and valuing the viewpoints of all participants. Together, the theories prompted consideration of the social and environmental context of the broader setting of the research and guided and influenced how the research was conducted.

Building on the theoretical framework of this study, the next chapter provides a detailed account of the carefully selected research approach, and the processes, plans, and procedures that were used in this study, and how these led to a research design for conducting the research in the "real world" (Gray, 2009). This culminated in a novel methodological approach to the investigation of autism and family relationships that included young people with autism and their family members.

Chapter 4: Research Design

Introduction

This chapter presents the research design employed for the study. This includes a description of the qualitative participatory methodology and phenomenological approach to the research and how these informed the methods that were used for data collection and analysis. The methods section of this chapter details the research procedures undertaken in the study, including the *epoche,* the initial conceptualisation of the study, the sample of study participants, ethics approval, advertisement for and recruitment of participants, data collection, and data analysis.

Due to the recognition of the distinctiveness of study participants, and to the importance of supporting their self-determination throughout the research process, the research strategies and methods employed in a study adopting a participatory methodology may not always adhere to standardised research methods, but rather can draw on multiple strategies (Bergold, 2007). In this study, the participatory methodology supported the need to adapt research methods in response to children and young people (Bergold, 2007; Coburn & Gormally, 2015; Levy & Thompson, 2015). This meant that the methods used in the study emerged through discussion with participants, with a particular focus on appropriate adaptation and flexibility to suit children and young people with autism (Bergold, 2007; Crotty, 1998; O'Kane, 2008).

Qualitative Participatory Methodology

Conducting qualitative research involves recognising and adopting an ontological view of multiple realities (Creswell & Poth, 2018) and taking an epistemological stance that realities are socially constructed from human experience (Cohen & Manion, 1994; Mertens, 2005). Qualitative research aims to explore a variety of perspectives by utilising open-ended questions and primarily words as data (Creswell, 2018). Researchers using qualitative methodology strive for in-depth understandings and explanations of individuals' perceptions and experiences of a phenomena and the influence their surrounding context has on their views (Creswell, 2018; Denzin & Lincoln, 2008). These approaches assist researchers to explore concepts that are multifaceted, and context driven (Creswell, 2018). Qualitative research is well suited to explore a subject that is not fully conceptualised, and which contains sensitivity and emotive complexity (Oktay, 2012); such research addresses the "…lived experience from the perspectives of those who live it and create meaning from it" and "…combines advocacy with research and complex social processes" (Padgett, 2008, pp. 15–16).

The benefits of participatory qualitative research are well recognised in the literature (e.g., Ennis & Wykes, 2013; Michalak et al., 2007; Mjosund et al., 2017; Rose & Kroese, 2018). A qualitative participatory methodology upholds the significance and value of involving research participants throughout the research design and knowledge production processes (Bergold, 2007). The approach is recognised as a meaningful way to break down barriers to translation in efforts to make sure the research outcomes generate benefits for the community or groups included in the study (Long et al., 2017). Participatory research must also recognise and destabilise "…the traditional power imbalance between researcher and participant" (Nelson & Wright, 1995, p. 1).

The participatory model adopted for this study acknowledged children and young people as active social agents in the telling of their *life worlds* (Bergold, 2007; Davies, 2005). In the context of this study, a participatory research methodology facilitated an approach to "join with" and "learn from" rather than "speak for" or "intervene into" children's and young people's lives (Cannella & Lincoln, 2011, p. 83). This ensured that the research question and aims of this study developed from the perspectives of the young people and their parents, whose involvement was in co-reflexive activities (Bergold, 2007; Moore et al., 2016).

Participatory methodology has been recently recognised as an approach to research that can enable meaningful input from people with autism (e.g., Fletcher-Watson et al., 2019). Participatory methodology can include "…leadership by autistic researchers, partnership with autistic people or allies as co-creators of knowledge, engagement with the community in general (e.g., via social media) and consultation with relevant individuals or community organisations" (Fletcher-Watson et al., 2019, p. 944). In this study, developing understanding through the lens of people with lived experience of autism was central, recognising that these participants' experiential expertise can contribute to the design and processes of research that involves them and that can produce benefits for them (Dey et al., 2019). Experts by experience are recognised as co-producers of care targeted towards them (e.g., Byrne et al., 2018; Dey et al., 2019; Gordon & O'Brien, 2018). This approach helps research to focus on how participants are involved and can generate research findings that "…better meet their needs, values, and purposes" (Scholz et al., 2019, p. 359).

Phenomenology

This study's qualitative methodology was informed by a phenomenological approach. Phenomenological studies are interested in understanding the human experience of a particular phenomenon and in understanding how people make sense of their experience of the phenomenon (Lester, 1999; Moustakas, 1994). As a research approach, phenomenology is suited to exploring and describing the life worlds or shared experiences of participants by focusing on their views, feelings, and experiences (Creswell & Poth, 2018; Laverty, 2003). The purpose of a phenomenological approach is to provide a voice for those involved in the study (Neubauer et al., 2019).

There are multiple approaches to the German philosophy of phenomenology, with two major approaches being hermeneutic (interpretive) phenomenology (van Manen, 1990) and transcendental (descriptive) phenomenology (Moustakas, 1994). These two approaches have been put forward by two historical advocates—Heidegger and Husserl, respectively. They each represent certain philosophical assumptions about experience, and each has its own methods for organising and analysing data (Hein & Autisn, 2001; Neubauer et al., 2019).

For studies guided by a transcendental phenomenological approach, *meaning* is the central focus of the study. Transcendental methods are widely used in the social sciences; they aim to explore and describe the lived experience of participants and their engagement with a phenomenon, as the researcher grasps the phenomenon "…freshly, as for the first time and is open to its totality" (Moustakas, 1994, p. 34). Data are collected and analysed to reach a description of the participants' experience, as the researcher "brackets" or removes themselves from the interpretive process (Neubauer et al., 2019).

Studies led by hermeneutic phenomenology employ reflective interpretation of the data, where the researcher acknowledges their position in the research, and their interpretation of the data accounts for the time, place, and historical setting of the participants (van Manen, 1990). When considering phenomenological approaches, researchers need to carefully consider the methods of analysis and outcomes that are most suited to the objectives of the study and how they contribute to the phenomena, what is known or not known, and how each approach builds on or adds to the object of study (Lopez & Willis, 2004).

Application of Phenomenology to This Study

This study employed both hermeneutics and transcendental methods and concepts to address the research question and research aims. The approach and methods for this study can be viewed as *bricoleur*, in that they merge compatible principles and methods (Denzin & Lincoln, 2000). Scholars recognise that borders between qualitative methodologies are permeable (Broadhurst & Mason, 2020; Charmaz, 2014; Starks & Trinidad, 2007). In merging harmonising principles and methods, this study recognises the limits of any individual approach to qualitative research, and that individual approaches might not fit exactly with the requirements of a particular study's data collection and analysis processes (Broadhurst & Mason, 2020).

The object of both methods of phenomenological inquiry is to make voices heard (Lopez & Willis, 2004). In the current study, hermeneutic phenomenological methods helped in evaluating whether contextual features of participants' experiences might have relevance to therapeutic practice (Svedlund et al., 2001). Transcendental concepts were used to foreground the perspectives of the young people with autism, to include their views whenever possible, and regularly refer to these views. Methods guided by a transcendental approach were used in this study for this purpose, as they encourage in-depth insight into underexplored phenomena (Beck, 1992; Broadhurst & Mason, 2020; Denzin & Lincoln, 2011). The study methods are described next and make up the remainder of this chapter.

Methods

Epoche

Initial conceptualisation of the research began early, when I, as the researcher, reflected on what I could bring to a study focused on family relationships and autism. This included my personal history, ethical and value stances, and my own experiences with the research topic. A phenomenological approach to qualitative research defines this process as the *epoche*, meaning to "refrain from judgment" (Moustakas, 1994, p. 34). This reflexive phenomenological technique takes the form of a description that accounts for the researcher's involvement or connection with the research topic, including a commentary on the perspectives and experiences that were brought to the research.

Epoche is acknowledged in Moustakas's (1994) transcendental (descriptive) approach to phenomenology. Reflection or epoche as a technique used in the qualitative research process is common across many qualitative approaches, including grounded theory and ethnography (Creswell, 2018). Epoche is also used as the first step of data collection and analysis, referred to as the "phenomenological reduction process" (Moustakas, 1994, p. 34), when the researcher is looking to initially engage with the data collection and analysis in a novel way, to set to the side their understandings of the phenomenon, and draw their attention to those told by the participants before turning to the literature (Moustakas, 1994).

As I considered the topic and research question, I was guided by Moustakas's words as I allowed new ideas, experiences, perceptions, and people into my consciousness. Moustakas (1994, pp. 7–8) instructs that, for the duration of this process, "…references to others, their perceptions and judgments must be put aside to achieve epoche and only the researcher's perceptions are retained as indicators of knowledge, meaning, and truth." A summary of the key points from my guided epoche (Moustakas, 1994, pp. 7–8) for this study is provided below.

The epoche process was undertaken at conceptualisation of the research and throughout the periods of data collection and data analysis of the current study. I (the researcher) recalled my own personal experiences of autism and my professional experiences of working with young people with autism and their families, throughout the past decade. Through a continuous process of self-reflection and bracketing, three noteworthy sets of experiences flickered through my mind.

First, there were reflections of the time spent living with my family, whose understanding, support, and acceptance instilled a belief in me to follow and trust my senses and the feelings within me. This contributed to ongoing development and improvement in my sense of awareness of my body in space, my mind in time, and my senses through both space and time. My positive family relationships informed my rationale for wanting to explore the strengths and contributions of young people with autism in families and to foreground them in research.

I recalled, that as an adolescent, I spent a large amount of time at home. Initially, I was deeply involved in hobbies and personal interests, and then later in adolescence this occurred for reasons related to mental health. Time spent at home placed some strain and difficulty on the family and on relationships with my mother, father, and brother, including social withdrawal and psychological disconnection. Finally, I considered the relationship with my family in the last two years, not only regarding the positive ongoing contributions they make to supporting me and accepting me for who I am and who I am not, but also for the ways in which I bring joy to their lives, such as through humour, through conversations and sharing my passions with them, and through the ways I positively influence their views of human experiences.

I reflected on these experiences and acknowledged the influence they had on this research, such as my own family experiences of being supported and accepted. This constant self-reflection helped me to remain aware of any significant bearing or weight that these personal memories might have had on the research. This led me to an acceptance that the experiences of others with autism and their families may be quite different to my own. For example, areas of diversity and divergence might include families with a young person with autism and intellectual disability, families with multiple children with autism, single parent families, those from cultural backgrounds different to my own, and families who might not provide the same level of support for the young person to be and express who they are.

Sampling Plan

Four different groups of participants were targeted for this study. In total, 44 participants from 18 families were recruited to participate in the research. The descriptions of these participants are provided below. The sampling was designed around recruiting through families to reach and work with individual members. The participants sought for each group were: young people 12–19 years of age with an autism diagnosis; siblings with a brother or sister aged 12–19 years of age with an autism diagnosis; fathers of young people 12–19 years of age with an autism diagnosis; and mothers of young people 12–19 years of age with an autism diagnosis. The intention was to have approximately equal numbers in each participant group, and to allow for exploration and description of conditions and meanings across all settings until saturation was reached. To achieve this, it was expected that around ten to twelve participants would be recruited for each participant group (Hennink et al., 2017; Luborsky & Rubinstein, 1995).

Purposeful sampling was employed to target participants who had specific, predefined traits or conditions and to assist with identifying possible information-rich cases connected to the topic of investigation (Palinkas et al., 2015). No restrictions on family structure were imposed on the sampling plan. Family members were those considered as “mother,” “father,” “child,” “brother,” “sister,” “husband,” “wife,” or “partner,” and definitions were to be determined by the family members themselves.

The criteria for participation in this study were that the participants had lived experiences of autism in the context of family, were willing to discuss and to understand the nature and meaning of family and autism and were agreeable to participating in one interview and willing to possibly partake in a follow-up interview. Participants also needed to permit the researcher to audio record and/or take notes of interviews and to publish findings from the data in a dissertation and other publications.

Table 1 shows the number of study participants in each participant group and provides details of their characteristics. The total sample included 12 mothers, 12 fathers, nine siblings and 11 young people with autism. At a total of 44 participants, saturation of interview data was assessed to have been reached and a good representation from each of the participant groups achieved. The participants were drawn from a total of 18 families; 12 of these families had between two and seven participants, and in six families only one member chose to participate (either a father or mother). Of the 18 families, five were multiplex families, meaning that multiple members in the family had a diagnosis of autism (Sanders, 2013).

Table 1

Participant Groups, Numbers of Participants, and Gender of Participants

Participant groups	**Young people with an autism diagnosis aged 12–19**	**Siblings**	**Mothers**	**Fathers**
Number of participants	11, of whom 4 had an intellectual disability	9	12	12
Gender of participants	4 females 7 males	7 females 2 males	12 females	12 males

Of the 44 participants who were interviewed, 23 identified as female, made up of 12 mothers, seven sisters, and three young people with autism; 21 identified as male, made up of 12 fathers, two brothers, and seven young people with autism. One young person with autism identified as “LGBTQI plus”. The type of professional support the young people with autism have received included social and emotional therapy supports, carer/disability support for daily living tasks e.g., washing, preparing food, toileting, dressing and showering, group social skills development, psychology and mental health supports, occupational therapy and speech pathology supports, and sibling play group supports.

Of the 18 families, five had one parent (mother) caring for the child/ren with a diagnosis of autism. Two of these five families had sole care of their child. Of the 12 mothers, two identified as divorced, one identified as widowed, one identified as a partner of a couple, and eight identified as wives. Of the 12 fathers, one identified as single, and 11 identified as husbands. A total of five fathers and five mothers participated in the study together as husband and wife. Approximately 20% of participants identified as having a cultural and ethnic background other than Australian and White and 11% of participants reported that English was their second language, however, were fluent in their speech.

Since the study was undertaken in the ACT, the socio-economic status of participants was not included. According to the 2016 Census, the Australian Capital Territory had the highest proportion of people living in relatively advantaged areas (55% in quintile 5) and the lowest proportion in the most disadvantaged areas (0.7% in quintile 1). These figures reflect the same results that were observed for 2011 and 2006 (ABS, 2011). Previous research indicated that disadvantaged people in this territory were more dispersed across advantaged areas than most other States and Territories (Wise & Matthews, 2011).

Family Advisory Group

A family advisory group was established to help formulate the study. The decision to include an advisory group in this study was informed by several Australian and international autism research and ethics guidelines (Australian Catholic University Ethics Guidelines, 2021;

Cooperative Research Centre for Living with Autism, 2016; Good, 2020; Gowen et al., 2019; Martino & Schormans). These are resources for researchers to learn how to involve participants in research, as well as involve themselves meaningfully in research with people with autism and other disabilities in research studies.

Best practice suggests that people with autism and their families can benefit from research when they are included throughout the research process, from design to dissemination; however, efforts and attempts to do this are recent (Cooperative Research Centre for Living with Autism, 2016; Pellicano et al., 2018). New research approaches that involve people with autism and their families can help focus research on topics relevant to the community, and research findings should be suitably distributed and translated into practice to be used for the benefit of the community (Cooperative Research Centre for Living with Autism, 2016).

This study was informed by two families who each included a young person with autism. These families were invited to partake in the research in an advisory role and were engaged in the initial inception stages of the study. To ascertain potential interest from the local community, autism support organisations in the ACT were contacted and information distributed about the project and advisory role. Two families expressed an interest in the project and were willing to offer their time and expertise in several research activities for the study. Members of the family advisory group were two mothers in their late forties, one father in their late forties, one female sibling thirteen years of age and two male young people with autism, both nineteen years of age, one of which had an intellectual disability. One family was from a white Australian background and the other family was from a background other than white Australian.

The family advisory group and researcher met at key stages of the study and in person whenever possible. Meeting as a group helped to ensure that diversity of opinions could be shared and discussed in an open forum and the researcher was responsible for managing this and to debrief with supervisors as required. Meeting in person also helped to ensure that the young people with autism had an opportunity to participate through verbal communication, and with the support from their families as needed, as the young person with intellectual disability had limited reading and writing skills. Outside of this, the researcher kept in contact with the families through email and telephone contact, with most of the communication occurring through the parents. This method is a limitation of the advisory group including the composition and input of the group as the advisory group could gave more comprehensively captured the voices of the young people with autism.

Each family contributed to several research activities which included defining the research question and aims and gave expert advice on a number of issues, including language for identity and diagnosis, interview methods for young people with autism and intellectual disability, the target age of the young people with autism to be recruited for the study, interview schedule questions and practising/piloting interviews, ethical considerations, potential sensitivities and practicalities when involving young people with autism in interviews, and member checking of the transcripts and findings.

As the study progressed, the families expressed an interest in remaining involved where possible and were updated at each stage of the study. This included providing study progression updates, discussing interview techniques, and sharing the development of interview schedules and themes. This process was iterative, freely moving between the advisory group, the literature, the data collection, and the analysis of the data.

Ethics Approval

This study was approved by the Australian Catholic University (ACU) National Human Research Ethics Committee (HREC), study registration number 2019-33H. Approval for data collection was granted from 08/04/2019 to 31/12/2019. A copy of the study approval letter is provided in Appendix B. The Australian Capital Territory Education Directorate provided approval to contact government schools in the Australian Capital Territory (ACT). The application for ethics approval required documentation about this study and information to help the ACU HREC to understand the study protocol. The study protocol had to comply with the National Statement on Ethical Conduct in Human Research, the Australian Code for the Responsible Conduct of Research, the ACU Code of Conduct for Research, the National Privacy Principles (NPPs), the Information Privacy Principles (IPPs), and ACT legislation for advertisement and recruitment through public schools.

As part of the documentation required for ethics approval, a research guide and protocol document were developed. This document detailed all the necessary steps and actions that the researcher would take to conduct the research in an ethical and safe manner that would cause no harm to the study participants. This included evidence that the processes for interviewing parents, children, and young people with autism were appropriate and informed consent would be provided (Parsons et al., 2016). The document also contained protocols for responding to disclosures of abuse or other harm. No disclosures were made by participants during the research.

The guide was developed with considerable reference to best practice guides published by the Cooperative Research Centre for Living with Autism (2016) and authors Gowen et al (2019) and the principles detailed above. The guide also included best practice research protocols when conducting research with vulnerable children and young people developed by research staff at the Institute of Child Protection Studies, Australian Catholic University (e.g., Moore et al., 2016). The guide also drew on the experience of the researcher who had worked for over a decade as a family practitioner with children and young people with autism and their families. Therefore, the materials developed and used were based on approaches that had already been well established, including for conducting research with vulnerable populations.

Participant Recruitment

The strategy to recruit participants for this study involved contacting community organisations and government-funded schools in Canberra, ACT to seek support to advertise the project through their services. These included autism support services, local schools, and local youth and family disability support services. Recruitment took place over a 3-month period. A local autism centre in the ACT was consulted for the use of appropriate language and recruitment advertisement text. A Learning Support Assistant contracted to an ACT specialist education school who had experience working with young people with autism with intellectual disability helped inform the use of accessible language on the advertisement and on the information letters and consent form for young people with autism with intellectual disability.

Following these consultations, a comprehensive study information letter was given to all recruitment agencies and to participants and their carers/support people. Four study information letters were developed, personalised to mothers, fathers, siblings, and the young person with autism. An augmented, modified picture-based information letter was developed for those young people with autism with alternative communication and intellectual disability. A copy of the study information letter is provided in Appendix C.

The advertisement materials stated that participants were entitled to a $30 shopping voucher. It is recognised that some families with a young person with autism experience time and resource demands and financial strain (Amato, 2000; Amato & Keith, 1991; Hines et al., 2013; Larson, 2010; Marshall & Long 2009; Tint & Weiss, 2016). It was important that this was acknowledged in participants' involvement in the study, and the voucher was also a way to thank them for their time, their expertise, and their contribution to the study, and to assist with any associated travel costs.

Recruitment included advertising through schools' and organisations' newsletters and bulletins. A sample of the recruitment pamphlet for young people with autism is provided in Appendix D. Organisations willing to assist with recruitment had the research advertisement material available on their premises and also emailed out the documents to eligible families. For participants who were being recruited through agencies or schools, the agencies and schools were asked to use their discretion in referring participants who they felt would be able to participate without any adverse effects to themselves or others.

The Youth Coalition of the ACT agreed to facilitate the assistance from their member organisations, including the Family Coalition of the ACT to identify and refer suitable participants. Following a successful application approval process, Autism Spectrum Australia (Aspect) posted a listing on their Facebook page for one month and published a page about the study on its website for the duration of the study recruitment period. As well as direct contact from workers in services and schools, it was also advantageous to advertise the study in places such as drop-in spaces, health clinics, and community newsletters to seek out potential participants.

Because autism support services and schools were involved in recruiting their clients for the study, there was a strong possibility that these organisations' staff members knew who was interested in participating. However, no person or organisation was explicitly notified of any person's agreed involvement in this study, and no participant withdrew from this study.

Initial Contact with Participants

Parents interested in participating in this study, after receiving the advertisement material from their school or service, contacted the researcher directly. The service or school could also seek permission to provide the potential participant's contact details to the researcher, who would then contact them to explain the study, provide further information, and answer any questions. The researcher then arranged a time for an initial meet-up if the potential participant indicated their desire and consent to proceed with meeting to discuss the interview process. During the initial contact the researcher also sought to establish whether the young people with autism and their siblings were willing to participate. If the whole family was interested in participating, the researcher made a time to interview the parents, with subsequent times made to interview the young person with autism and siblings who were also willing to be interviewed.

As participation was voluntary, each participant was given the opportunity to participate in this study and could withdraw without reason at any time. From the beginning, the researcher informed all members in the family that they were invited to voluntarily participate in the study. Family members could participate even if other members in the family did not wish to do so. When recruiting participants from a single family, independent invitations and consent forms were presented to each member to support individual consent being provided, without being persuaded by the consent or non-consent of other members. Separate conversations were initiated with each member to confirm their willingness to participate. The consent process, alongside the interview process, is described further in the sections below.

Interview Process

A primary method used to collect data in interpretivist research is in-depth interviewing. This allows the researcher to investigate and prompt consideration of ideas and experiences by inquiring into participants' thoughts, perceptions, and feelings (Wellington & Szczerbinski, 2007). Understanding the methodological considerations relevant to family group interviews is important, especially when research includes children and children with disabilities; however, there is limited guidance in the literature, and few processes have been described (Ummel & Achile, 2016; Voltelen et al., 2018).

Researchers who have conducted interviews with parents and children together have highlighted that separating parents and children for isolated interviews could hinder children's readiness and inclination to communicate with the researcher, which in turn can act to silence children's voices (Voltelen et al., 2018). Research with families is regularly conducted in the home environment, and children may be habituated to and familiar with the presence of parents; they thus could feel more at ease and better supported with a collaborative interview method, encouraging them to express their views more than in an interview conducted alone (Eggenberger & Nelms, 2007; Irwin & Johnson, 2005).

This study was informed by the work of Voltelen et al. (2018, pp. 521–523), which provides the following guidance when designing family unit interviews: (1) ensure informants understand what participation means; (2) give participants a choice between individual or group interviews; (3) find a suitable context for the interview; (4) extend the period of giving informed consent; (5) provide motives for participation; (6) explain their confidentiality and anonymity; and (7) protect children's safety.

Tensions can arise when involving members from one family in group interviews, such as conflicts in relationships that lead to disagreements between family members (Voltelen et al., 2018). Despite this, family unit interviews can be a valuable method to discover intricate and complex elements within families and between family members, and also provide participants with a unique opportunity to explore and share their experiences together (Ganong & Coleman, 2014; Morgan et al., 2013). Due to the inherent complexities in family relationships, careful attention must be paid to design and planning when conducting family unit interviews (Allmark et al., 2009; Norlyk et al., 2015; Sohier, 1995).

In this study, families were provided with the option of either group interviews or individual interviews and could choose the location of the interview. Most participants chose to be interviewed in their family homes, although some parents chose to be interviewed at work or at a café close to their work, and one participant chose to visit the Australian Catholic University to be interviewed. All participants consented to audio recorded interviews.

A total of 44 interviews with 18 families were conducted across all participant groups. The length of recorded interviews ranged from 4.38 to 135 minutes. The average length of interviews overall was 60 minutes. The length of recorded interviews with mothers was between 27 minutes and 136 minutes, and the average length of these interviews overall was 79 minutes. The length of recorded interviews with fathers was between 30 minutes and 184 minutes, and the average length of these interviews overall was 66 minutes. The length of recorded interviews with siblings was between 4 minutes and 73 minutes, and the average length of these interviews overall was 31 minutes. The length of recorded interviews with young people with autism was between 4 minutes and 78 minutes, and the average length of these interviews overall was 28 minutes. There were four interviews of under 6 minutes in length. These were interviews with siblings, a group with some of the youngest participants in the study, and interviews with young people with autism with an intellectual disability. Mothers' and fathers' interviews were the longest, as shown above.

Where possible, interviews with multiple members of the one family were conducted in succession. This was mainly due to time and logistic constraints, but also to minimise the potential for participant responses to be influenced by others in the family (Eisikovits & Koren, 2010). Most family members chose to be interviewed separately; however, two families chose to be involved in the interview process when their young person with autism with intellectual disability was interviewed. The parents of these young people explained that this was for practical and comprehension reasons, and was not because of any perceived safety risk, lack of confidence in the researcher, or distrust of the research process.

Where possible, interviews with participants continued until no substantively new data were captured (Strauss & Corbin, 1998). Participants were offered a second interview or were given the opportunity to contact the researcher via email if questions were not all covered or if there was a need to clarify or explore responses in more detail. A total of five parents—three mothers and two fathers—followed up with emails providing further data. This information was included in the analysis of data.

Confidentiality

Throughout the research, efforts were made to reduce the likelihood of family issues being exposed or relationships being threatened. Providing interview options for families was important, as potential issues about parent/caregiver or sibling burden related to the young person with autism may have arisen, or participants may have felt they could not speak freely (Haahr et al., 2013). Each family member who participated in an interview was assured that their information would not be shared with their family members or with any other person. Participants were, however, informed about the limits of confidentiality. This was explained before interviews were scheduled, and then again at the time of interview. Participants were told that any information disclosed that deemed them, or others, at risk in terms of their safety or experiencing abuse or harm, these concerns would be communicated to an appropriate person or agency to support their welfare.

As families signed up to be in the study, participants were also advised about the limits of internal confidentiality (Tolich, 2004); that is, their statements might be recognised by other family members in the dissemination of the findings. Before each interview began, participants were advised that they could choose what to disclose, and they understood that any safety concerns would be reported, and that support would be available to them after disclosure. No safety or confidentiality concerns were reported by participants nor by anyone else involved with this study.

Participants were also informed about the processes for maintaining confidentiality throughout the data analysis and write-up of the findings. This included deleting any identifying information from transcriptions, as well as removing participants' names and replacing these with alternative codes. Participants were informed that codes would be substituted with aliases when using interview data in the thesis. Participants, services, or schools who had an interest in the findings of the study would receive a summary of the main findings without participant identifiers. Participants were assured that only researchers had access to participant identifiers.

Reflexive journal notes were kept during interviews to maintain alertness to any potential risks of breaching of confidentiality between family members. For example, this involved writing down information about key family events or information already discussed by another family member participant. These recorded details acted as reminders to remain neutral if one family member shared information that conflicted information provided by another member, or if a participant asked what another family member had said in their interview. This journaling was a useful and important exercise for ensuring participants' privacy, anonymity, and confidentiality.

Consent

Consent in the study was an ongoing process that was negotiated and renegotiated. Participants were provided with multiple opportunities to reaffirm or withdraw their consent to participant in the interviews. Participants were provided with information about the study and led through a tick box consent process that ensured that they understood the nature and scope of the study and their involvement within it and the ways that they could consent or choose how to participate throughout the research process. Participants were asked to reaffirm their consent throughout the interviews.

The voluntary nature of this study was highlighted in all documents and in conversations with potential participants. These documents and conversations included information that participants could end the interview and withdraw their consent to participate in the study at any time without fear of consequence. Information was provided to participants that the study was not connected with the school, support service, or agency through which they accessed the study information, and their involvement would not affect their supports, services, or schooling.

Parental consent was required for young people under the age of 18 who wanted to be interviewed. As well as parental consent, children and young people were also taken through an assent process involving a tick box form detailing information about the study, their rights, and the researcher's obligations. They signed this form, or could audio record their assent if they preferred this or if they were not able to provide their written name. Copies of the consent and assent forms are provided in Appendix E. An audio recording of the discussion between the researcher and the participant that clearly indicated the information provided, the decision-making processes, and the provision of informed consent was saved as part of the interview data.

Supporting Participants in Interviews

The significance of including the voices and perspectives of children in research is uncontested (Lewis & Porter, 2004), and suitable methods for their participation in research and for appropriately reflecting their voices and views have been developed (Cridland, 2014; Lewis & Porter, 2004). This study drew on some of this existing body of methods for supporting children in research (e.g., Christensen & James, 2008, Johnson, 2011; Mahon et al., 1996; Moore, 2012; Moore et al., 2016; O'Kane, 2008) and adapted these methods for some participants with autism. This use of the methods was to help lessen the power imbalance evident not only between adult researchers and children, but also in the ways that research is designed and conducted, often from the perspectives of people without autism.

Participants had choice and control in the interview, such as the choice to finish the interview any time or not to answer questions or discuss issues they felt uncomfortable exploring or sharing. If a participant showed distress, the researcher would action the steps from the "Research Interview and Distress Protocol" (Draucker et al., 2009). However, no participants showed obvious signs of distress. Participants were given a list of contact details for support services. Services were available to discuss concerns following the interviews and to provide direction to support and referrals if needed. The contact details of the University Human Research Ethics Manager were also provided to participants.

To help prevent and mitigate any discomfort or upset due to children or young people's involvement in the research, the family and young person with autism was invited to ask any questions about the research and to meet the researcher before deciding if they were still comfortable in proceeding with an interview. This was an important part of the process, as people with autism can experience anxiety around changes to routine, and anxiety and distrust about new and unknown situations and people (Auert et al., 2012). Nearly all families took up this invitation and all those that did agreed to go ahead with the interview.

When families met with the researcher prior to the scheduled interview, dialogue included how best to accommodate the young person with autism and their preferences for the interview. This meant identifying suitable and appropriate methods for conducting the interviews with the young person with autism. Several options to assist families and their young person were offered. For example, a young person and their family could choose to have the interview conducted with another person in the room with the young person and researcher, someone that the young person knew, trusted, and felt comfortable with, and who knew the young person well. This could also be a support worker. Another option was for the family and/or the young person to be interviewed by someone they knew, such as a support person, instead of the researcher. All participants chose to be interviewed by the researcher and no additional support people were present.

While interviews with all participants were guided by the same interview protocol, participants' involvement in the research was based on an individualised approach. The protocol was designed to check in with participants to identify concerns. Young people had access to three coloured circles, one red, one yellow, and one green. Circles were intended to be used where young people did not feel comfortable giving a verbal response. Each interpretation of the colours was discussed with the young person, with the final meanings attributed to the circles by the young people. As an example, if a child or young person pointed to a red circle in response to a question, they were asked if it meant, “Stop, and move onto the next question,” and that they did not wish to answer the question. Orange could mean, “This is OK, but I may not answer,” and green could mean, “This is OK, I am happy to answer.” No concerns were identified.

When being interviewed, if a child or young person got distracted, bored, distressed, upset, or disengaged, consideration was given as to whether this was an indicator of a desire to withdraw their informed consent. Seeking to clarify how the child or young person was feeling and reminding them they could stop the interview, have a rest, or continue the interview at another time was an essential part of ongoing consent. When interviewing a young person with autism, the researcher also needed to be alert to additional cues, as people with autism may experience difficulties in social situations, need extra time to answer questions, and can find it difficult to communicate and interact with others (Amaze, 2018).

Extra time was provided for each young person to understand and respond to the questions. The researcher presented a question in another way if the young person did not initially understand. Information was presented to the young person with autism in a form the family determined the young person would understand (e.g., pictures, symbols, gestures, vignettes). These data collection tools that supported the interview guide are detailed later in this chapter.

For three of the four young people with autism and intellectual disability, the interviews ended when one young person said “bye-bye” (this was one of the very brief interviews) and the second participant left the room to go to their computer. The third participant experienced strong sensory experiences and excitement being in the interview (as confirmed by their mother and speech pathologist), and their mother and speech pathologist decided to end the interview. An attempt was made to check in with the young person that they wanted to end the interview. At that point, the young person began drinking a beverage their mother had made them, and they went into the loungeroom and began playing with their iPad. Once the young person had settled, a second opportunity was provided to the young person to continue with the interview. The young person did not engage in this attempt, so the interview did not recommence.

Benefits of the Interviews for Participants

Many parent participants reported finding the interviews therapeutic. At the end of interviews, multiple parents let out a sigh, followed by a comment such as, “Oh, that felt good,” and, “Wow I haven’t spoken with anyone about this before,” and, “What a great therapy session.” These parents reflected afterwards on the limited opportunities they had previously had to discuss their family experiences and the influence autism had on them, and how autism impacted and influenced their relationships with family members. Throughout the process of the interviews some parents discovered new insights and ways of thinking about their identity and came to a better understanding of the influences autism had on their family. Parents were thankful for the opportunity to talk about themselves and their family.

While no participants showed obvious signs of distress, some fathers, and mothers and one sibling teared up during interviews. Constructing safe spaces for participants to be in during their involvement in research is a critical part of participatory methodology and methods (Bergold & Thomas, 2012). During the interviews, this was implemented by taking pauses, allowing space and time, checking in with the participant, allowing more space and time, and then, once the participant confirmed that they were willing and ready to proceed, consent was obtained again from the participant to continue with the interview.

Approach to Data Collection

This study used a cumulative, iterative, and synchronised process for data collection, in which the data recorded during each stage of collection shapes and informs the next (Strauss & Corbin, 1990). Theoretical sampling, constant comparison, and theoretical saturation were used to develop the focus of participant interviews and the techniques used during data collection (Strauss & Corbin, 1998). This involved recording interviews with participants, transcribing to text, and then alertly and carefully reading the text to apply codes to events, actions, processes, and phenomena (Charmaz, 2002). The data collection of recorded interviews with participants and initial analysis phases proceeded simultaneously. A description of the qualitative methods and the steps that guided and informed the analysis of the data are provided later in this chapter.

Moving back and forth between conducting interviews and analysing data ensured the development of codes and constructed themes were continuously checked by participants (Charmaz, 2002; Morgan, 2008). This process helped the researcher to further develop and refine the interview questions based on the developing themes constructed from the participant interviews. For example, in this study many families described themselves as either neurotypical or atypical families (feeling different to others or not) and talked about how this perception impacted family relationships. The initial analysis of this data generated the development of high-level categories and questions for use with subsequent participant interviews (Braun & Clarke, 2006). These categories were then refined and elaborated on until no further data collected from participants provided additional insights relevant to the research question and research aims.

Design and Approach to the Interview Guide

Whilst the aim of the thesis is not to address what the best methodological approaches are for including participants from an autism or, more broadly, from a disability perspective, to accommodate those who have communication and/or intellectual challenges, it is appropriate to include a description and rationale for the communication methods employed in the research for data collection with participants with autism and communication or intellectual challenges. This is provided in the proceeding sections.

An interview guide was followed to make sure the research question and research aims were addressed. The initial interview guide was developed by drawing on the literature and the expertise of the family advisory group. A copy of this interview guide is provided in Appendix F. The interview guide lists broad, open-ended questions on topics related to the research question and research aims; these questions were asked of all participants. The topics covered were family relationships, family interactions and communications, family identity, positives, and strengths of being a family, and services families accessed. The topics avoided imposing preconceived concepts of family identity, relationships, and interactions on the participants.

Whilst each participant group covered the same topics, the style and approach of the interview guide was adapted for siblings and young people with autism. These adaptions to language and phrasing of the questions included adjusting or simplifying questions to suit some of the younger study participants. An augmented, modified picture-based guide was developed for young people with autism with communication differences and/or intellectual disability. A sample of these interview guides is provided in Appendix G. In all interviews, prompts were used to explore experiences in greater depth, including family identity, relationships, and interactions. Open-ended questions encouraged families to share their experiences and stories, captured in their own words.

The approach to the interview guide meant that all young people could choose how they wanted to explore the interview themes and answer the interview questions. They were able to choose from a range of activities within the interview setting, such as drawing family trees, using strengths cards, drawing timelines, or using other creative strategies to help them address the interview questions.

When a participant began exploring other areas of their lives that deviated from the research question and aims, the researcher listened and supported them through providing a safe space to share, in line with established participatory methods (Bergold & Thomas, 2012). The researcher then asked the participant how that area or experience in their life they were sharing might connect with or relate to the topic of the study.

The interview guide was designed to conclude the interviews by asking participants to explore or identify any positives and strengths about autism in their lives and, if not, to identify areas that could be enhanced or improved in their lives. Wishes or hopes for the future were discussed with young people, closing with their top three wishes and hopes and what they would do for families with a young person with autism if they oversaw a program in Australia developed for families.

Using the Interview Guide to Collect Data

Interviews with participants were informal and conversational, and further questions were asked to support participants to develop their responses. Interviews with parents generally began with sharing something about their family, their background, and circumstances, including why they wanted to be involved in the research. Most parents used similar ways to share information, usually beginning by describing their life before their child was diagnosed, through to diagnosis, the impacts of autism on the family, their experiences with schools, services, and support, and then their current life. Questions and prompts arose naturally as parents shared their experiences of autism and family relationships.

Interviews with young people required a more structured question and response method; however, most young people, once talking and comfortable, appeared to relax into talking openly and freely. The interviews were conducted in a flexible and sensitive way that was respectful of the age, circumstances, capacity, ability, and interests of young people. Three key interviewing principles were adhered to during each interview to minimise distress and achieve constructive outcomes. These were minimising power dynamics/restoring control, providing information, and communicating and presenting warmth (Campbell et al., 2010).

Guided by these three principles, interview techniques to facilitate in-depth descriptions included using positive and encouraging body language, non-verbal affirmations, active listening, and paraphrasing to confirm understanding of what was said. For young people with autism, activity sheets titled “All About Me” and drawing were used as methods to begin the interview and to establish rapport between the researcher and young person. This included the researcher asking the child a series of questions about their strengths (e.g., what are three nice things people say about you, or what are three things you are good at and Enjoy). Young people were offered the opportunity to interview the researcher, taking turns to ask some questions; this technique helps limit power dynamics and establish some rapport (Moore, 2012; Moore et al., 2016). It was important to acknowledge participants' sharing of their stories and the experiences they had disclosed during the interview, and to close on a positive element of discussion. By doing this, the participant was ideally left with a positive or neutral feeling, as opposed to closing on a negative or difficult time or event in their lives, potentially leaving the participant with some level of distress.

Collecting Data From Young People With Intellectual Disability

In total there were four young people with autism with intellectual disability who each required customised interview questions, methods of data collection, and interview techniques. Prior to these interviews the researcher met with each family to workshop modified questions for the young person with autism with accompanied intellectual impairment. Each young person had diverse needs in terms of their communication, comprehension, and sensory input/behaviours. A process was followed in these meetings: to listen, acknowledge, learn, adapt, and apply; actively listen to what families and young people shared; acknowledge participants' expertise; learn by example; adapt to new environments and people; and apply expertise and knowledge.

Each family decided it was important that a parent was either involved with the interview of the young person with autism and intellectual disability or remained in the same room during the interview. Each family expressed unique reasons for this, including behaviour management and assisting with phrasing and interpretation of questions asked to the young person. The experiences of collecting data from these four young people are provided below.

After meeting the parent of one young person with autism with intellectual disability and the young person themselves, they both agreed to take part in separate interviews. The mother mentioned that the young person would probably not engage with the researcher, and they would have to “work hard for it,” as the young person was not usually open with people they did not know and building up long-term relationships was important for this individual. This was observed when engaging with this young person, who was happy to have an initial “ice breaker” conversation but then moved to repeatedly saying “bye-bye, bye-bye, bye-bye.” This was one of the very brief interviews.

For another family with a young person with autism and intellectual disability, the family asked to see the questions before meeting, as they wanted to check if they were suitable and appropriate for the young person. The family deemed the questions appropriate and suitable, but with some syntax and prose modifications. The mother of this young person explained that their son processes information visually and by association, which contrasts with a linear thinking style (Grandin, 2009). The young person would need to relate questions back to specific incidences or events in their life to form an answer to a question. During the interview process the young person was given additional time to respond and was supported by their mother, who asked them the same or a similar question but in a modified or *associated* way, including using different key words to assist the young person to answer the question. A description of this processing style is captured in an example used by Grandin (2009, p. 1):

> My mind is associative and does not think in a linear manner. If you say the word "butterfly," the first picture I see is butterflies in my childhood backyard. The next image is metal decorative butterflies that people decorate the outside of their houses with, and the third image is some butterflies I painted on a piece of plywood when I was in graduate school. Then my mind gets off the subject and I see a butterfly cut of chicken that was served at a fancy restaurant approximately 3 days ago. The memories that come up first tend to be either early childhood or something that happened within the last week.

Some people with autism are echolalic, a term that refers to "…a meaningless repetition of the words of others" (Grossi et al., 2013, p. 1). This can occur when asking people with autism questions and is often associated with frontal lobe impairment (Grossi et al., 2013). Additionally, some individuals with autism are thought to lack a *theory of mind*—that is, an inability to infer emotions and thoughts in others. This was conceptualised initially as *mind blindness* (Baron-Cohen, 1991, 1995). Further research has indicated that some individuals with autism lack introspective self-awareness or self-related processes (Morin, 2011). This is demonstrated when some individuals with autism are asked the question, "What are you going to do tonight?" In this question, the "you" is interpreted and processed as referring to the person asking the question, not the person the question is being directed at. This was evident in discussion with some of the families who had young people with autism with intellectual disability.

One family stated that their young person with autism had accompanying brain damage and was echolalic. Additionally, the young person preferred very concrete single-faceted sentence structures and not open-ended questions that are most often associated with qualitative research (Crotty, 2018). Some people with autism can have difficulties when asked open-ended questions; therefore, providing structure to an otherwise abstract question or task can be helpful for them (Watson et al., 2013; The Watson Institute, 2019).

An example to illustrate the sort of difficulties that could come up with open ended questions includes, “What do you like about your mum?” would elicit a response of silence. However, asking the question, “Is mum nice?” would elicit a “yes” response or a “no” response. Following that question with, “Why is mum nice?” would elicit the response, “Nice mum”. It is important to note that echolalia and difficulties with open-ended questioning do not always signal a lack of understanding or comprehension. It may be the young person’s way of saying, “I don’t want to answer this question,” or, “I do not have a response for you.”

These are some examples of the challenges of using a standard qualitative research design when engaging with young people with autism and those with an intellectual disability. A further challenge is presented when the young person is non-verbal or is non-verbal and only communicates with a specific picture-based learning and interactions. One young person with autism in this study was non-verbal, had high sensory needs, and communicated through a prescribed and specific language board, personalised to the individual’s way of communicating and processing information.

The language board was developed using an online vignette symbol program. The mother of the young person explained that the family uses the core vocabulary displayed on the board and uses folders to click through that give more options. To communicate with the young person, the family member speaks out loud as they point to symbols on the board and make signs and gestures with their hands. To interview this young person, the mother supported the researcher to communicate with the young person through their language board. The interview was a collaborative process that encouraged the researcher to listen, acknowledge, learn, adapt, and apply.

Data Collected for Analysis

Data in this study included information gathered using an interview guide with associated aides, follow-up emails, the researcher's reflective notes, and audio recordings, field notes and other documents used during the sessions with the participants. Memos and field notes written in a research diary as well as verbal recordings after interviews with participants helped the researcher document any observable bias, and to record thoughts and questions to pose to the research supervisory team for debriefing and supervision sessions, and to use for analysis (Morgan, 2008; Shaw & Holland, 2014; Van Manen, 1990).

All data collected were included in individual transcripts for each participant. The primary source of data available for analysis was data collected from the interviews. As verbal interviews dominated the data, the voices of young people with intellectual disability were overshadowed in the presentation of the findings. This methodological limitation is discussed in the section Study Limitations, Chapter 7.

Management of the Data

Data collected, predominantly interviews and field notes, were managed using the Nvivo 12 Plus program, which is software designed to collect, store, and analyse unstructured and non-numerical data. Data were also analysed manually in Microsoft Word and printed hard copies of the transcripts were marked with a highlighter and pen. After the initial rounds of analysis, the research questions and their respective *nodes* were input into Nvivo 12 Plus for ease of management and searching. Data were stored securely online in the university cloud server, and hard copies of all research documents were kept in a lockable filing cabinet on the Australian Catholic University Canberra campus.

Data Analysis

Qualitative data analysis works to construct or generate "…emerging themes, patterns, concepts, insights, and understandings" (Patton, 2002, p. 261). Qualitative studies typically construct an analytic framework, which is an arrangement of connected and interrelated concepts or categories to explain an essential process (Suter, 2012). The approach, and methods for data analysis in this study can be viewed as *bricoleur*, in that they merge compatible principles and methods (Denzin & Lincoln, 2000). Scholars recognise that borders between qualitative methodologies are permeable (Broadhurst & Mason, 2020; Charmaz, 2014; Starks & Trinidad, 2007). In merging harmonising principles and methods, this study recognises the limits of any individual approach to qualitative research, and that individual approaches might not fit exactly with the requirements of a particular study's data collection and analysis processes (Broadhurst & Mason, 2020).

To acquire an understanding of the meaning of the perceptions and experiences of young people with autism and their family members, an approach to data analysis utilising systematic, detailed, and rigorous procedures was required, consistent with a phenomenological strategy of balancing objective and subjective approaches to knowledge production (Moerer-Urdahl & Creswell, 2004; Moustakas, 1994; van Manen, 1997). This was achieved by using recognised techniques for qualitative and hermeneutic data analysis.

Individual interviews facilitated an analysis of connections or intersections between stories, capturing both an individual subjective version and an overarching family perspective. This enabled some information from multiple interviews to be analysed together and some information to stay separate (Eisikovits & Koren, 2010) i.e., the interviews were analysed within individual stakeholder groups and then compared and analysed within a family unit and then compared between the 18 families.

Ongoing consideration was given to designing and selecting data analysis methods that upheld paradigm and method congruence (Denzin & Lincoln, 2017). This methodological triangulation (Annells, 2006) meant that analysis supported the epistemological and theoretical approach of the study, as well as meeting the criteria for the study's participatory methodology. This required the researcher to flexibly draw on multiple analysis strategies to address the research questions. These strategies aligned with the aims and objectives of the study, were suited to the study participants, and contributed to addressing gaps in literature (Bergold, 2007; Coburn & Gormally, 2015; Levy & Thompson, 2015; Scholz et al., 2019). Mixing and matching qualitative approaches and methods is becoming increasingly common and can bring new synergy; however, clarity in presenting the methods is critical (Denzin & Lincoln, 2017).

The analysis of the data for this study aimed to generate common themes as well as report on divergent views and experiences that emerged throughout the dataset, with a focus on "…close qualitative engagement with the experience" (Broadhurst & Mason, 2020, p. 18). This was achieved by ongoing engagement with and immersion in the data, with a focus on the experiential features of participants' intimate first-person accounts shared throughout the interviews (Gallagher & Zahavi, 2008). This produced a collective experience of the meaning participants attached to the phenomena (see, for example, Eberle, 2014; Gallagher & Zahavi, 2008; Giorgi, 1997; Moran, 2000; Moustakas, 1994; Polkinghorne, 1989; Sokolowski, 2000), but also allowed for divergent viewpoints and experiences to be captured and presented.

Once the data are collected, an interpretivist researcher can use a relativist method to analyse the data. Thematic analysis, grounded theory, or phenomenological analysis are approaches to data analysis that report on findings about participants' experiences and meanings base on the life worlds of study participants (Creswell, 2013; Laverty, 2003; Saldaña, 2011). In this study, the aim was to generate *thick* descriptions for an in-depth understanding of how the study participants made sense of and experienced the impacts of autism on family relationships. The term thick description refers to a focused and detailed account of study participants' lived experiences, events, or situations (Denzin, 1989). Specifically, the researcher seeks to describe in detail social contexts and experiences that are rich and meaningful, with an emphasis on emotional substance, attempting to illuminate the world of the participants under study (Suter, 2012).

This study employed grounded theory and phenomenology concepts, processes, and techniques to arrive at findings, which are presented as themes, from a thematic interpretation of the data. Illustration of the global themes from thematic analysis was aided by thematic networks (Attride-Stirling, 2001). The remainder of this chapter describes the concepts, processes, and techniques used in this study. The global themes and write-up of the findings from analysis are provided in Chapter 5.

Thematic Analysis

Thematic analysis (TA) is a qualitative method that can be applied across a range of epistemologies, interpretive frameworks, and research questions (Braun & Clarke, 2014; Charmaz, 2006; Lorelli et al., 2017; Nowell et al., 2017). TA is used to identify, analyse, organise, describe, and report on themes generated from datasets (Braun & Clarke, 2006). While providing methodical systemisation to textual data, it also allows for a deep and rich exploration of a dataset's underlying patterns (Attride-Stirling, 2001).

TA can account for the "how" and "why" of a phenomenon in phenomenological studies, and it can be used to scrutinise the factors that reinforce, influence, or contextualise specific processes or phenomena, such as those observed in grounded theory studies (Braun & Clarke, 2019). Consequently, TA offers the potential to address a variety of research questions and the potential to do so under a variety of different approaches (Braun & Clarke, 2019). TA, with the aid of thematic networks (Attride-Stirling, 2001, p. 386): "…web-like illustrations (*networks*) that summarize the main *themes* constituting a piece of text", was the primary tool applied to analysis of the data in this study. Thematic maps are used in the presentation of the present study findings as an organising tool to clearly depict analysis and facilitate communication and understanding for the reader (Attride-Stirling, 2001).

Applying Phenomenology Concepts and Processes to Data Analysis

Concepts and processes for phenomenological analysis (Moustakas, 1994; van Manen, 1990) helped to generate meaning from findings, and to contribute to knowledge about how young people perceive and experience autism. A phenomenological approach guiding the thematic analysis ensured the focus remained on participants' subjective experiences and sense-making (Guest et al., 2012; Joffe, 2011). Thematic analysis has long been applied in phenomenological research due to its robust and methodical systematisation of textual data (Dapkus, 1985). From a hermeneutic phenomenological approach, thematizing meaning from interpretation of the data highlights the essential meanings reflected in participants' lived experiences (Ho et al., 2017; van Manen, 2016).

Applying Grounded Theory Processes and Techniques to Data Analysis

Iterative grounded theory processes and techniques informed and guided the data collection and methodical analysis in this study. A grounded theory approach to data analysis is focused on developing original knowledge constructed from data (Oktay, 2012) to generate conceptual understandings of the phenomena being studied, which are rooted or "grounded" in the specific research process and social context (Charmaz, 2008, p. 398; Charmaz, 2014, pp. 10–11; Ritchie & Lewis, 2003, p. 12). The constructivist style does not view theory as something emerging from the data in an observable sense; rather, it is the researcher who actively constructs, categorises, and draws meaning from the data (Charmaz, 2008, p. 402).

Knowledge that is grounded is "…inductively derived from the study of the phenomenon it represents" (Strauss & Corbin, 1990, p. 23). In this study, grounded theory methods drove the iterative process of data analysis, generating the global level themes and organising themes (Strauss & Corbin, 1998). A grounded theory approach to data analysis is characterised by its emphasis on staying close to the data, and involves the use of constant comparison of cases, incidents, phenomena, persons, and events to uncover social processes (Strauss & Corbin, 1990).

The analysis of social processes and the specification of relationships between conditions, actions, and consequences are what sets theory apart from description (Strauss & Corbin, 1990). This means focusing on issues that are of greatest concern to the research participants to account for their patterns of behaviour (Glaser, 1998; Glaser & Strauss, 1967; Glaser, 2014). This strategy helps to minimise the influence of other knowledge when coding and generating themes, and ensures the data are grounded in participant experiences.

Incorporating grounded theory processes in the analysis of the data in this study assisted with building findings that were "…faithful to and illuminated the area under study" (Strauss & Corbin, 1990, p. 24). This was of particular significance given the history of those with no lived experience of autism often speaking for or behalf on people with autism (Boxall & Ralph, 2009; Milner & Kelly, 2009; McDonald, 2015). The use of thematic analysis informed by grounded theory processes is informative for social research with certain cultural groups, or groups of people who are marginalised or stereotyped (Charmaz, 1990; Heydarian, 2016), such as people with disability or people with autism, who are among the most marginalised groups of people in society (Agmon et al., 2016).

As the data collection of recorded interviews with participants and initial data analysis phases proceeded simultaneously, ideas and themes developed during interviews with participants (Charmaz, 2002). It is at this stage of simultaneous data collection and analysis that attempts are made to seek out *deviant* cases, a grounded theory method where the researcher seeks out instances in the data which contradict an emerging hypothesis (Seale & Silverman, 1997).

In the current study, specific participant groups were sought out and asked direct questions. Their responses were then checked for, or tested against, a hypothesis in the data analysis phase. This involved asking participants either direct or closed questions. For example, "Other parents have told me that having a child with autism is draining and exhausting. Is this your experience?" This strategy was employed as an attempt to counter or refute a theory, or the themes generated from the collection and analysis of data; in turn, it was able to strengthen or confirm the developing themes or theory (Charmaz, 2002).

In addition, grounded theory offered a systematic approach for capturing, recording, ordering, and handling the complex dataset. A structured approach to the analysis was both welcomed and required, as a hermeneutic phenomenological approach to data analysis has limited formal processes, and phenomenologists place great emphasis on the interpretive processes that are embedded within lived experience research (Danaher & Briod, 2005). Whilst hermeneutic phenomenology is a dominant qualitative research methodology across many academic disciplines (Tuffour, 2017), its processes have been queried by some scholars (e.g., Giorgi, 2020) for their obscurities and lack of standardisation. The procedures of grounded theory were used to help address the complexity of the large dataset, as well as to limit some of the obscurities of the hermeneutic phenomenological processes.

Reflexive Journaling as a Data Analysis Tool

Reflexive journals operate as analytic memos when constructing grounded theory (Charmaz, 2006); they can be useful when working through the analysis of the data and may inform initial patterns, themes, and concepts (Saldaña, 2011). In this study, reflexive journaling was performed after each interview with a participant, using pen and paper as well as audio recordings to capture information quickly and in situ. Journaling included documenting initial impressions of the interview and participants' moods, emotions, and body language. It also recorded initial reactions to what the participant shared, and the researcher's feelings towards this; connections with professional practice or personal life; and reflections on the physical environment, and any impact this may have had on the participant or the research (Saldaña, 2009).

The logging of ideas during data collection and initial analysis phases assisted in the development and refinement of themes at later stages of the analytical process. Reflexive journaling also helped to transfer thoughts to concrete form, and journaling was used to record possible coding ideas (Braun & Clarke, 2006; Saldaña, 2009). This was particularly useful in supporting the iterative approach to data collection and analysis (Strauss & Corbin, 1998) as data analysis phases progressed from one to the next (Charmaz, 2006). The three main data analysis phases are now described in detail.

Phases of Data Analysis

Phase 1

Phase 1 began with transcribing each interview and then reading and re-reading the transcripts multiple times to gain familiarity with and immersion into the dataset (Rubin & Rubin, 2005). After this was completed, a process of *complete coding* was conducted on each individual data transcript (Smith et al., 2009). Complete coding is a hermeneutic analysis technique which requires the researcher to record comments, including descriptive, semantic, and abstractive comments, as well as identifying initial themes, assigned line-by-line to each transcript (Smith et al., 2009).

This process was conducted initially to find "…anything and everything of interest or relevance to answering [the] research question, within [the] entire dataset" before applying a targeted eye to the analysis process (Clarke & Braun, 2013, p. 206). Adopting these processes early meant the data were initially managed openly, with knowledge and research literature put aside throughout analysis until concepts and categories began to emerge from construction of the data (Gibbs, 2018; Moustakas, 1994; Oktay, 2012). This also helped to avoid any data being overlooked and drew attention to divergent views or experiences (Clarke & Braun, 2013).

The phenomenological process of epoche (Moustakas, 1994) helped suspend any researcher bias throughout the initial coding stages, before turning to the literature, and reflexive journaling helped in continuing to manage this throughout the study. Coding was then informed by the detailed literature review, complementing the openness to participants' accounts of autism and family relationships and how they were organised and described.

The results of the complete coding process across 44 transcripts (incorporating data from all sources, including information gathered using an interview guide with associated aides, follow-up emails, the researcher's reflective notes, and audio recordings, field notes and other documents recorded during the sessions with the young people and families) generated a significant number of statements, comments, and initial codes. These were then grouped together and labelled as initial basic themes grounded in participant language (Charmaz, 2006; Gibbs, 2018; Oktay, 2012; Starks & Trinidad, 2007).

After this process, family dyads (sibling, parent-child, partner) were selected and separated, and another initial round of sorting and organising was undertaken. Once this was completed, a timeline, or storyline, of family events was collated into a collective experience, constructed in Nvivo. This captured an overarching representation of families' lives in the context of autism; from this, key transition periods throughout participants' lives were selected for further examination. This process served a practical purpose by helping to manage, sort, and make sense of the complex dataset, as well as a theoretical purpose, by helping to generate ideas around initial codes and the development of themes.

Once the data were sorted and organised into a timeline or narrative of families' lives, sections in the dataset that related to the research question and aims (i.e., that focused on family relationships) were then highlighted for a round of deeper analysis and reflection using selective coding procedures in phase 2 of the data analysis, as described below (Bogdan & Bilken, 2003).

Performing an initial in-depth examination of each transcribed interview assisted in the development of a detailed overview of, and connection with, the data. This process also helped guide the phenomenological processes of horizontalization and textural-structural descriptive synthesis of the accounts of young people with autism (Moerer-Urdahl & Creswell, 2018; Moustakas, 1994).

Horizontalization, defined as "…the grounding or condition of the phenomenon that gives it a distinct character" (Moustakas, 1994, p. 95), was used first. This involved selecting significant statements from the transcripts related to the experiences of young people with autism (Moustakas, 1994). These statements presented a range of perspectives from the young people with autism and family members (Moustakas, 1994).

A textural-structural synthesis presents a narrative to the reader of the textural "how" and structural "what" of the experience of research participants; in this case, the experience of being a young person with autism (Moustakas, 1994). The textural-structural synthesis was constructed from the interview transcripts of the young people with autism. This is a process through which the researcher blended the voices of the young people with autism with the researcher's knowledge. Participant member checking confirmed that these were reflective of the young people's perspectives and experiences.

Performing an initial in-depth examination of each transcribed interview also helped to focus on relationship factors in the data and sift out other indirect or tangential participant quotes. These were set aside or *parked*, to be return to in the future to check for any meaning or connection with codes or themes constructed during more advanced analysis phases. Many quotes set aside were utilised in later phases of analysis. This helped provide additional context discovered via the process of *zigzagging*, a term which refers to the identification of alternative patterns of thinking and drawing links between "seemingly unconnected" points across the data (Patton, 2002, p. 514).

The analysis then proceeded to more selective *compare and contrast* coding methods; these are used in grounded theory studies and were applied across the entire dataset (Smith et al., 2009). Selective coding focuses on specific parts of the data of importance to the researcher when attempting to address the research question (Clarke & Braun, 2013). This second phase of the data analysis, guided strongly by grounded theory processes, is now described.

Phase 2

Phase 2 focused specifically and attentively on the research question and aims; in this phase, an iterative process was used to arrive at a result by repeating rounds of analysis (Strauss & Corbin, 1998). The objective was to bring results closer to discovery, with each repetition (iteration) presented as global-level themes. The grounded theory staged approach put forward by Harry & Klingner (2005) guided and informed phase 2 of the data analysis. The staged process is detailed below.

Open coding is the first step to analysis, where data are divided into segments and then scrutinised for commonalities that reflect basic codes or developing themes. As common themes are identified through the analysis of data, divergent viewpoints and experiences are also identified and highlighted. As detailed above, once the initial complete coding across the dataset was conducted, each transcript was read through again with a focus on insights connected to relationships. It was helpful to code rather quickly, line by line or in sections of text, including sentences and paragraphs, and to not over-focus on deep thinking whilst coding, especially during the first read through. This helped limit the forcing of codes. It was important to not jump to abstract theoretical levels and to treat the early codes as questions to further explore as analysis continued.

Axial coding is a procedure for exploring relationships amongst the codes or themes (Strauss, 1987). This involved focusing in on relationships and connections between the basic codes or themes and causal or intervening conditions to create the organising themes. The organising themes create meaning and context for the basic themes. For example, in this study, themes of “atypical identity” and “feeling different” were driven by “attitudes to autism” and “stereotypes and stigma.” Here, the relationship of basic codes and themes was explored by making initial connections between them to organise them (Patton, 2002).

Selective coding is the process of selecting central codes or global themes to generate a narrative that links with the other themes. Here, selective coding involved linking the global themes to other organising themes, checking for the flow of logic between the initial coding of the data to arrive at the basic themes, connecting the basic themes to create an organising theme, and then generating global themes that held or brought out the essence of the data (Attride-Stirling, 2001). Global themes summarised and captured the key concepts that affected participants’ experiences. A sample of basic themes maps is provided in Appendix H.

Thematic network maps (Attride-Stirling, 2001) were used to construct a visual of the above process and aid as a final visual summary presentation of the global themes identified throughout the findings presented in Chapter 5. In this stage of analysis, multiple global themes of the phenomenon were generated, and a narrative that ran through the themes was constructed to uncover the social processes (Strauss & Corbin, 1990).

A process to ensure rigorous coding was used. This included the development and peer review of the codes by the research supervisory team. This process checked that data had not been misinterpreted and that researcher bias was addressed. The supervisory team read through the data multiple times, verifying the codes and themes for reliability and validity. Following these discussions, changes were made to focus more on subsystems and dyads within families and their dynamics, interactions, and connections between each other. This resulted in bringing the data closer to the research question and led to a heightened level of analysis.

Discussions took place with the research supervisory team to confirm interpretations and settle on the global themes. The family advisory group checked these findings for meaning and significance with families' own understandings of their experience (Broadhurst & Mason, 2020).

Phase 3

Conducted alongside the staged inductive analytical process described above, a thematic analysis technique called *pattern matching* (Trochim, 1985, 2000), a process to align data to theoretical propositions, was conducted. Pattern matching offers value for managing and analysing complex datasets (de Vaus, 2009; Yin, 2009).

As the grounded theory processes employed in the present study developed through inductively generating codes and themes constructed from observation data (Strauss, 1987), pattern matching was a valuable procedure as it "…always involves an attempt to link two patterns where one is a theoretical pattern and the other is an observed operation one" (Trochim, 2000, p. 73). This involved asking the questions, "Here's an idea, what does it mean? Can it be confirmed or rejected? What are contrary, competing explanations? Can they be ruled out?" (Suter, 2012, p. 365). This helped to make sure data was theoretically supported and informed, and that it was not driven by searching for specific outcomes (Charmaz, 2006).

Searching through and reviewing the dataset section by section, constructed theoretical themes were matched with emerging observational codes (Suter, 2012). This process helped keep analysis of the data aligned with the study's constructivist epistemology. As the data from multiple participants was worked and reworked, meaning was *inductively derived* (Strauss & Corbin, 1990, p. 23), and an understanding of the phenomenon present in participants' life worlds was developed theoretically from the "…subjective meanings of their experiences" (Creswell, 2014, p. 8). The analysis of the social processes and the specification of relationships between conditions, actions, and consequences are what sets theory apart from description (Strauss & Corbin, 1990).

In this final phase, this analysis, and interpretation of the constructed narrative (generated from phase 2 of the data analysis) is presented as a series of key study findings, informed by literature, and adding a conceptual layer to the global themes. The key study findings and a diagram illustrating the conceptual framework are provided in Chapter 6.

Data Validity

Validation strategies were used to maximise the trustworthiness of this study (Creswell, 2013). Experts (Creswell & Miller, 2013; Lincoln & Guba, 1986) recommend using three sources of data in research studies to meet the criteria for triangulation. Creswell & Miller (2000, p. 127) define triangulation as "…a step taken by researchers employing only the researcher's lens, and it is a systematic process of sorting through the data to find common themes or categories by eliminating overlapping areas. A popular practice is for qualitative inquirers to provide corroborating evidence collected through multiple methods, such as observations, interviews, and documents to locate major and minor themes." In this study triangulation from various data sources helped to verify the study's research methods, data collection, and theoretical framework, "…rather than a single incident or data point in the study" (Creswell & Miller, 2000, p. 127). Sources of data included interviews, activities/worksheets from interviews with participants, and observations to confirm triangulation of data (Patton, 2002). Codes and themes developed through analysis of the data were supported by the theoretical framework of this study. Furthermore, current qualitative and quantitative studies investigating family relationships and autism confirmed the emergent codes and themes generated.

Member Checking

Member checking ensured the interview transcripts were correct and valid (Moustakas, 1994). First, the family advisory group was invited to check and confirm that the literature reflected or resonated with their interpretation of their family experiences. Second, after interviews were completed, all participants in the research were sent a copy of their interview transcript and were invited to check it for accuracy to confirm and add credibility (Creswell, 2013). This step occurred again throughout data analysis. Third, participants were then given a copy of the initial construction of themes and were invited to give their feedback. Feedback was collected from most families on the accuracy of interview transcripts and three families provided feedback on the initial themes, expressing agreement with them. Email correspondence detailed participants' responses. One father responded: "I definitely can relate to these, and it is interesting to know that other families in the study share similar experiences to us." Another participant replied: "We certainly identify with these findings."

For the young people with autism and intellectual disability, member checking occurred in person with the researcher, the young person themselves, and their parent/s. As each family decided it was important that a parent was either involved with the interview of the young person with autism and intellectual disability or remained in the same room during the interview, it was decided that the process of member checking should occur in a similar way. Like the interview process, this was to assist with behaviour management with phrasing and comprehension and interpretation of questions asked by the researcher to the young person for the purposes of checking their transcripts for accuracy to confirm and add credibility (Creswell, 2013).

Chapter Summary

The research approach, processes, plans, and procedures employed in this study were managed in accordance with specific literature in the field of qualitative research design (e.g., Creswell, 2014; Creswell & Poth, 2018; Crotty, 1998; Gray, 2009). This chapter detailed the selection of a suitable methodology and tools for the design of this study. This involved several decisions and included exploring existing philosophies and theoretical perspectives behind the many ways of conducting research; procedures of inquiry (i.e., how the research could be best planned and implemented; and multiple and varying research methodologies and methods for data collection, analysis, and interpretation (Creswell, 2014).

Examining the research process led to developing a suitable research design for conducting research in real world settings (Gray, 2009), culminating in a novel methodological approach for research about autism and about relationships in families that have a member who is a young person with autism. In terms of the research design, phenomenology offered a suitable approach to the study, as it places emphasis on the meanings that people assign to phenomena.

This chapter demonstrated that by using an explorative inductive approach the researcher is positioned to discover the internal logic of the participant (Gray, 2009). The research aimed to "…explore and unpick people's multiple perspectives in natural field settings" (Gray, 2009, p. 27). Grounded theory offered a useful framework to approach the data. Examples of grounded theory concepts and processes employed in the study were theoretical saturation and constant comparative analysis, along with the constructed design of the research, which evolved during the research process because of data analysis suggesting new directions (Patton, 2002).

This chapter outlined how the approach to the research was influenced by multiple qualitative research approaches, methods, and analysis techniques that culminated in a constructivist, interpretivist model, framed by a relativist position, and which adhered to a qualitative participatory approach. Chapter 5 presents the findings of the research: the culmination and outcomes of the methodology and methods of this study.

Chapter 5: Study Findings

Introduction

This chapter presents the findings of the study. The findings focus on the insights from the perspectives of young people with autism, siblings, and parents, presented as global level and organising themes. The analysis of the data suggests that multiple core themes were common to family members within and across the 18 families that participated in the study. The themes capture the shared and diverse experiences of the 44 participants and are detailed with selected quotes from young people with autism and their family members. Additional quotes from participants that substantiate the findings further are provided in Appendix I. The use of detailed, contextualised direct quotations assists the reader to visualise, hear, and feel participants' perspectives and experiences.

Thematic network maps (Attride-Stirling, 2001) provide a visual presentation of the themes. The study findings conclude with an integrated version of all network maps of the study findings' global and organising themes. This provides a schema of findings about family members' perspectives on how autism impacts the relationships between family members, and the family as a unit (see Figure 7).

The findings provide a deep understanding of how young people with an autism diagnosis perceive and experience their condition within their family. They also provide accounts of family members' perspectives on how autism impacts relationships between family members, both negatively and positively, and the family as a unit. Finally, family members' perspectives on how external responses to autism impact on their family relationships are provided. To protect the anonymity of participants, pseudonyms are assigned to each participant, and these are used consistently throughout the chapter.

How do Young People With Autism Perceive and Experience Their Condition Within Their Family?

This section of the findings presents the views of the young people with autism. The findings are organised around one global theme and offer an insider account of being a young person with autism within a family. This account is considered in the context of family interactions and dynamics, and the relationships that the young people with autism had with their family members (e.g., mothers, fathers, and siblings). The young people's insights and experiences of autism within their family is presented in detail using illustrative quotations throughout the global theme of *Being different and feeling different to others*.

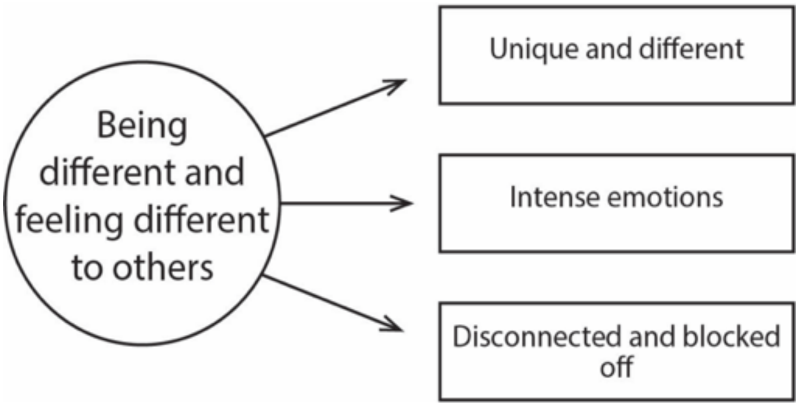
Global Theme: Being Different and Feeling Different to Others

Most young people with an autism diagnosis had an awareness of feeling different and being different to others without autism. Young people's experiences are reflected in the accounts of their interactions with family members. For some young people, feeling different was described as a disconnect from their family members and being in their own world. Most young people attributed their intense anger, stress, and anxiety to autism, and most reported times they were not in control of their behaviours. Just one young person with autism shared that although they identified as being "autistic," they still felt the same as other people who were not autistic. Figure 1 illustrates organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Additional quotes from participants that substantiate findings further are provided in Appendix I.

Figure 1

Network Map of Global and Organising Themes for Young People With Autism



Unique and Different

Each young person with autism had their own understanding and definition of the condition. Jim remarked, “I know what autism is, but it’s our own definition. It’s different for everyone.” Most young people recognise the condition in themselves and see it as a special part of who they are. Joanne shared, “I have autism, it’s a part of me. It makes me unique, and I know that this makes me special.” Nina wanted others to know that “if someone’s on the spectrum, they’re all different and special in their own way.”

Some young people described “being on the spectrum” as a different way of acting, thinking, feeling, and communicating. Ken explained that “autism just means I think differently. I act differently, some things I do can be different…sometimes I have different ideas…I think that's what makes me, and us, different." Feeling different was a shared experience reported by most young people with autism.

This also included all young people with autism with an intellectual disability. When asked if they felt different, Jake (a young person with autism and intellectual disability) replied with, "I feel different. Different to other kids." Lance understood autism to be a behaviour and explained why he felt different because of the condition:

> Lance: I do feel different. I have different problems. I have different struggles. It's not that autism is in your control, but I think behaviour to some extent can be adapted. I feel like it's [autism] something that can be worked around.

Joanne recognised autism as a part of her personality: "To me, it's an aspect of my personality that sometimes blocks me off, but sometimes also gives me greater insight into the world." Will understood autism "as a mental problem. It makes me feel a bit different to others, but I am not sure why." Some young people with autism drew a distinction between thinking, or knowing, they were different, and feeling different. Ken explained, "I feel different to other people, but I am the same. Even though I'm different on the inside, we're all the same. Everyone is a person."

Young people's sense of feeling different was influenced by those around them, without autism. Rory recalled he first noticed this difference in primary school: "I began to realise that I was different and strange and that the way that I behaved was very different to the rules of the other kids around me." Ken shared that despite feeling different to others, he considered this a positive characteristic of having autism: "I feel different. I'm actually proud that I'm different. I like it."

A few young people's understandings of autism were influenced by their parents' descriptions of autism. Jim recalled: "I remember reading that autism means selfishness. I asked Mum if I come across as selfish and we had a talk about how sometimes it's a bit 'My way or the highway' approach." When discussing the anxiety and stress they experience, Joanna recalled: "One thing mum said once, autism is a heightened form of anxiety because there's some sort of obsessive-compulsive disorder that comes with it, having to double check a lot of things."

Many young people with autism felt so different to others that it reduced their sense of belonging. Lucy explained: "I think that I am different, but I feel like I'm really different". I don't really feel like I belong." For Lance, being different to others without autism was something that used to affect him. Over time, Lance embraced his difference and dealt with his difficulties: "I do recognise and these days I do embrace my difference. I used to be self-conscious about it. I used to be upset about being different."

Intense Emotions

Emotions played a significant role in the lives of all young people with autism. Young people described the intensity of their emotional, social, and physical experiences resulting from autism. Because of the condition, most young people could not spend lengthy amounts of time with their family members. Nina explained: "After a while I find people a bit draining. I have to get away. It's not that I don't like the person, it's just that I need breaks to be on my own."

Many young people described the different ways that autism could make them act differently to others. Jim explained: "It can make you physically different in the way you act, and emotionally different, so you can become a lot more trusting of people, and you might have a lessened sense of judgement." Lucy explained that having autism is something that affects her emotionally, physically, and socially:

> Lucy: autism is something that holds me back. Emotionally, sometimes physically and socially. Sometimes I'll say something and then I'll be like, "I should not have said that." Sometimes I feel like I can't do something because I'm on the spectrum. I'd say that it's a way that perhaps autism makes me feel different from someone that doesn't have autism.

Many young people found it difficult to understand their family members' feelings:

> Lance: I find it difficult to read my parents' emotions. Ever since I've been a little kid, I've said, my parents are grumpy and talk in a kind of a strange, stressed way. I feel this kind of oppressive, stressed presence, but that feeling is in me. I don't really know what they're thinking or feeling, and that has caused a lot of strain and difficulty in the relationship.

Others, such as Joanne, thought that autism made it easier for them to connect with their family:

> Joanne: I'm very highly empathetic…Connecting with the world includes connecting with other people's emotions. It's especially helpful when I need to deal with [my brother] because he's highly emotional.

Most young people with autism shared the anger they experienced. Being angry led to frequent conflict between family members. Ken described one of the "downs" of family life was "having fights or you might not agree on something." Some young people with autism were aware of the impacts their anger had on themselves and others in the family:

> Ken: I can get really angry. I go from zero to Hulk mode in a few seconds. I try not to get angry. It's so hard, trying to figure out why. I can get angry about some little things like [my sister] asking me something when I'm focusing on something, and just getting infuriated.
>
> Lucy: My sister and I have our fights. More often than I prefer. Mainly started by me, but sometimes I start them for no reason. I don't know why I start them because I know I don't want to fight … I've just let the lion out of the cage, I can't do anything about that now, let's just let it run free. It's difficult to keep the lion in the cage.
>
> Nina: Sometimes I won't put things in the best way. I have a tendency to not really talk but, to lash out, and that's not the best way."

Disconnected or Blocked Off

Nearly all young people described feeling disconnected from their family members. For Joanne, this included not knowing "unwritten social rules" and how to follow them: "I'm not very socially good. I'm pretty sure there are a few unwritten rules out there that I still have no idea what they are and how on earth to follow them." Nina, as well, described not understanding these kinds of rules: "I do think that this world is still a puzzle to me, like how people act and how rules are."

Most young people found it difficult to relate to or connect with their family members. Lance explained that having autism creates a disconnect between himself and his parents:

> Lance: There is a sense of control and understanding and rapport that is vastly reduced.

> It affected the family dynamic in that you have a very detached kid who wants to follow his own interests. There was a disconnect, but also there was a lack of will on my part to make a connection. I didn't see any purpose in that. It did mean that I had a quite strange relationship with my parents.

However, a few young people found it frustrating that their family members did not understand, them:

> Lucy: He doesn't understand me, so I don't like to see him very often. I'd like him to contact me and want to talk to me, and want to invite me over to his place, to hang out and spend time together.

A small number of young people with autism and intellectual disability did not report these or similar experiences of feeling disconnected from their families. These young people focused on sharing what they liked about their family and the kinds of activities they enjoyed participating in with their siblings, such as swimming and watching TV. They also shared that they felt happy when they were out in the community.

The findings now turn to presenting family members' perspectives on how autism impacts the relationships between family members, and the family as a unit.

What are Family Members' Perspectives on how Autism Impacts the Relationships Between Family Members, and the Family as a Unit?

The findings presented here on the impact of autism on family relationships are derived from data gathered from family members of young people with autism. The section details the positive and negative impacts autism had on relationships between family members and the family as a unit. This section also highlights the experiences of families with a member who is a young person with autism and intellectual disability to draw attention to some of the differences between the families with and without a member who is a young person with autism and intellectual disability. Families' insights and experiences of autism within their family are presented in more detail using illustrative quotations across four global themes. These themes are *Growth in relationships through adversity* (partner dyad*)*; *Close relationships despite the challenges* (sibling dyad); *autism first, relationships second* (parent-child dyad); and *Our challenges, our solutions* (family unit). They are presented in turn below.

***Global theme: Growth in Relationships Through Adversity (Partner Dyad*)**

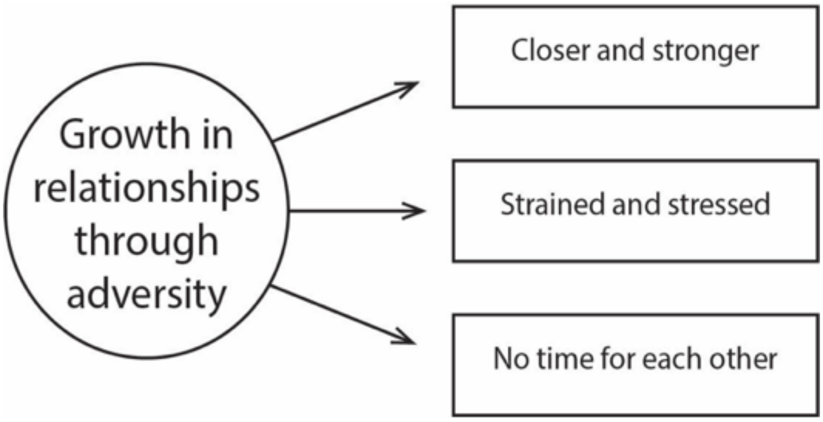
Couples experienced stress, strain, conflict, and disagreement in their relationships with one another, as well as significant challenges to spending time together, alone. Constant and intense parenting and caring responsibilities left couples with limited time together, and they experienced breakdowns in their communication with one another. Couples shared their feelings of emotional absence and distance from one another, and some felt forced to stay together due to a fear of parenting their child with autism alone.

In contrast to these challenges, some couples experienced an increase in their communication with one another and felt their relationship had become stronger. They reported feeling closer to one another, describing an awareness of the need to focus on creating special time together as a couple. Most couples experienced the impact on their relationship of having a child with autism as "a make-or-break situation"; these couples experienced growth in their relationships through the adversity associated with parenting their child with autism. Figure 2 illustrates the organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Additional quotes from participants that substantiate findings further are provided in Appendix I.

Figure 2

Network Map of Partner Dyad Global and Organising Themes



Closer and Stronger

For some participants, the relationship with their partner was strengthened by teamwork, sharing parenting duties, and making the effort to support each other. Maintaining communication and affection were key facilitators in couples' sense of closeness. Adam reported:

> Adam: My wife and I have always striven to stay on the same page. To co-parent, to keep each other informed, and to bolster the other one when we're feeling weak. We've always tried to maintain good communication because we know that we need each other for support because we don't have anybody else. We have to join to support [our child], and we have to support each other, and give each other cuddles.

Monica described the approach she and her husband took to supporting each other throughout the difficult times they experienced raising their children with autism:

> Monica: We've had our ups and downs and times of despair and that. But I must say when I go through despair my husband is a rock. And when he goes through despair, I find a solution. So, it's good that way.

Dennis reflected how an overfocus on his child caused relationship difficulties with his wife. This brought about an awareness for him to make time to strengthen his relationship with his wife, and he understood the situation provided an opportunity to build upon:

> Dennis: You have to do special things because you realise you are focusing so much time on [their] needs then that clearly problematises the relationship with [my wife]. I need to set aside time to strengthen that relationship. In an odd way it's the problem part of it that enables you to see that you actually have to build your primary relationships. It provides an opportunity to work on strengthening those relationships.

For most wives, the relationship with their husbands was strengthened by working together through difficult and challenging times, such as their child receiving an autism diagnosis. Margaret disclosed that the process of becoming stronger in her relationship with her husband happened over time. Once united as a couple, Margaret emphasised the rewarding outcome of working through the situation with her husband:

> Margaret: It took quite a bit of time for us to stop questioning where anything went wrong. You're looking for an excuse to blame something, to find an answer. But there is no answer. It's made us stronger as a couple. It can be a make-or-break situation. It tested us as a couple and seeing that we came through it, that's one of the really good

> things.

Janette disclosed that raising her child with autism and intellectual disability was an intense and challenging experience, which was shared with her husband. She reported that their experience was not discussed with or understood by many others, which contributed to an experience of increased closeness:

> Janette: It's made my husband and I closer because we have both gone through this pretty intense thing that it's hard to talk to a lot of people about, because not a lot of people understand what it's like. I think it's strengthened our relationship. When you are faced with something challenging, it either breaks you or brings you closer.

Strained and Stressed

Most couples disclosed the strain that autism placed on their partner relationships. For most husbands, the relationship dynamic with their female partner was characterised by disagreement or discord, stress, and overall greater difficulties. Dennis explained the impact on the bonds shared with his wife and having to work harder to maintain these bonds: "Having a son with autism and intellectual disability, there's the stress on the bonds that I have with wife, and it's that constant stress that means I'm having to work harder."

Greg reported on his wife's frustrations at being the only person in the family without autism. Greg reported his female partner's frustration arose because she did not understand how her family thought, which placed a strain on their relationship:

> Greg: My wife cannot understand how we think some of the time, she has got somewhat used to it, but it still frustrates her. She's the only neurotypical in the house, so it's a fairly big strain on her. This is a strain on our relationship.

For all wives, the relationship dynamics with their husbands were characterised by fighting, arguing, upset, stress, and breakdowns in communication. Cindy described the dynamics in her relationship as being "pretty rocky ... fighting, arguing, and not wanting to do this by myself."

Francene described the amount of stress on the relationship with her husband as "lots more" and Nairi characterised the relationship with her husband as "full of tears and full of shouting." For one family, receiving the diagnosis of autism for their child created an emotional distance between the parents:

> Margaret: Me and my husband went into a state of mind where we got a bit lost from each other, didn't know how to communicate to each other about it that well and discuss it as a problem. … It was a difficult time.

For two wives, their responsibility for most of the caring duties for their child with autism created physical separation, resentment, and emotional tension in their relationships with their husbands. For example:

> Cindy: I am the one that does the overwhelming bulk of looking after our child, while they go off and do fun stuff. It's had a huge impact on our marriage. Lots of resentment on my part about the unequalness of it. If it wasn't for our child, we probably would have gone our separate ways.

No Time for Each Other

Most husbands and all wives shared that time spent together as a couple was limited and was affected by autism. Husbands reported the impact on the relationship with their wives as a lack of downtime together. James reported that he and his wife never got to have time away together:

> James: We don’t get time together and that’s something that we should work on. We would love to get away for a weekend, but there’s so many issues from a practical point of view. I think even if we did achieve that, we’d spend half the weekend worrying. We’d be worrying about our son’s care and if he’s causing too much trouble.

For two husbands, time spent together with their wives was affected by the need to focus large amounts of time on their child’s care. Adam reported on the level of care required for his son, resulting in he and his wife taking turns to manage their son’s needs. This forced them to spend time alone which resulted in less time spent together as a couple. Adam noted: “Our son requires intensive maintenance when you’re having to constantly manage him. There’ve been times when I’ve just reached my limit and my wife had said, you just go off, I’ll take it from here.”

For most wives, managing time was a challenge as they juggled the emotional and physical needs of their child with autism. Janette explained that she and her male partner focused “so much time on his needs, the challenge is just making sure that we have time for each other.” Francene expressed it was difficult to spend time with her husband: “to share is tough, you spread yourself thin. Our relationship is really challenged with a child like this.”

Global Theme: Close Relationships Despite the Challenges (Sibling Dyad)

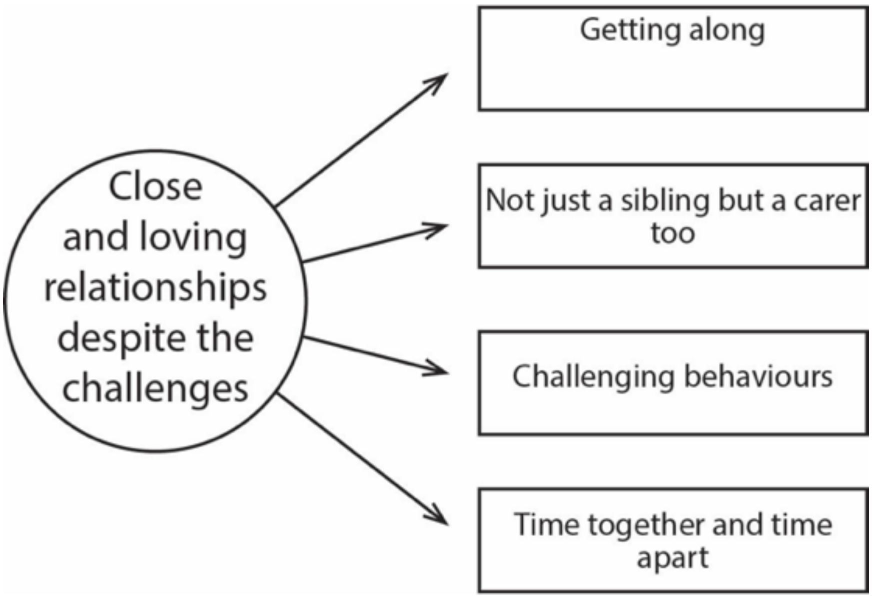
Siblings experienced a range of aggressive physical behaviours from their brother or sister with autism such as kicking, punching, and hitting, and verbal behaviours, such as swearing and arguing. Common challenges that impacted the sibling relationship included overexcitement and limited self-control, rudeness, and fixations or obsessions of the sibling with autism. Siblings expressed internalised frustration, a feeling described as “rough times,” usually when their brother or sister with autism acted unkindly towards them or was being difficult for all family members. Some siblings described “working around” their brother’s or sister’s moods, emotions, and behaviours, and reported that time spent together was short and unenjoyable. Siblings shared that because of challenging behaviours, they found it “hard to cope” living with their brother or sister with autism and needed time away isolated in their rooms.

Some siblings experienced a struggle to connect with their brother or sister with autism, including difficulties in relating to and understanding them. Most older siblings and a few younger siblings experienced additional challenges in the sibling relationship, such as caring for and looking after their brother or sister with autism. Siblings shared their worries and concerns for a future spent caring for their brother or sister with autism, particularly siblings with a brother or sister with autism and intellectual disability. Despite these concerns, most of these siblings experienced a relationship free from sibling rivalry or harassment. Notwithstanding the difficulties and challenges in the relationship, and siblings’ concerns about an ongoing caring role, all siblings expressed love towards their brother or sister with autism and reported “getting along” with them.

Figure 3 illustrates the organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Figure 3

Network Map of Sibling Dyad Global and Organising Themes



Getting Along

Families reported siblings as close to and protective of their brother or sister with autism. Despite the difficult and challenging relationship dynamics within the sibling relationship, all siblings reported that they got along with or loved their brother or sister with autism. For example, Sarah said, “We get along”; and Martina said, “We like to get along a lot”. Luke reported, “I get along with them great”; and Amandi said, “Me and my brother, we love each other. We actually get along really well.” Nearly all young people with autism reported liking, loving, or getting along with their siblings.

All young people with autism and intellectual disability shared that they liked their siblings and emphasised that they enjoyed doing activities with them, such as going to the zoo, catching the bus, going to the markets, and swimming. For example, Kevin said, “I like my sister. [I enjoy] going to the zoo [with her].” Jake reported, “I like my sister, she’s a nice girl. [I enjoy] going [to the] markets and catching [the] bus.”

Most siblings also shared examples of how much they enjoyed hanging out and playing with their brother or sister with autism. For example, Layla said, “My sister is really funny, she can do a funny voice and it’s really funny and she says jokes and she plays around, it’s a lot of fun, I like playing with her like that.” Chris shared that “[my sister] and [my brother] are my favourite people in my family.”

In most families, the sibling dynamic fluctuated based on the behaviour of the young person with autism and the interactions between siblings. Families with multiple siblings generally characterised the sibling dynamic as a typical sibling relationship, regardless of the brother or sister with autism. In most families with a young person with autism and intellectual disability, the sibling relationship dynamic was typically described as close and loving. Amandi described the dynamic with her brother:

> Amandi: [Our relationship] is a lot closer and has been for a lot longer than average. Longer than families if they didn’t have someone with autism and disability. We are really close as a result.

Some parents in families with a young person with autism and intellectual disability as a member described their siblings as being protective of their brother or sister with autism. Janette expressed an appreciation of her daughter’s attitude towards her brother, remarking that her daughter felt: “very positive about [her brother with autism] and very protective.” For the remaining families with a brother or sister with autism and intellectual disability, sibling relationship dynamics were absent of conflict or rivalry. Amandi reported on the absence of conflict in the relationship with her brother:

> Amandi: A lot of friends throughout my life are absolutely at their siblings' throats. They've always been complaining, "Oh, my sibling did this, they're so annoying. We had this massive fight, this, that, and the other thing." I stop and go I don't know what that's like. I don't really know what it's like to fight as siblings.

Not Just a Sibling but a Carer too

Nearly half of all families described a sibling relationship dynamic that differed from a typical sibling relationship. In families where boundaries between siblings were clearly defined, sibling relationships presented as typical. In families where boundaries between siblings were not clearly defined, the sibling without autism took on an additional or alternate role that included being a carer or a parental figure.

Families reported the relationship between siblings as strange, interesting, and different. Eileen described her relationship with her brother as "a bit of a strange relationship because I feel like when he does bad things, I also tell him not to do it even though he's older than me." Daryl characterised the relationship between his daughter and son as "interesting" because "Jemma will mother him [brother with autism] and look after him and forgive him for any of his poor behaviour choices that he may annoy her with."

All families described caregiving duties as a challenge to the sibling relationship. Amandi shared the challenges she experienced in caring for her brother with autism and intellectual disability:

> Amandi: It's probably I to think that it is a different relationship because it's really not,

> because I am very much his carer. Challenges would be the fact that I do genuinely have to look after him. If I'm looking after him, I can't just sit down and do my work and let him do his thing. I need to make sure he's staying out of stuff. I need to make sure he gets fed.

Amandi reported on her two roles in the relationship, one as a carer and one as a sister:

> Amandi: I automatically shift into a caring role, but not in a bad way. Not like I'm just his carer and not his sister. I was happy to look after him, he's, my brother. I love him and from quite early on I knew how to look after him.

In most families with a young person with autism and intellectual disability concern about siblings' future care responsibilities for their brother or sister weighed on family members' minds. Eileen explained she wanted balance, seeking to have a "normal life" and see her brother:

> Eileen: I still want to be able to see [my brother] a lot but also have a relatively normal life when I leave home would be good. I guess just being able to have my own place and grow up and do usual things and have kids and have a job. I'd like him to be part of my life, but I wouldn't have to always be taking care of him.

One parent expressed concern about a sibling's possible future disengagement from the family system because of the caring she was providing for her brother. Monica (the mother) really hoped that her daughter "doesn't get sick of it all and run away when she gets older."

Challenging Behaviours

Nearly all families with siblings disclosed a range of challenging behaviours that characterised the sibling relationship dynamic. All siblings reported their brother or sister with autism purposely kicking, punching, or hitting them, often accompanied by verbal outbursts, such as swearing.

Some families reported that autism played a significant role in the number of arguments between siblings. This affected how siblings felt about their brother or sister with autism. Sarah reported:

> Sarah: [My sister] gets too much sometimes. She has autism so she’s not always going to be like a normal sibling, because we have a lot of arguments. I reckon if she didn’t have as much, autism, like she didn’t really have autism, then I reckon we could definitely prevent more arguments. Because sometimes I really don’t like her, at the time.

Eileen said her sister can be “really rude and mean, she swears at me a lot. When she’s being mean she’ll say very unnecessary things and kick and punch at me.” Sarah described physical and verbal conflict with her sister:

> Sarah: He used to hit me and kick me a lot which I was kind of fine with, I just hit him back or fight him. He does a lot more verbal stuff now and I don’t like that, like swearing at me.

Will, describing his brother as “difficult,” said that his brother “jumps on me and attacks me and swears at me.” Parents also described how physical behaviours impacted their children’s relationship. Tamara (mother) shared that her daughters “don’t typically get on well … she kicks her sister … take it too far and push[es] her sister off something.”

Many parents and some siblings reported that overwhelming stress led to meltdowns, escalations, frustrations, and self-harm. Amandi shared that her brother “can tell when someone loses their patience with him [due to stress], and he will escalate." Several families disclosed the impact anger had on the sibling relationship.

Families reported a variety of irritating behaviours. For example, Judy (mother) described her child with autism as "picking at his sister or pulling his sister up on something." Kate (sibling) said about her brother: "He does things not because he's trying to be annoying, and some of the things he does aren't just because he's a brother, it's because he's got a couple of things going on, autism is one."

Time Together and Time Apart

Most families disclosed the negative impacts autism had on the time siblings spent together. For families with one sibling dyad, the sibling dynamic was often described by parents as fraught with difficulty. Families reported that siblings isolated themselves or needed time apart from their brother or sister with autism.

Many families reported that the behaviour of the young person with autism was the primary reason why siblings retreated. Daryl (father) reported that his daughter without autism found it "very hard to cope sometimes; it's hard to cope with someone always trying to invade her space." Nairi (mother) mentioned she was trying to find her daughter respite away from her brother with autism: "With her anxiety now, his behaviour sincerely impacts on her. She is needing a lot more respite herself."

Some siblings felt torn, wanting to spend time with their brother or sister with autism but feeling they had to stay away to avoid arguments. Sarah shared that she wanted to be able to spend more time peacefully with her sister with autism:

Sarah: I want to spend more time with my sister, like peacefully. I would be here on

> the couch doing things, but I'm afraid that my sister is going to say something to me, and I won't either want to answer it, or feel the need to answer it. So that's why I go to my room. I'm scared that she's going to yell at me or do something. I know there's going to be an argument.

A few families reported on erratic, repetitive, or obsessive behaviour that impacted on the quality of time that siblings spent together. For some families, the repetitive or obsessive interests of the young person with autism limited the types of activities siblings could share and impacted the enjoyment for some brothers and sisters. Eileen reported:

> Eileen: I'll do things with him like go on the trampoline. He'll really want me to do it. … But it's not that fun to go on the trampoline 50 times a day. Some things that he wants to do, I don't necessarily want to do. Sometimes I do it and sometimes like, no!

For a few families, unpredictable behaviours impacted the time siblings spent out together in the community. Cindy (mother) shared: "It's hard for him to take his brother [with autism] out because he gets worried about what he's going to do. He'd run off into the traffic, it's about his safety, he was unpredictable."

Siblings across several families reported on the difficulty of understanding and connecting with their brother or sister with autism. Siblings described ambiguity or uncertainty in the relationships with their brother or sister with autism. For example, Eileen said, "I guess I get along with my brother. Sometimes, I don't know, I just exist with him." Kate reported, "I've struggled to connect with them ... I still don't quite get that perspective." Amandi recalled the presence of her brother whilst growing up, but the absence of a playmate:

> Amandi: Growing up I was like, "My brother has a brain problem, so I don't have

> anyone to play with at home." Maybe I wouldn't have felt so, not sure if alone is the right word, but isolated and like an outlier.

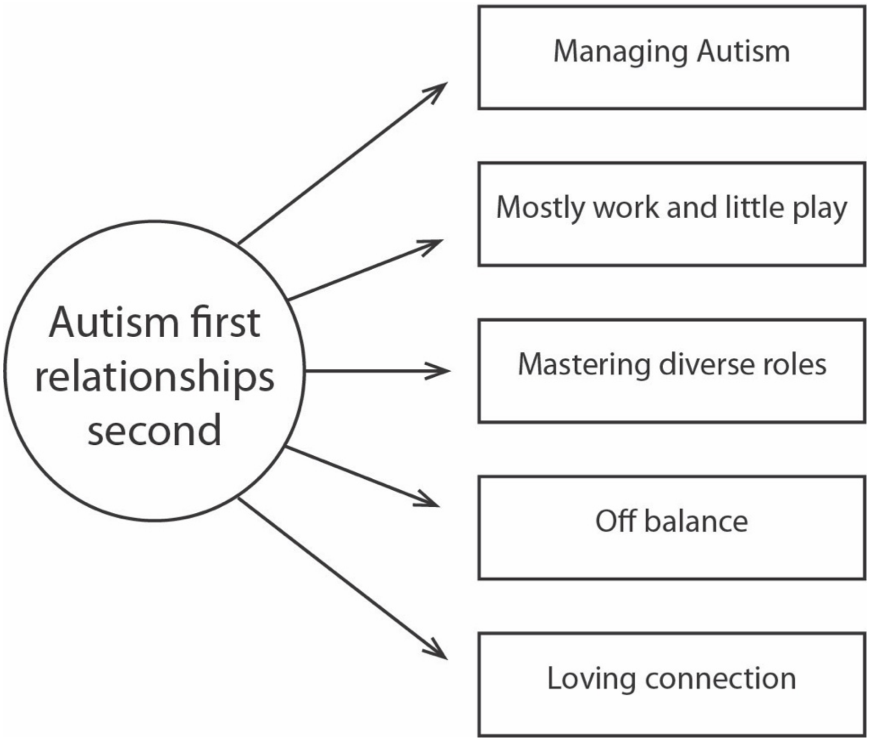
Global Theme: Autism First, Relationships Second (Parent-Child Dyad)

Parents experienced a range of challenging physically and emotionally draining behaviours, including violence, abuse, meltdowns, rudeness, bullying, and repetitive fixations. Additional impacts experienced by parents were challenges and struggles related to sensory processing, communication, and emotional regulation. Mothers' time spent with their child was driven by coaching, guiding, teaching, and skill building, including investigating and problem-solving issues. Typically developing children experienced physical and emotional isolation and withdrew and disengaged from their parents. However, despite the impacts had on parents' mental health and on the relationships with their children, they described joyful and positive experiences of raising their child with autism. Parents described the relationship with their child as being loving and real, with long-lasting connections.

Figure 4 illustrates the organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Figure 4

Network Map of Parent-Child Dyad Global and Organising Themes



Managing Autism

Most families disclosed a range of negative behaviours that characterised the parent-child relationship. These were physical and verbal behaviours and communication and sensory behaviours, which impacted the relationship between parents and children in varying ways.

The most prevalent behaviours reported by mothers and fathers were anger and violence. Helen (mother) shared that her son had “so many negative behavioural issues. He’s got a lot of violence issues. He’s been very explosive, and that’s been much, much harder to deal with." Francene (mother) described anger building within her son: "You can tell when he was getting angry, clenched fists, he'd start stomping." Adam (father) gave the following explanation about his son: "He carries a lot of anger, he sometimes is oppositional, getting angry and shouting."

Emotionally draining behaviours were reported by all parents, including attention seeking and verbal insults. Cassie (mother) disclosed:

> Cassie: You're emotionally drained from the behaviour issues. When you have kids telling you they hate you, and you have a lot of them with suicidal tendencies. I still get upset, even though that it's not directed at me. It's just emotionally draining, having all that thrown at you.

Some parents described the influence of their child's autism-related repetitive and fixated behaviour'. Janette (mother) recalled times when she felt that her son was "completely swallowed by these incredibly strong needs for routine and obsessions. You can start to feel yourself trapped in that world as well." Other restricted behaviours included repeated or copied phrases, addiction to tasks, and the need for routine. For some mothers, these behaviours impacted them directly:

> Maya: He had challenging behaviours, which were really unbearable at times. The autism part is the no attention span, addicted to completing tasks, and constant tasks, all the negative experiences.
>
> Tamara: A lot of the autistic traits is I think being fixated on stuff and just the social unawareness. She thinks she's not speaking in a rude way or not being abusive or bullying or something, which actually she is, just absolutely unaware. I tried to

> separate for her, her behaviours versus you. You're a beautiful person, some of your behaviours are filthy.

Nearly half of all families described communication and sensory issues that impacted the relationship between parents and children with autism. For example:

> Margaret: There was a lot of sensory issues with him. Sensory triggers as well as a lot of sensory output from him when he couldn't get the words out. There'd be a lot of surface banging and a lot of objects being, not thrown around, but being banged on surfaces to communicate his needs.

Cassie (mother) explained how her daughter's communication "varies with her mood … we're focusing on how we phrase things and the language we use when interacting." Gary (father) explained his son's limited communication: "He either can't communicate or can't understand. Clearly my son is autistic, he has very limited verbal communication skills and doesn't understand social cues at all."

Parents felt frustrated and confused when their child could not communicate with them. For example, Margaret (mother) recalled: "It was very confusing at the time, frustrating as well because we had a kid who couldn't communicate because he was nonverbal for a very long time." Daryl (father) said, "There was a lot of us learning how to manage him and how to manage his communication and behaviour, so that we didn't have spectacular problems, like going into shops and him lying in the alleyways screaming." For some families, difficulty communicating with their child with autism impacted on members' expected roles in the family:

> Mikel: We try to help him understand that whatever he does, he's like a role model for

> the younger one, even if he's doing the wrong thing. That's the challenge for us, to kind of make him understand you are the bigger one, you are the elder brother.

In some families, limited communication impacted parents' sense of connectedness with their child. Tamara (mother) shared her grieving as she described the absence of connection with her child:

> Tamara: I've gone through a period of grieving. When I was looking at my baby, I felt there was going to be that instinctive connection. I definitely felt bonded with her, but I didn't feel a connection with her. The grieving was about the connection not being there. I expected that to be present with my child. My child was not looking at me, was not tracing, was not smiling at me and all that. She never took joy and shared it with you. I was not in her life. She was not in my life.

Mostly Work and Little Play

All parents reported that an increased workload from caring for their child with autism had a direct impact on mental health and wellbeing. Parents tried to manage and to negotiate a balance between caring and spending time together as a parent and child. Extra work was described in different ways, including physical work, such as cooking and cleaning; guiding, and understanding wants and needs; learning personal characteristics; and resource building and implementing house chores, life skills, and routines.

Some families reported on the need to learn and understand their children's unique needs and characteristics and the extra work it took to guide their children, and balance and understand their wants and needs. Some parents described the extra effort it took to organise family activities with their children:

> Adam: We tried to do things and we did a lot of things. We took our son on trips. We did take him overseas on a couple of occasions. We took him camping. We took him to lots of museums, we did a lot of things. I'm not sure that we did as much of these things as maybe some other families, but where we did do them, it was more work.

An increased demand on parents' work and caring duties not only made parenting difficult, but it also impacted mothers' and fathers' mental health and wellbeing. Adam (father) described living life with "constant uncertainty":

> Adam: You live with this constant uncertainty. It's like you're inching your way across ice and you're waiting for the sound of cracking to know when to retreat. It you're not retreating, you're falling. You have to live within limitations, and you have to reframe your expectations to what's realistic and try not to grieve too much about those things that you haven't been able to do just because you could not, but because there was no way you could relinquish responsibility for your child, you did not want to nominate them as not capable.

Many parents described parenting as a burden and were left feeling frustrated and tired for different reasons, which impacted overall positivity in the relationship. Janette (mother) explained: "You start feeling really tired and start to feel less positive about having a child with autism." Gary (father) described his own and his wife's frustration when parenting their son with autism: "My wife and I would definitely get frustrated with [our son] because he doesn't understand us, or we can't understand him. As parents, obviously you have to try and restrain that as much as possible."

Increased frustration and tiredness reduced parents' capacity to manage and direct the relationship, further reinforcing an imbalance in the structure of the parent-child relationship and in family members roles.

> Francene (mother): You have to look at what's in front of you and go, "OK, what are the problems? What's going on?" Constantly evaluating and re-evaluating and prioritising and re-prioritising and reassessing and just taking what comes in front of you and seeing what's the most pressing need now. If you can't adapt and change, then who's going to suffer? It's the child, the parent, the dynamic, everything.
>
> Adam (father): When you have a child like [our son with autism], and particularly when he's your only child, in some ways that child's behaviour and preferences shape your behaviour. We recognised we were adapting to his needs. We did make attempts to make him conform to our needs, but that went nowhere. We just learned a set of responses, and behaviours, and routines that helped us do that. We were constantly trying to be aware of all of these contingencies so that we could smooth the path to get [our child with autism] from here to there and back again.

Mastering Diverse Roles

All mothers and fathers reported managing multiple, and for some ambiguous, roles in the parent-child relationship. Adam (father) reported on his many roles in the relationship:

> Adam: I've become my son's case worker and advocate and Uber driver. I've really been his case worker from diapers. It has been down to me really to help him navigate his life. I home schooled him, I got him touch typing and I got him giving presentations and doing research in history, we went on field trips.

Some parents reported on their protective and caring role in the parent-child relationship. For example, Gary (father) said, “I’m his protector” and Maya (mother) said, “I feel like my daughter, and I really need to protect him, we are the carers of him.” Dennis (father) reported on the necessity of a caring role in the relationship, and his efforts to see the role as positive: “A caring role is necessary, trying to generate a positive identity about being the carer, just focused on my son’s needs, that’s my primary goal.”

A small number of parents reported on the additional role of being a friend to their children with autism. For example, Greg (father) reported: “Neither boy has any friends—their friends are myself my wife.” Tamara (mother) described the all-inclusive relationship she had with her daughter, and how the relationship overlapped and enmeshed into multiple areas of their lives: “I was her everything; her parent, her friend, her shoulder to cry on, her person to go to the movies with, someone to go shopping, someone to play a game.”

For many mothers, the relationship with their child with autism emerged as caring and was structured around the child’s wellbeing. The relationship dynamic was characterised by time spent coaching, guiding, teaching, or building and developing their child’s skills and character to ensure they had successful relationships and functional lives.

Off Balance

For most families, the young person with autism was the centre and focus of the family. This was due to the additional care and support needs that the young person required. Because of this, many parents struggled to balance the time they spent with their children. For example, Francene (mother) reported: “I definitely feel that I struggle to give each of them enough time and as much attention as they would individually like.” Tamara (mother) said, "Sarah always has to wait. She probably feels like she's stuck in the corner, and nobody pays attention to her."

As a result, some siblings felt jealous of their brother or sister with autism. James (father) reported: "We haven't had real, serious discussions. I think she knows that [her brother] needs that extra support and ongoing care. She does get quite jealous over the level of attention we give him." Concerns over the imbalance in the parent-child relationship were observed across all family member groups:

> Lance (young person with autism): I think that neurotypical sibling often gets short-changed. They have to wear some of the burden of care of the person on the spectrum if not directly in terms of supporting them. They don't get nearly as much attention, and they have to be more self-reliant.

Parents also found it difficult to manage the emotional needs of their children without autism. Douglas (father) shared: "[My daughter] struggles because the other two have acquired our attention and she has felt emotionally not as tended to as the other three. I've got to consciously focus to give her time." Kate (sibling) expressed her worry over the time taken away from her younger sister because of her brother's needs: "I do worry that with my brother having autism, going to his appointments, that takes away time from my younger sister."

Unbalanced attention and the limited amounts of meaningful time parents spent engaged with their children without autism left some of these children feeling isolated and emotionally neglected by their parents. Eileen reported that the focus of her parents' attention on her brother with autism had both positive outcomes and negative outcomes:

> Eileen: My parents let me do a lot of things that other parents don't. I don't really ever

> get in trouble from them because they have got their hands full with my brother. They're more focused on him and I am less challenging than he is. I think that's a positive thing most of the time. Sometimes it can be not a positive thing because they don't seem to mind as much when I do bad things but also when I do really good things they don't mind as much either.

Dennis (father) shared: "I'm sure [my daughter] wishes there was mother-daughter time. Emotional needs would come up and emotional requests would come from her to say, I want more time with my mother." Many parents were aware of the unbalanced nature of parent-child relationships. In one family, James (father) described how he and his wife took turns to give each child some focused time and attention:

> James: We try to balance things as much as we possibly can. We used to do a bunch of things together in the early days, but now we try to break things up a little bit more and take turns and give everyone a bit of a fair share. I might have some time with [child not with autism], while [female partner] does an activity with [child with autism], and then we might switch over and swap roles.

Some other parents had group discussions with their children without autism as a means of checking in with their thoughts and feelings. Francene (mother) reported: "[My daughter] is getting more of a voice, the more isolated she's felt, she's now coming forward to tell me, 'I want to spend time with you mum.'"

Loving Connection

Despite the challenges to the relationship between parents and children with and without autism, and the negative impacts autism has on these family members, nearly half of all parents in the study shared the joyful and rewarding experiences of parenting their child with autism and described the positive outcomes such experiences had on the parent-child relationship. Most parents who reported on these elements had a child with autism and intellectual disability.

A range of positive characteristics that parents observed in their young people with autism helped to build a closer parent-child relationship. For example, Maya (mother) remarked about her son: "He has a very sweet personality, he's very lovable, he's a very sweet person. I think that has made us bond really closely." Adam (father) shared: "I like my son. I love him; he's a quirky and interesting, charming person." Colin (father) described his relationship with his daughter with autism as affectionate and close: "Her autism is unusual in that she is affectionate, enjoys hugs and has never shown any tendency towards violence or anti-social behaviour. My relationship with her is close."

Parents shared that autism helped to create a sense of bonded relationships and loving connection with their children. James (father) shared:

> James: Even though he's much older, we've still got that really loving connection. I feel with my son we've got that real relationship still. He does a lot with me—we go to the football together and we have a nurtured relationship. I feel like I'm really getting mileage out of that, whereas I wouldn't have got that mileage from a normal child.

Maya (mother) discussed the bond created between her and her son with autism: "I have a feeling that we have created a bond, rather than if he was normal and mainstream." Lance (young person with autism) shared his sentiments towards his parents; he praised them for their support and the positive outcome this has on the relationship:

> Lance: I give my parents tremendous credit for everything. I couldn't have done it

> without them. There's a huge amount more understanding. I'm a lot better at communicating and as I've become a more responsible adult and I've changed so much. Things are going better than ever now. I just love them to bits.

Global Theme: Our Challenges, Our Solutions (Family Unit)

The family unit dynamics were impacted by a range of physical, emotional, and social behaviours, including self-harm, anxiety, overstimulation, anger, and the limited social and emotional awareness of the young person with autism. Parents described relationships as a family unit to be "fractious," "fraught with friction," and "structured on compromise," and a young person with autism shared that autism in the family was "a disadvantage for us as a whole." Some parents reported that without regular support and respite their family's capacity to cope declined. Without support, family members began to "snap" at each other, and this placed a "stress on the bonds" between family members and the family as a unit.

Some young people with autism shared how the condition impacted on them directly, causing stress and anxiety, and explained how this affected their relationships with others in the family. Some young people did not want to burden their families with their stress and anxiety, or with their need for emotional support and reassurance.

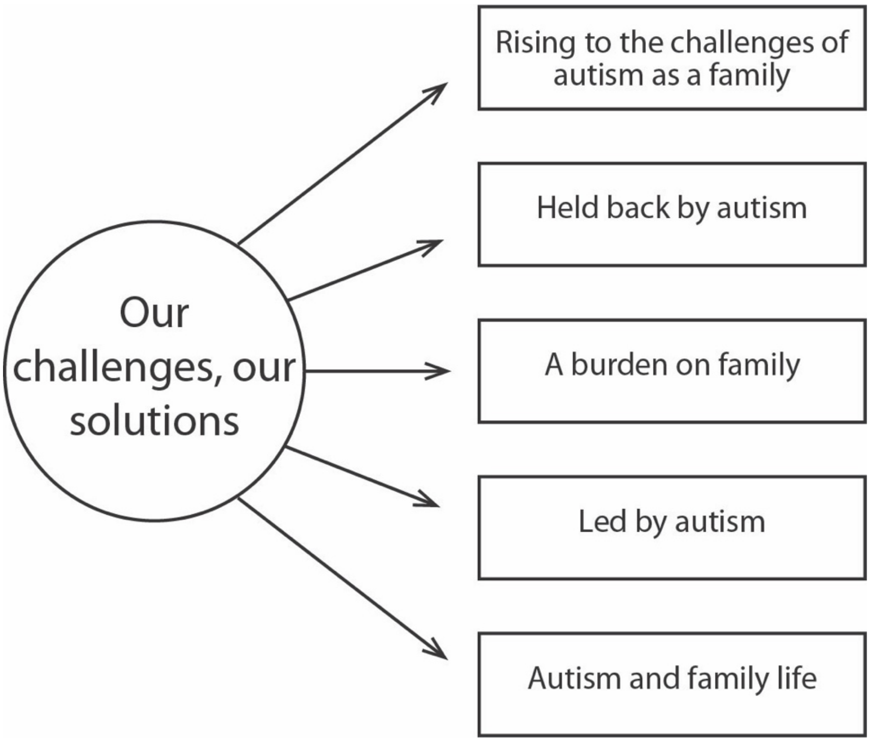
Parents and siblings explained the family as a unit was "governed" and "directed by" autism, and that autism had a significant influence on who they were as a family and how they saw themselves. For participants, time together as a family was impacted by physical and emotional exhaustion from fights, upsets, and tantrums. This prevented the family from being together and reduced family members' sense of connecting and belonging as a family.

Reflecting on families' ability to remain optimistic and work hard to strengthen and maintain their close family relationships, attention is given to what families did to support each other. Participants, "rising to the challenge of autism" in their family, described the positive and rewarding effects these efforts had.

Figure 5 illustrates organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Figure 5

Network Map of Family Unit Global and Organising Themes



Rising to the Challenges of Autism as a Family

About half of all families in the study reported using a range of strategies to establish “very close” relationships between members. Some of these strategies included sharing memories together as a family, checking in with each other, and making the time to understand and get to know each other. Families who worked together, using these and other strategies, successfully addressed challenging behaviours such as anger, violence, anxiety, and stress:

> Cassie (mother): By teaching our children—and ourselves—to deal positively with feelings not only allows us to be truthful, but it also saves all that energy we would otherwise spend suppressing or dumping our emotions to be put to far better uses, which will carry us through years of growing, changing, and coping with difficult times.

Other ways that families strengthened their relationships included planning family activities, setting family boundaries, and establishing routines. When family members “maintained a united front” they developed resilience and felt more connected with each other. A few families reported they were “doing really well,” and wanted to be acknowledged for the “great system” they had in place as they successfully managed challenges:

> Margaret: If you’ve got it under control you want to be acknowledged for that strength that you have. I want somebody to say, “Look, you’re doing a great job. You’ve got a challenge, you’ve got a great system, you’re doing really well.”

Dennis (father) spoke of “rising to the challenge” of having a son with autism:

> Dennis: By rising to the challenge of having a son with autism and intellectual

> disability you're having to work harder. Through that constant work on the primary relationship with the child with autism, you're working with the other people in your family to manage that problem. And it builds up teamwork and your relationships around managing that. It strengthens you and strengthens those relationships.

Tom (father) described similar positive outcomes through parenting their child with autism: "It's made me a much more tolerant and understanding person … made me a better dad." Monica (mother) shared that working methodically step by step helped her family to balance time together:

> Monica: So, what are the steps that we need to do to get to this point, how are we going to get there? What do I need to do now? That's my strong point.

Maya (mother) mentioned that patience and listening were two key factors to a "smooth" dynamic at home: "If my daughter and I show endless amounts of patience with him, things go well. … A lot of patience from me makes things go smoothly at home." Cassie (mother) noted that taking a break was a good way to reset her emotions:

> Cassie: When anger and stress become overwhelming, both children and adults can learn to take a time-out—not as a punishing confinement but as a way to cool off and feel better so that a situation can be dealt with calmly.

Families established cohesive relationships between members to strengthen the overall system. This assisted the family to work through difficult family situations, such as conflict or arguments. Two mothers, Monica, and Stephanie, described how their family members worked through problems together and got to know each other:

> Monica: We maintain a united front and we ensure we have strong bonds between

> family members. We don’t have a lot of fights, but when a disagreement arises, we try to work through it as best we can so that everyone is reasonably happy. We are affectionate with each other, lots of encouraging hugs and sensory rewards for cooperation.
>
> Stephanie: We develop resilience by getting to know each other, go for the things that are likely to be enjoyable and that work. Positive family experiences are fostered and maintained because the children regularly like to go over all the wonderful memories we have as a family.

Joanne (young person with autism) and Kate and Maya (mothers) described resilience in their families as “endless patience … a lot of patience.” Joanne (young person with autism) shared that when “something bad happens, it is overwhelming for all of us, but we pause and work through it, we soldier on as best as we can.”

Close family relationships were described by young siblings and young people with autism with intellectual disability through their verbal and physical expressions of enthusiasm. Some younger siblings worked through the “All About Me” activity sheets, and through actions and gestures they communicated that they had a sense of closeness and connectedness with their families. For these young people, it was activities such as playing, “hanging out,” going out into the community, and spending time in each other’s company that contributed to their sense of closeness with other family members. Kate (sibling) shared that she felt close with her family when “we’re in each other’s company, and we’re not necessarily doing anything.”

Held Back by Autism

Family members were driven apart from each other in several ways, including through violence, anger, fixations, and conflict. Francene (mother) shared that it was difficult to live with her son due to his aggressive behaviours:

> Francene: [My son] can be difficult to live with, as he doesn't "let things go" or can't "just look away." His outbursts, his anger, his aggression that he might not be able to control, his impulse control, picking at his sister or pulling his sister up on something.

Kate described how her brother's agitation and impatience made living with him difficult: "He's agitated at things and doesn't have the patience to stop and think about other ways to work through things. He can be quite difficult to live with."

A lack of understanding and shared perspectives held back some family members from connecting and forming close relationships with each other. Sarah reported that she removed herself from family events to avoid conflict with her sister with autism. Sarah reflected on her wish for "spending more time together as a family, because I know I'm a problem of not spending the time. I'm up in my room because I am afraid that I'll create an argument. I really don't like them." Greg (father) explained that relationships between members in his family are impacted by a reduced or absent shared perspective or shared understanding or relatedness between members:

> Greg: We can all have somewhat fractious relations. … Sometimes it can be difficult to see the positive outcomes, as everyone seems to have a different viewpoint. We have all experienced the same thing, but we all take startlingly different points of view. It is a particular strain on the relationships with the boys' mother, because she doesn't

> understand the way the rest of the family thinks. We all have difficulty expressing our opinions in a way that is respectful to the others at times.

A Burden on Family

Most young people with autism recognised how their condition impacted them directly, and some provided insight into the impacts and demands this had their families. All parents and siblings felt the burden and demands that autism placed on the family as a unit. Parents emphasised a great need for regular respite, which included some time spent away from their child with autism:

> Maya (mother): If he had a good overnight respite place where he could go and enjoy going that would have been a massive blessing to the whole family. Not just learning living skills, but it gives a break to [his sibling] and myself.

In one family, Janette (mother) shared she needed some time spent alone with her daughter without autism and explained the problems that developed between them without regular breaks from the young person with autism in the family:

> Janette: It is really important that we have some time together without [child with autism]. It is tiring meeting his needs all day, every day. If you don't get regular breaks, you start getting snappy, your ability to cope becomes less.

Without regular respite, parents reported a decrease over time in their capacity to maintain and strengthen relationships in the family, and an increase in their sense of disconnect between family members. Dennis (father) explained that the bonds or connections of relationships in his family were impacted due to the constant management of the primary relationship with his son with autism:

> Dennis: There’s the stress on the bonds that you have with other members in the family if you have a child with autism and an intellectual disability. It impacts on the quality of your relationships in a negative way because you’re constantly having to manage this primary relationship with the child. It takes away your capacity to maintain and strengthen your relationship with other members of your family, because you’re constantly working with his needs.

Led by Autism

All families identified the central role of autism in their family life, describing it as “a pivotal point in the family,” a “big influence,” and “one that directed and limited family life.” Francene (mother) and Adam (father) commented on how the family and members in the family were shaped and governed by autism. Francene commented: “Half the time we don’t even realise how much the autistic element is governing our lives, but when we sit down and consider it, it is far more prominent that we care to admit.” Adam (father) made similar remarks:

> Adam (father): The family shapes itself around the preferences, needs, limitations of the family member with autism. So too, I think that mums, dads, siblings also look at themselves through the lens of the person and their lives with autism. In many ways [my child] defines me. Defines me in so far as they place fences around what I can and cannot do, be what I can and cannot be.

Across all families, mothers, fathers, and siblings reported that autism limited family activities. For example, Monica (mother) said, “It does limit the places we can go as a family.” Eileen explained this meant “less going out and doing things in public places; we can’t go and see movies because he [sibling with autism] will get upset, and we can’t go to restaurants because he will throw a tantrum if he can’t eat something.”

As well as autism limiting the places families could go and spend time together, some families reported they had no capacity to socialise as a family. Dennis (father) reported: “We don’t socialise as a family, we’re tired, we’re out of whack permanently. We don’t do as many things because of autism.”

A small number of siblings and mothers described how autism directed family life, which included following prescribed routines. Kate explained that, for her brother with autism, “if something doesn’t work out for him, something in the morning routine, then he won’t want to go to school, and everything sort of shuts down. So that can be a bit difficult.” A sibling from another family, Eileen, explained that as a family “we follow certain routines otherwise he gets really stressed.” Routine and sameness were common patterns in families’ lives. Karen (mother) described her family life as “very much governed by routine sameness. There’s not much variety.”

Autism and Family Life

Nearly half of all families reported that autism influenced their perceptions of family life. For the remaining families, autism had no bearing on how they perceived themselves as a family, and most of the members in these families described their family as being “just like any other family.” Mothers, fathers, and siblings described an “overarching acceptance of family life not being the norm” (Monica, mother), and some considered themselves as “a diverse family” (Kate, sibling), or as an “atypical family, as one of our family members is neurodiverse” (Daryl, father).

Some participants considered the day-to-day functioning of the family. For example, Greg (father) said, “We do not function as a typical family unit—we rarely do the same thing together—up until recently we didn’t share meals together. Another mother, Stephanie, described her family as atypical but living in a neurotypical world: “autism has a big influence on our lives because of the reaction of the neurotypical world around us. We are atypical, but we have a foot in both worlds.” Dennis (father) perceived his family as atypical, and shared how autism disrupted his family’s life story as they confronted their own expectations of what it was to live a normal life and to be a normal family:

> Dennis: You have an expectation that your family will conform to norms of neurotypical life and there’s this realisation that’s not going to happen. Then there’s the adjustment around the child with an intellectual disability and autism. It’s always on the inclusion, exclusion line. … You’re never really sure how disrupted life is going to be, and you’re constantly trying to live up to expectations of family life. It’s so different to the norm.

For some other families, autism had no influence on how they perceived their family life. They described their families as “normal,” like other families: “We don’t identify ourselves as an atypical autistic family. We say we’re a very normal family” (Margaret, mother). Some siblings thought autism “doesn’t make my family different” (Martina, sibling), and others, over time, came to the conclusion their families “are normal, but normal in our own way” (Amandi, sibling). Francene and Maya (mothers) and James (father) described their families as being as normal as all other families and households, and that they shared commonalties with all families across Australia: “We’re a family, like all other families. We try to believe we are like every other family" (Francene, mother). Maya (mother) shared that she aimed to give her children "a normal life, this household is very similar to other normal households, just all that normal stuff. Dysfunctional at times but I don't see us as a different family." James (father) focused on the normality of his family life, "grasping" onto it and not wanting disability to impact it:

> James: We have a lot of common things in our family that all families across Australia have. That's having the parents working, kids going to school. We've got a mortgage. We go on holidays. We do try to have a social life and we have our own social interests. We're trying to live our lives as best we can. I wanted to grasp onto the normality of life. I don't want disability to affect our life and our lifestyle.

While some families reported family life as different and others reported it as normal, most families experienced a similar impact of autism on time they spent together. In most families, striving for time together was a balancing act, affected by arguing, exhaustion, and the need for members to spend time alone. Stephanie (mother) explained that some "normal" family routines did not work for her family: "Typical things like dinner is not something that works for us during the week. Everybody is exhausted. This is the worse time of day to get four people on the spectrum together." Impacts on how families functioned was reported by some participants, and an absence of doing "happy" things together as a family was mentioned by Dennis (father): "We're spending less and less time doing stuff functionally as a family. It's a constant balancing act. We're not actually having family time where we're doing happy things together as a family." In addition to these impacts, parents described dividing the family into smaller groups for breaks, a fear of creating arguments, and needing time alone. Dennis (father) explained that his family tries to plan for “mother-daughter time, we have on occasion father-daughter time, and we’re all sort of managing our own kind of needs and relationships.”

As families reported on the problems of spending time together, mothers Margaret, Stephanie, and Francene shared that they used careful and considered planning to achieve positive family time together. Francene explained that there is “so much thought and consideration that goes into every aspect of that decision. Positive family experiences are always something we aim for, but they also take careful planning and a need for flexibility.” Margaret (mother) highlighted “quirks” that her family members “have to look out for, and the triggers and the pre-planning that goes into going out or doing things.” Space and tolerance were important factors for families with multiple members with autism, and Stephanie (mother) explained that she took on the lead role for “managing” her family: “I’m the conductor, trying to keep everybody in time. I said to them last time, ‘we’ve got four Aspies in the house, you need to be a bit more tolerant of each other. Give each other space.’”

The findings now turn to present family members’ perspectives on how external responses to autism impact on family relationships.

What are Family Members’ Perspectives on how External Responses to Autism Impact on Their Family Relationships?

The findings presented here extend beyond micro-level dynamics within families to examine family members’ perspectives on how external responses to autism (e.g., responses from schools and disability services, and the wider cultural and social responses to disability) impact on their family relationships. Central to this, is the observation that autism is interwoven and interconnected with many aspects of families’ lives. Together, these external responses to autism draw attention to the influence the environment has on families', the impacts this has on their family relationships, and how families with a member with autism are made to feel different to other families because of external responses to autism. Families' insights and experiences are presented in detail, using illustrative quotations throughout the global theme of *Made to feel different*. Additional quotes from participants that substantiate findings further are provided in Appendix I.

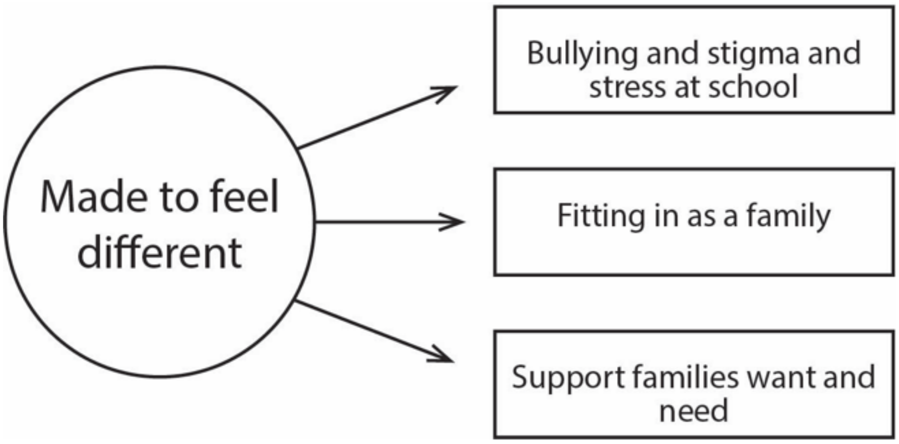
Global Theme: Made to Feel Different

Families report that school and disability service organisations' responses to autism, both the positive factors and the stress and the pressures that occur in these settings, flow into families' homes and impact family relationships and family members' wellbeing. Broader external responses to autism, including disability policy, funding, and the structure of services and institutions that families access, isolate families from their communities and indirectly impact on family relationships. Pressures and expectations of cultural and social ideals also enter families' homes to make them feel different to other families, reinforcing their sense of isolation.

Families react to these external responses to autism, and they highlighted in interviews the kinds of supports they want and need to combat some of the challenges they face. They need these supports to create meaningful and positive family experiences, which, in turn, promote strong family relationships. Families commented on the types of supports that could be offered but that were not available or easily accessible at the time of their interviews. Figure 6 illustrates organising themes that were constructed within this global theme. These organising themes are presented and supported with participant quotes.

Figure 6

Network Map of External Responses to Autism Global and Organising Themes



Bullying and Stigma and Stress at School

The experience of school for young people with autism was observed to have an impact on the relationships at home for all families. At the time of their interviews, many relied on school as a main source of support as they waited to join and access funds through the National Disability Insurance Scheme [NDIS]. The NDIS enables families to access supports without using their own funds. Families described a range of factors that contributed to a poor school experience, such as the school environment, particularly classrooms.

School classrooms. Some parents described classrooms as difficult, busy, and noisy places with high amounts of sensory stimulation for their child with autism. All families understood the school environment as a place that was, in general, not suited for young people with autism. Noise was a major factor that parents identified as an issue for their children with autism: “I actually feel it’s a noise issue ... because all the kids coming in, yelling, screaming, and moving the furniture, and crashing into him" (Nairi, mother). Once home, after school finished for the day, some parents reported their young person with autism shutting down or melting down, as a release after holding in their stress and emotions. The home environment was a place young people could release the stress of school:

> Corey (father): They'd come home from school and be completely shut down … we have a lot of behavioural issues where they've been rather violent … everyone finds it hard to believe that they will misbehave, because they're perfect at school. But they're perfect at school because they pin it all up inside, then [it] unleashes when they get home.
>
> Helen (mother): He just couldn't cope with the classroom setting … keep up and function ... the social stuff to deal with … the noise to deal with. All the things that make a classroom so difficult … he was not functioning in the classroom. He was just shutting himself down, blocking everything out. ... He gets home, and all hell breaks loose.

As well as noise, parents understood classrooms to be unstructured and disruptive settings for young people. For example, Corey (father) said, "I think a lot of it is the sensory overload, it comes from just being in disruptive classes." Adam (father) had similar observations: "The school classroom we realised was such a busy environment. … Kids are sitting on the floor, there's things fluttering all over. There's lots of handing out of papers and lots of meaningless talk and discussion.

Peers. Young people with autism felt stigmatised and were bullied by peers at school. Stigmatisation and bullying occurred in both primary and high schools. Lucy (young person with autism) reported feeling uncomfortable talking about autism with friends, and felt awkward when peers would use the word “autistic” to describe someone or something in a negative way:

> Lucy: Only one person really knows that I have autism. Most of my friends are aware of it, but we don’t talk about it. … I don’t really feel comfortable talking about it. I don’t really feel like I belong when I say that … I’ll feel really awkward. … Lots of boys, for example, in the year, will joke that something is autistic. … I’m glad it is never any of my friends.

Siblings of young people with autism reported feeling uncomfortable disclosing their autism to peers, and parents were aware of this discomfort. For example, Stephanie (mother) said: “They’d seen how his sibling had been treated over the years, they were worried that that might apply to them.” Possible repercussions if siblings did talk about having a brother or sisters with autism were mentioned. For example, Luke (sibling) noted that “people will act differently around you, treat you differently. It’d be a lot more difficult to do things.”

Jim (young person with autism) recalled other students with autism being bullied at their school because of how they acted: “I remember boys from my old school who had it [autism] quite a bit worse, and they were picked on because they acted different.” Many parents confirmed the bullying and teasing these young people with autism encountered at school:

> Cassie (mother): They’re getting a lot of negative stuff because of it, so as far as I understand, autistic is an insult you use in the playground to label other children. It’s now “the” [go to] word. If you do something inappropriate or socially out there, they’ll say, “What’s wrong with you? Are you, autistic?”

Helen (mother) reported the challenge of primary school for her young person with autism due to stigma and bullying:

> Helen: Primary school overall was very challenging for them. They were bullied a bit in the early childhood centre. Then when they went to primary school and they saw the Learning Support Units, and they saw the other kids there and they saw the other kids teasing them. They made a very conscious decision they didn't want anybody to know that they had autism.

Bullying and stigma not only affected young people with autism but also affected their siblings. Sibling Eileen reported feeling uncomfortable talking about her brother's autism diagnosis at their current school because other students made jokes about autism:

> Eileen: I don't really feel comfortable talking about it in school because people who you know make jokes about it [autism]. … Not necessarily my friends, but saying, "Oh, you're such a retard" to people. Or "You're autistic." It's like a joke. Or "I'm so autistic," because it's like, I'm weird or something.

Some siblings at school had to take on a caring role outside of the family home. Amandi was made to feel different when peers made comments about her brother with autism:

> Amandi: [There have been] multiple instances where I was trying to make my own friends, have my own lunchtime, and anytime he had like a tantrum or breakdown they'd [peers would] be like, "Oh, your brother's in this part of the school." I'd have to go find him and then look after him. … I guess the way I realised that it was different was because everyone else made it obvious.

Teachers. A small number of young people with autism experienced hostile and negative interactions with teachers. Teachers were described as having a negative impact on the wellbeing of a small number of the young people with autism. These teachers overall were described as people who did “not listen,” were “unforgiving,” who “shouted” and “got angry”. Lance shared that “the teachers that were bad were teachers that would shout at me and get extremely angry. I had a couple of teachers who were quite physically forceful. That was very unpleasant.” Lance reported what he remembered most about teachers were how “authoritative” they were:

> Lance: The teachers were always, in my point of view as a little kid growing up, an oppressive force … what I remember most of all about teachers that really hurt me as a little kid, was how authoritative they were.

Parents who repeatedly tried to interact with teachers throughout their child’s schooling described teachers who had no skillsets for understanding or managing their young people with autism. Stephanie (mother) said, “It’s that lack of understanding that the teacher has which is the critical factor. … If you don’t understand why I’m behaving the way I am.”

Rob, Dwayne, and Adam (fathers) shared their experience of teachers at schools. Their accounts are provided below, in turn:

> Rob: They had no skill set for understanding or managing children. [My child] didn’t fit into a normal box. They’re very limited in what they can offer.
>
> Dwayne: The schools need to do more. They need to be more flexible and be prepared to learn new techniques.
>
> Adam: Most teachers had not heard the term Asperger’s syndrome. Their idea of

> autism was the Rain Man stereotype. They had no idea about what the spectrum of behaviour might be let alone how to intervene for kids on the spectrum.

Some parents commented on teachers who did not understand young people with autism. This also included some teachers' limited sensitivity to and awareness of the needs of young people with autism:

> Adam: There were a few unfortunate events where [my child] was made to feel victimised and stigmatised. It was one class trip. [My child] was told they couldn't go because the school just said, "Well they've got Asperger's syndrome. They might run off. They might act out. They might do something, so therefore they can't go."

Home schooling. Because of young people's negative experiences at school, four families in the study had chosen to remove their young person with autism from school, and home schooled them. These families who experienced great challenges with the school system and teachers felt they had no other option but to remove their young person with autism from school and to home school them. These parents had no formal supports: "That's probably the biggest area that's hard for us is not having enough support in school" (Francene, mother). Adam (father) described his son's increased anger at both school and home:

> Adam (father): He was exhibiting some quite angry behaviours at home. They were angry at school. They were angry at home. They were unhappy … in a bad, negative space. … I home schooled, which was tough because they weren't the most willing pupil. They were still carrying a lot of anger. They sometimes were oppositional. But I couldn't do that forever because I think the home-schooling gig is a difficult one. If you are carrying too much emotional baggage you can't achieve that level of

> emotional detachment that you need to teach a child.

Young people with autism who home schooled identified positive aspects of one-to-one tuition in the home environment with a parent but were also conscious of the demands and impacts this had on their relationship with their parent.

Isolation. Many other young people with autism in this study had at some point in their schooling taken long periods of leave or absences from school due to the school environment's impacts on their wellbeing and mental health. Poor experiences at school left some young people with autism reliant on their parents for increased emotional and social supports, as well as friendship. Home schooled, Lance (young person with autism) described the friendship his father provided to him and the importance of the friend role in their relationship:

> Lance: Probably one of the main things they give me is friendship, especially my dad. I don't have many friends, especially since I left school because I didn't really rely on friend groups or friend networks

Families' absence from school, or the limited interactions they had with others at school, contributed to feelings of isolation. All mothers of young people with autism described the isolation they experienced during these school years. Cindy (mother) reflected on the difference between her primary school and high school experience: "[High school] is a little bit alienating. I don't think we put ourselves out there nearly as much as we did [in Primary school] ... I think you do start living a more insular life in a way."

Fitting in as a Family

Over time, families became aware of the differences in their lives compared with other families without autism. Dennis (father) reflected, “There was a development of an awareness that our life path was going to be quite different … a special needs kind of existence … key elements of existence that seem so autistic that you couldn’t really ignore that.” Stephanie (mother) reported that cultural norms emphasised their family’s sense of feeling different from other families, and highlighted the need to fit in with social expectations:

> Stephanie: To show them how to operate in the neurotypical world, are you basically rejecting who and what they really are? Walking that fine line of saying, “I really love you and I think you’re fantastic and special to me, but you know, you need to fit in here.”

For families like Stephanie’s, trying to fit in and function within social norms and expectations meant not drawing unnecessary attention towards themselves. This was an important consideration for families when they left the home to go out into the community:

> Monica (mother): We go for the small wins and celebrate when they happen. For us, to go out into the community and return home without calling attention to ourselves, to fit in, is a positive experience and seen as a huge win.

In the community, families received negative comments and judgement from others when their child with autism became overwhelmed with the sensory input of the environment. Nairi (mother) said: “I got so sick of trying to explain, ‘He’s not a naughty boy. He’s just got sensory issues and cannot cope.’” Maya (mother) recalled, “I can remember when he was quite young and he was having tantrums at shops, I've got stares from people, people were staring at us and that annoyed me. I felt judged."

Parallel to families' experiences, the media's portrayal of families who lived with autism and disability as "super families," who overcame autism through a lived experience of "tragedy, persistence, then triumph," left many families further isolated from the world outside the family. These families described being caught between "a special needs existence" or "disability world," and the mainstream community's needs and wanting to fit in with these.

Parents commented on the stereotypes and misconceptions about autism that they had faced in the community. Karen (mother) explained: "There are lots of wrong ideas, people with autism are cold, unemotional, lacking in empathy. My daughter is such a warm, loving person." Health professionals, including general practitioners and paediatricians, were some of the groups that provided inaccurate information about the condition. Margaret (mother) commented: "The doctor said, 'Oh, autistic kids don't make friends.'" Janette (mother) had a similar experience, commenting that "the paediatrician had very strong views … things like children with autism just sit in the corner and rock." Parents challenged some of these views with examples from their families. Janette explained: "The stereotype that a child can't show you love or affection. Obviously, I knew that Jake was affectionate … there's a more nuanced understanding around the spectrum and children, they do show their family love." Reflecting on the difficulties young people with autism experienced, Lance (young person with autism) commented on how people with autism are defined by others primarily by their difficulties:

> Lance: Apart from very intense interests, I think a lot of the time [people with Asperger's syndrome] are way more easily defined by difficulties. They're way more

> easily defined by things that people struggle with, anxiety, depression, trouble talking to people, expressing oneself, and dealing with certain situations.

Lance reflected on the experience his parents might have had when raising him: “They may not have had an enjoyable experience raising me because they were told there was going to be so many difficulties.”

Support Families Want and Need

Young people with autism commented on the value of being connected with a health professional, including a social worker or psychologist who helped young people express themselves emotionally, as well as helping them socially. This helped to create or influence positive impacts on family relationships:

> Lucy: If I have any problems, she helps me, shows me, and finds a way. She talks to me and shows me ways and skills, how to exit conversations better. She teaches me friendship skills, social skills. It gives me a chance to escape and express my emotions. It then helps me in life.

Most young people with autism identified several main qualities they valued in their support person. The person was described as someone they could talk to, who “actually listens” and “actually helps” solve problems, and who taught them skills, including friendship skills and social skills, and how to be less stressed. Young people with autism also identified benefits of seeing a support person, which included “a chance to escape myself”, “a chance to have some time to myself and do stuff I want,” and “an outlet and avenue to express emotions”. Ken shared that his support people of choice were “psychologists, because I know that it’s been good for me to get stuff off my mind.”

As well as wanting and needing to be listened to and supported in their family relationships, young people with autism stated the importance of service providers having a greater understanding and more knowledge of autism in families, and of how families themselves perceive and experience autism. Young people wanted service providers and professionals to understand that each young person with autism is a distinct individual: "People are saying that everyone on the spectrum's the same, but that's not true. People on the spectrum are a bit different and the needs of people on the spectrum aren't the same" (Nina, young person with autism). All families agreed that this gap could be addressed if organisations employed people with autism and their family members:

> Joanne (young person with autism): Most of the staff should at least be on the spectrum, or least somewhat neurodivergent. It's important so that the people in [the support service] know what kind of things to expect and what kinds of things to do with these families from their own experience.
>
> Monica (mother): When organisations are hiring, they shouldn't be hiring people that have degrees and no experience in disability. Because they haven't lived it. They should be hiring people that have lived it. Understand it. Have seen all the different shades and flavours.

Young people with autism recognised the importance of individualised supports for themselves and their families:

> Jim (young person with autism): I would say probably try to get people, adults, and children, who are on the spectrum, to talk about their experiences, and what they struggled with within the family, and what they found supportive within the family.

> Families can take that on from the autism perspective. … Either the people with autism from the family or not, talking about how growing up was for them, in whatever environment they had, and how it could have been improved, and how what's really beneficial for them being a family.

Some young people with autism and some siblings recognised the need for supports groups for parents:

> Lance (young person with autism): Fostering connection between parents I think would be a good thing. Parents not feeling like they're alone and feeling like they can talk to others, but also not feeling like they're just being jammed in with people who are dealing with a completely different struggle.
>
> Kate: [Support] for the parents, a group to get together to talk about the difficulties of parenting a child with autism, because I think they probably are the ones that struggle the most. … I think that would be beneficial, to work together, not only as a parent with a child that has autism but working together as parents … Mum and Dad take very different approaches when it comes to [my brother]. Obviously, they're both doing their best, but I think communication with the child, and then communication with each other, would probably be a really good service.

These supports suggested by Lance and Kate correspond with findings presented throughout the global theme *Our challenges, our solutions*, which revealed the limited amount of time parents spend together to provide care and parenting for their child with autism. Support groups like these might help parents to feel more connected to each other and united in their approach to parenting.

Parents, in considering the supports they needed, suggested that service providers could have longer operating hours and flexible practice models: "Being more flexible on operating hours would be helpful. Working families find it so hard to meet our children's needs, let alone try to get time for fun outings" (Francene, mother). Cassie (mother) explained that parents appreciated services that visited the family home, as this meant the family did not have to "juggle":

> Cassie: Because most parents are flustered. … The exhaustion's a constant thing and everyone I've spoken to is physically drained. … I've found it much easier to do things when people come to us. I think most parents really appreciate services that come into their home because they don't have to juggle. … If more services are helping with the day-to-day stuff, or even someone taking all the kids out to an outing ... more intensive supports.

These supports suggested by Francene, and Cassie correspond with findings presented throughout the global theme *autism first, relationships second*, which showed that increased care-related workloads and parental duties take up most of parents' energy and time. Supports like those suggested could mean families have more choice and flexibility in how they spend time together.

Supports identified by siblings included mentor support groups, to help reduce isolation and caring responsibilities for siblings, and supports to address sibling conflict and arguing. Siblings wanted to get help in coping with arguments that occurred daily:

> Amandi: I wanted a siblings group because it's [caring is] very weird and I would have very much appreciated if someone, growing up, told me, "Hey, it's OK" … Cause it's

> very different talking to someone about caring who has no idea what's going on. … I never had anyone to talk to about that stuff … maybe I wouldn't have felt so isolated or like an outlier … it would be nice to have that sort of commonality between me and someone else.
>
> Sarah: First, people could ask them [siblings] what it's like at home for them, getting to know the family. I would ask them, are there many arguments at home? … I would help with that. Because I know arguments are a really big thing in this house … like I said before we cannot go one day without an argument.

The findings presented in this global theme considered the wider context outside of the family as a unit. Young people with autism and their family members reported how external responses to autism from school, media, service providers, and professionals, and broader social norms and values, influenced them and their families and impacted on family relationships. This included families who struggled to fit into the community, who felt rejected from their schools and peers, and who did not have access to suitable supports. These factors led to increased challenging behaviours displayed by the young people with autism, including physical, emotional, and social behaviours such as, anxiety, overstimulation, and anger. Jointly, these factors draw attention to the importance of being aware of the setting created by the physical or social environment, the influences this has on young people with autism and their family members, the impacts on family relationships.

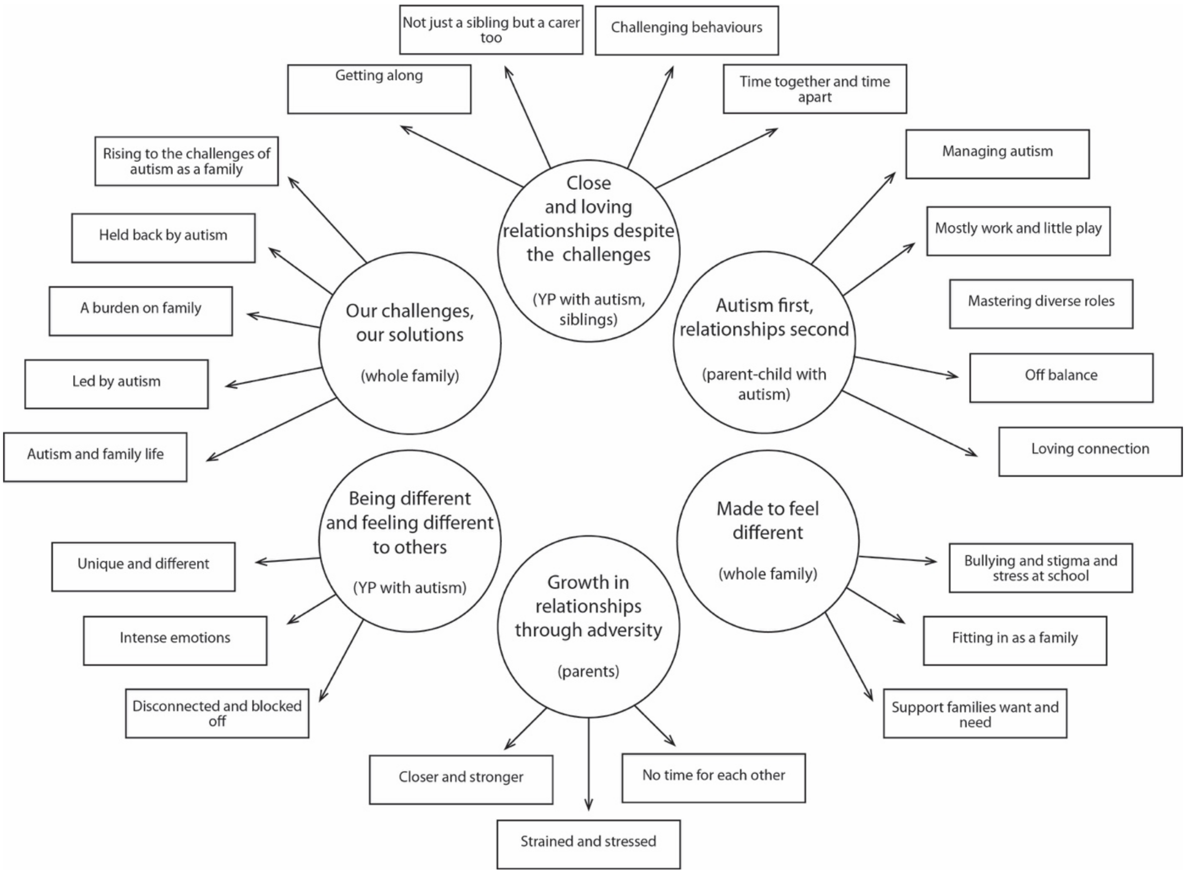
Summary and Schema of Findings

The global themes presented in this chapter indicate that the role autism played within the relationship dynamics in families was significant. Participants described their family relationships as fractious, hard, difficult, limited, fraught with friction, and structured on compromise. Despite this, key factors that supported strong and close family relationships emerged throughout participants’ accounts. These included working as a team through planned family activities, setting routines, actively working to develop family skillsets, sharing memories, checking in with each other, and making the time to understand each other and getting to know each other.

Key factors that supported strong and close relationships for young people with autism emerged from the data, including spending one-on-one time with family members who provided reassurance, support, secure connections, attention, and care. Key factors that supported special and close relationships for fathers, mothers, and siblings emerged; these included increased communication between one another, working through challenging times together, a focus on creating special time together as a family, and the influence that caring for the young person with autism had on the level of closeness and protectiveness across family relationships. This chapter concludes with an illustrated integrated version of all network maps of the global and organising themes (Figure 7), which presents a schema of findings of family members’ perspectives on how autism impacts the relationships between family members, and the family as a unit.

Figure 7

Schema of Findings



Note. YP is young person.

Chapter Summary

This findings chapter presented the insights of young people with autism and their family members whilst exploring the topic of family relationships. By adopting a childhood studies and disability studies lens, the findings of the study have been inclusive of the perspectives of young people with autism. Their perspectives have been foregrounded whenever possible to provide insights into their lives and the relationships within their families.

The experiences shared by young people revealed some of the ways autism influenced young people's interactions with their family members, and how this impacted their relationships. Also, initially providing a description of how the young people with autism perceive and experience their condition helped to frame and contextualise the accounts and insights provided by other family members. These findings also highlight differences in perceptions and experiences, including around some of the challenges, as well as rewards and strengths, that autism brought to the family.

Applying a systems lens to the findings shifted the focus from within the family to analysis of factors outside the family, to highlight how relationships can be impacted and shaped by the external responses to autism in the broader contextual circumstances of families' lives. In Chapter 6, a discussion of the key study findings is presented, with a focus on the new insights that have emerged from the perspectives of young people with autism, siblings, and parents.

Chapter 6: Discussion of Key Findings

Introduction

In response to the gaps in the literature identified in Chapter 2, this study investigated the impact of autism on the relationships between family members, and the family as a unit. To achieve this, it considered the perspectives of mothers, fathers, siblings, and young people in the family who have an autism diagnosis. In doing so, the research produced a framework for practice, presented in this chapter, and discussed further in Chapter 7.

First, this chapter situates the study findings in the context of previous research. This discussion shows that this study is generally supportive of the findings of the studies included in the literature review (Chapter 2), and that the findings do not substantially contradict any of the studies.

Second, the chapter brings together the study findings provided in Chapter 5 to advance our understanding of the impact autism has on the relationships between family members, and the family as a unit. It does this by presenting an integrated discussion of key study findings, with a focus on the new insights gained from the perspectives of young people with autism, siblings, and parents.

Third, these key study findings are conceptualised as a framework that helps to organise the findings and assist in understanding how the behaviours and patterns that may occur in families drive underlying social processes (Strauss & Corbin, 1990) that disrupt family members' sense of connectedness with each other and with the family, and impact on family relationships. A detailed description of this process and a conceptual framework are provided (see Figure 8). The framework provides a way to understand the impact autism has on the relationships between family members, including suggestions as to how and why these impacts are occurring. The framework also helps to understand what the impacts of autism might mean for families, including the meanings families give to these impacts.

In Chapter 7, suggestions as to how the conceptual framework can be translated and applied as a model for practice with families is provided. The practice model has the potential to be used to guide and inform interventions with families, with the goal of educating, upskilling, and supporting families to effect positive change from within the family system. This outcome of the research helps move towards the development of a holistic family support intervention for practice with families with a member who is a young person with autism. This intervention is centred within a dual approach of enhancing and strengthening family relationships and promoting family and social connectedness.

Situating Study Findings in the Context of Previous Research

The study responded to the limitations of qualitative studies exploring autism and family relationships, and the dearth of insights from young people's perspectives and their experiences of autism within the family. The impetus of the study was driven by a noticeable scarcity of interventions for families with a member who is a young person with autism, despite the acknowledged need to address the persistent rates of poor mental health, wellbeing and relationship outcomes experienced by family members caring for a young person with autism and by young people with autism (see Factor et al., 2019).

To inform interventions and practices for working with young people with autism and families, there is an identified need for research to focus on external responses to autism, and on the social and environmental factors that exist outside the family and their influence on this group (Kirby et al., 2016; Simpson, 2018). Qualitatively exploring the topic of autism and family relationships with young people diagnosed with the condition, and their fathers, mothers, and siblings, helps to address these knowledge gaps (see Chapter 2). The present study achieved this through an exploration of family dynamics, interactions, and behaviours with the study participants (see Chapter 1).

Chapter 2 reviewed the English-language studies reporting on the impacts autism has on family relationships. The findings generated from the current research are generally closely aligned with findings from other recent studies (e.g., Cridland et al., 2016; Goetz et al., 2019; Hickey et al., 2020; Hirsch & Paquin, 2019; Jones et al., 2019; Mazzoni et al., 2018; Nuttal et al., 2018; Orsmond & Fulford, 2018; Papp & Hartley, 2019; Roeyers & Mycke, 1995; Shivers & McGregor, 2019; Sim et al., 2016; Tudor et al., 2018), which found both positive impacts and negative impacts for families with a member with autism. This is evident from the issues that emerged from the accounts of participants in this study, as they spoke openly about their experiences of autism and its impacts on their family relationships, which are comparable with those identified in the review of the literature.

In the studies included in the review, some of the key issues also identified in this study were those within the parent-child relationship, such as parents spending more time and energy on the child with autism than on other children without an autism diagnosis in the family, which left other children feeling left out and withdrawn from their parents (Chan & Goh, 2013; Desai et al., 2012; Halloran et al., 2013; Nealy et al., 2012; Zechella & Raval, 2015). These findings correspond with the perspectives of parents, siblings, and young people with autism reported by participants in the current study.

Within the partner relationship, findings in earlier research of increased strain, stress, difficulties, conflict, and arguments in daily life impacting on the quality of partner relationships and affecting intimate alone time between couples (Desai et al., 2012; Hobart, 2008; Kuhlthau et al., 2014; Pottas & Pedro, 2016; Shur-Fen et al., 2012; Sim et al., 2016) correspond with perspectives of mothers and fathers in partnered relationships reported by participants in the current study. The themes of camaraderie between couples and increased bonding through caring for their child with autism evident in the literature (Nicholas et al., 2016) also correspond with the perspectives of husbands and wives, all heterosexual married couples, in the present study. Within the sibling relationship, earlier findings of significant behaviour problems leading to negative interchanges and having a negative effect on the relationship (Orsmond & Fulford, 2018; Pollard et al., 2013; Tomeny et al., 2017; Walton et al., 2015) correspond with perspectives of siblings, parents, and young people with autism reported by participants in the current study.

Quantitative studies (e.g., Hillman et al. 2016; Mazzoni et al., 2018; Riany et al., 2017) and studies using qualitative research designs (e.g., Corsano et al., 2017; D'Astous et al., 2013; Divan et al., 2012; McCabe, 2012; Prendeville & Kinsella, 2019; Zechella & Raval, 2016) conducted in different cultural contexts and across families from different cultures showed similar outcomes within family dyad relationships. The descriptive results reported in these studies showed some negative impacts on family relationships (e.g., increased tension between family members, and changes and disruptions in family structure and family member roles and responsibilities). Some of these results also showed positive impacts, such as an increased camaraderie amongst family members and a deeper connection and closeness in partner relationships. Overall, this study is generally supportive of the findings of the studies included in the review; however, this study adds a deeper understanding to our knowledge of how autism impacts family relationships, as discussed below.

Discussion of Key Study Findings

This section discusses the study findings provided in Chapter 5 to further our understanding of how autism impacts the relationships between family members, and the family as a unit. It does so by presenting an integrated, overall discussion of key study findings, with a focus on the new insights from the perspectives of young people with autism, siblings, and parents. This facilitates understanding of the behaviours and patterns within families that impact on their relationships. The key findings are discussed and further developed by drawing on findings from previous research.

The behaviours and patterns within families are understood to be disruptive factors in families that have a member who is a young person with autism; these behaviours and patterns have a direct impact on individual family members and a bidirectional effect on the interactions between family members. These disruptive factors include stress, anxiety, violence, anger, frustration, conflict, difficulty relating, and caregiver duties and responsibilities. The negative impacts of these disruptive factors can be buffered by several connective factors, which have a direct and positive impact on individual family members and a bidirectional effect on the interactions between family members. These connective factors include teamwork, open communication, family routines, spending positive time with each other, and making the time to get to know and understand each other.

These factors are interspersed throughout discussion of the seven key study findings. Concepts in the literature which help to interpret the findings are referred to, deepening our understandings of what is happening in these families.

Finding 1: Family Relationships are Impacted by the Physical, Emotional, and Social Behavioural Effects of Autism

This study found that time spent together for families was impacted by physical and emotional exhaustion related to physical violence and aggressive behaviours. Physical and verbal behaviour and conflict occurred in families, usually when the young person with autism was overwhelmed, stressed, or anxious; this was a shared experience for the young people with autism in the study.

The study identified that the signs preceding violence and aggression from the young person with autism, such as clenched fists or stomping, created a lingering feeling of constant uncertainty and alertness for mothers, fathers, and siblings. These family members did not know when to expect the young person's behaviour to escalate to anger, rage, or, at times, violence (Chapter 5). These behavioural effects of autism impacted negatively on all family members directly and affected familial interactions.

The findings suggested that although most siblings reported an uncertainty in their interactions with their brother or sister with autism, they also expressed a desire to want to spend time together as siblings, albeit peacefully. Fear seemed to be a significant factor driving siblings' sense of uncertainty. Siblings fearing arguments and fighting, including what their brother or sister with autism might say or do, such as yell or lash out at them, was a common experience for most siblings. Many young people with autism found it challenging to engage in a positive way with their family. At times, they did not know why they acted as they did but suggested that such actions could be the effects of their autism condition (Chapter 5).

What characterised the relationship of brothers with siblings with autism was like that of sisters with siblings with autism. The findings showed that many brothers and sisters would rather avoid their sibling with autism altogether than experience fear or worry about a likely negative outcome when they engaged with them. Siblings' collective accounts suggested that the fear itself and the apprehension around engaging with their autism sibling was a significant stressor for siblings. Over time, this could have a much greater impact on siblings and their relationships than the arguing or fighting.

This study presented data on how parents respond to the physical violence and aggressive behaviours of young people with autism. The parents in this study addressed this behaviour through problem solving, planning, and direct communication. Some other parents who found it difficult to address the challenging behaviours in this way described in detail and at length the emotional and physical toll these behaviours had on them as individuals and on their family as a group. Parents who handled challenging behaviours and worked through challenging events described the relationship they had with their autism child as close and connected. Some of the strategies parents used, such as open and direct communication, were recognised by the parents as having a positive outcome on families' connections and the closeness of family member relationships.

Some literature suggests that following a traumatic event and stress response, such as conflict, anger, or violence, family members often show signs of resilience and some *traumatic growth* (Campo, 2015; Jayawickreme et al., 2015). Resilience can be defined as the skill to manage demanding life events in physical, psychological, emotional, and social settings (Cridland et al., 2013), and traumatic growth is a form of positive interpersonal growth linked to coping with challenging or stressful life events (Cridland et al., 2013; Heiman & Berger, 2008). Families that "come together" after traumatic experiences can strengthen bonds and speed up recovery. This study's findings show, through the insights from the perspectives of parents, siblings, and young people with autism, how family relationships were strengthened through increased communication, by actively working through challenging family events, and by focusing on trying to create special time together as a family.

The research also indicates, through the insights of the young people with autism, that strong and close relationships for these young people can be created by spending one-on-one time with family members who provide reassurance, support, attention, and care. It is established in the literature that factors such as these contribute towards secure connections between individuals, "…when a person is actively involved with another person, and that involvement promotes a sense of comfort, well-being and anxiety reduction" (Hagerty et al., 1993, p. 293).

The study's findings are consistent with mothers' experiences of traumatic stress and growth related to parenting a child with autism presented in the literature (Wayment et al., 2018; Zhang et al., 2013a; 2013b). Finding 1 can be understood and developed by applying concepts of traumatic stress and growth. This finding has implications for understanding and providing effective support to parents and siblings of male and female genders. The demonstration of skillsets in families, and patterns of positive adaptions in these families, draw attention to what many of the families in the present study were already doing to build and develop resilience to buffer against some of the recognised impacts that autism has on family relationships.

Finding 2: Family Members' Coping Methods Buffer or Intensify Experiences of Stress Within Their Family Relationships

The study showed that some young people with autism perceived themselves as being different and acting differently to others because of their unawareness of "unwritten" social rules or etiquette, and how to follow these. For these young people, this meant that establishing close connections with family members was difficult, and this sense of difference led to a reduced sense of empathy and social motivation, despite clearly wanting and needing to connect with their families. In these young people with autism, this led to some potentially maladaptive coping responses to stress, such as withdrawing socially and emotionally from their family.

This study indicates that for some young people with autism their difficulty in relating to and connecting with their families led to increased anger and frustration directed at parents and siblings, which increased familial conflict. Several young people with autism in this study expressed their frustration when reporting they felt misunderstood by their mothers and fathers. Most young people with autism wanted the sense of their parents wanting to talk, "hang out" with them, and get to know them better.

Interestingly, some siblings without autism and several mothers and fathers reported limited understanding when interacting and communicating with the young person with autism and a difficulty in grasping their sibling's or child's perspective during the social interaction. In a small number of families where only one member did not have an autism diagnosis, this placed a strain on family relationships because the one member did not understand the way the rest of the family thought.

As identified in Finding 1, many parents and siblings in this study experienced frequent hostility and anger from the young person with autism. Siblings felt hesitant to engage with their brother or sister with autism due to a fear of increased conflict. Responding to this stress, siblings disengaged from their brother or sister with autism and reduced their interactions and communications in efforts to minimise conflict. This led to a physical separation and an emotional distancing and detachment between sibling dyads. In several families with multiple siblings, some with autism and some without autism, parents reported that siblings without autism would retreat to their rooms when faced with challenging behaviours from their brother or sister with autism. These siblings who withdrew also ended up isolated from other family members. This was evident in families with young people with autism and intellectual disability and those where a young person had autism without intellectual disability. Two siblings with autism reported feeling frustrated when their sibling without autism would disengage from them during arguments and leave the room.

This finding indicates potential disengagement in sibling relationships in these families. Disengagement in relationships is typically characterised by hostility and anger and is reflected in interpersonal distance by emotional and physical withdrawal (Bascoe et al., 2012). Disengagement in relationships produces a dismissing coping style and a stress-response strategy for managing conflict and is typically associated with poorer parent-child relationship quality (Cichy et al., 2013). Sibling disengagement as a specific style of detachment in family relationships (Hetherington, 1999, p. 196) is characterised by "…aggression, rejection, alienation and externalizing problems." Hetherington (1999) found that siblings in disengaged relationships "…avoid each other's company as much as possible and were actively complaining, critical, and aggressive when they did interact" (p. 327). The present study finding suggests the importance of developing good coping skills in siblings to manage stress.

The present study indicates that some young people with autism cope by withdrawing socially and emotionally from their family to spend time in their own worlds created from their imagination. Some other young people with autism cope by redirecting their focus on a particular interest. In the literature, coping is defined as "…reflective thinking, feeling, or acting so as to preserve a satisfied psychological state when it is threatened" (Snyder, 2001, p. 4). Social isolation, withdrawing, and avoidance behaviour are established in the literature as maladaptive coping strategies (Spirito & Donaldson, 1998). These behaviours are precursors to disconnectedness, characterised by social isolation and reduced or absent personal and intra-community relationships (Elliot, 2006). In addition to maladaptive coping styles, findings from the current study indicate how siblings and fathers, family members whose perspectives are underrepresented in literature (Lai & Oei, 2014), might use adaptive strategies to cope with challenging behaviours, situations, and events.

The present study also indicates that a positive reorientation of sisters' and fathers' attitudes towards disability can lead to their recognition and appreciation of the contributions the young person with autism makes to the family as a unit. For some parents in this study, this shift in attitude occurred alongside parents grappling with the loss of how they once lived their lives or the dreams they had once held for their family. This study also draws attention to the significance that hope, as an adaptive coping strategy, can have on family outlooks, and how parents are able to remain mindful of the possibilities for their families despite current challenges. These various coping strategies are recognised in the literature as buffers against stress in families and are seen as important to implement in families that have a limited support network and who rely greatly on extended family members (Luong et al., 2009).

Finding 3: Failure to Connect and Relate is Bidirectional Between Family Members With Autism and Those Without Autism

The present study found that some young people with autism found it difficult to read their parents' emotions, such as not understanding or misinterpreting what their parents were thinking or feeling. For some young people who found it difficult to relate to and connect with their families, this led to increased conflict and tension in the parent-child relationship and contributed to an emotional distance and physical withdrawal from one another. Sisters across several families struggled to relate to and connect with their brother with autism, and some mothers and fathers experienced a lack of connection in the parent-child relationship despite efforts to try to build these connections with their child with autism.

The present study's findings suggest that parents' and sisters' relationships with the young person with autism in the family are experienced as a physical presence but a psychological absence. A lack of reciprocating behaviours that parents reported in the interactions they had with their child with autism (e.g., smiling, laughing, eye contact, and tracking of gaze) contributed to a sense of loss and grief in the relationship with their child. Sisters who found it difficult to interpret or understand their autism brother's perspective experienced a sense of loss in the sibling relationship. Two sisters of brothers with autism and intellectual disability reported that their brother's restrictive and repetitive interests contributed to the sister's sense of an absence in the relationship. These findings are consistent with the "double empathy problem" theory, suggesting that it is not just people with autism who can misunderstand others, but they can be misunderstood by others, leading to a bidirectional failure of empathy (Heasman & Gillespie, 2017; Mitchell et al., 2021).

These findings could be understood and developed by applying concepts of ambiguous loss (Boss, 1977, 1999, 2004, 2009) within family relationships. An ambiguous loss results from an indistinct or complicated physical loss with a retained psychological presence, such as a missing person, or the loss or alteration of the psychological state of a person, such as when a family member is diagnosed with depression or another mental illness (Boss & Yeats, 2014). The theory was developed from family stress theory (see Carroll et al., 2007), which suggests that stress manifests in a family whenever there is change (O'Brien, 2007). The most severe stresses in a family are thought to be ambiguous and not obvious (Boss, 1999), such as the loss of normative family experiences (Collings, 2008; O'Brien, 2007). These stresses can also impact on one's ability to cope (Hillegas, 2012).

Most families in this study reported a loss of normative family experiences. This included parents' loss of the expectations they initially held for their children when they were very young, and siblings' loss of the expectations of a brother or sister they could play with and relate to. Families can be expected to continually reframe their expectations of family life; for example, they may do so as they come to terms with the autism diagnosis (Poslawsky et al., 2013) or with the effects the condition has on their families, as an ongoing part of the grieving process.

These findings are consistent with research about mothers' experiences of grief and loss first occurring when autism is diagnosed in their child (O'Brien, 2007), and are also reflected in research about mothers' experiences of parenting a child with intellectual disability, with grief recurring when their child does not reach normative developmental milestones (Rarity, 2007). The current study contributes insights about grief and loss from the perspectives of young people with autism, fathers, and sisters in their relationships with the young person with autism in the family. The data gathered from the young people with autism in this study contributes a novel insider account of grief and loss. The study also adds to knowledge an understanding that young people with autism experience grief and loss as a social and emotional disconnectedness from their parents alongside a yearning to connect with them. This study suggests that young people with autism and their parents both experience a loss of some form within the relationship, which may be as a potential unifying experience for parents and young people with autism.

Finding 4: Psychological and Emotional Entanglement Affects the Relationship Between Fathers and a Son With Autism

This study presented data on how the characteristics and effects of autism (e.g., anxiety, stress, and social withdrawal) in some young males with autism are mirrored in their father's behaviours and social preferences. Fathers' perspectives of this phenomenon were related to their sons' experiences of autism. These sons experienced autism as an overwhelmingness and overstimulation of the senses, which led to increased anxiety and stress and resulted in withdrawal from their family members. These young males with autism did not want to burden their fathers with these issues but called on them for emotional reassurance and help to manage these feelings and expressed a need to strive for greater emotional independence.

These findings suggest potential enmeshment in the father-son relationship in families. Enmeshment in relationships occurs from undefined or too *open* boundaries between members and is characterised by increased levels of interpersonal and emotional entanglement (Bascoe et al., 2012). Although enmeshed relationships appear to show affection and care, closeness and attachment are developed alongside minimal independence and unbalanced goals for each member (Barber & Buehler, 1996). This can impede the individuality process and affect the establishment and continuation of psychosocial development in family members (Barbarin & Tirado, 1985; Barber et al., 1994; Greenberger & Sorensen, 1974).

Finding 5: Sisters' Role as Caregivers in Families with a Young Person With Autism and Intellectual Disability

This study found that siblings, mothers, and fathers took on multiple roles in their relationships with the young person with autism in the family. Family roles reflect how responsibilities and tasks are divided within the family. These can be domestic roles, such as housework, as well social emotional roles, including emotion coaching and how family members react to emotions (Carpenter, 2010; Morris et al., 2007). The study indicates that all sisters of brothers with autism and intellectual disability took on a caregiving role in the sibling relationship.

A caregiving role in a family crosses broad domains of activity, and involves domestic, social, and emotional support and care provided to a family member. A caregiving role in the family changes over time and is related to the changing needs of the family member who requires care (Schulz & Eden, 2016).

In the present study, the role of sisters caring for their brothers with autism was a significant part of the sibling relationship and was both practically challenging and emotionally challenging for the sister. All sisters of brothers with autism and intellectual disability and most parents perceived the increased caregiver duties and responsibilities sisters undertook as concerning, particularly the ongoing care required for the young person with autism.

The study found that the sibling caregiver role was amplified in families where the young person with autism had an intellectual disability, typically requiring high levels of support and thus placing increased physical and emotional demands on all family members, in particular sisters. The research also suggests that additional caregiving duties for sisters may be present in single parent families and may increase further when the young person in these families has an intellectual disability.

The present study found that the type of care sisters provided to their brothers with autism was all-encompassing. It covered physical, emotional, and social care and occurred inside the family setting and outside the family, including in school. Some older sisters in families (over 19 years of age) felt a sense of vulnerability in their brother with autism, someone to be protected and cared for, supported, and watched over. Sisters' sense-making of the protective element of caring for brothers with autism helped sisters to come to terms with their additional caregiving duties despite the significant impact these duties seemed to have on sisters' wellbeing.

Some of the sisters spent much of their time at school managing and attending to their brother's care and support needs, which left sisters with limited time to develop peer relations of their own. In a small number of single parent families, both the mother and older sister's sense of protection over their son and brother with autism and intellectual disability increased their sense of closeness in their relationship.

The study findings suggest that sisters' ambivalence towards caring for their brothers with autism is associated with unclear boundaries and role confusion in the sibling relationship. This was observed with sisters parenting their older brothers with autism, and instructing them, or reprimanding them for poor behaviour. Sisters in two families "mothered" their brothers with autism and offered forgiveness for their (the brother's) poor behaviour. These findings draw attention to the gendered nature of caregiving in the sibling relationship, particularly in families with a young person with autism and intellectual disability.

These study findings are consistent with research about boundaries and boundary ambiguity in parents caring for chronically ill children (Boss & Couden, 2002). Boundary ambiguity is "…a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system" (Boss & Greenberg, 1984, p. 536). Boundaries refer to the functioning of the relationships and roles between different members of the family and the expectation about who does what within the family (Berge & Holm, 2007). Boundaries can either be open or closed, and ideally operate along a continually moving band which accounts for the fluidity and cohesion of the family (Olson, 1985). If boundaries are too *closed*, rigidity in the roles ascribed to family members can lead to social withdrawal within the family. If boundaries are too *open*, members may have difficulties in distinguishing between family roles, such as the blurred division between being a sibling and being a caregiver.

Finding 6: Family Support and Social and Community Connectedness as a Buffer Against External Responses to Autism

The young people with autism in this study provided novel understandings of the shared and distinct features of their autism. There is no current exact or definitive description or definition of autism that captures or describes the richness of these young people's experience, including the characteristics and effects associated with the condition. In the present study's findings, the global theme of *Being different and feeling different* indicates that most young people with autism perceive the condition as an intrinsic part of who they are, contributing to their sense of self and individuality as a person. For the young people in this study, having autism was a major reason that they thought they felt and acted differently to people without the condition. This difference was social, emotional, and physical. Interestingly, most young people with autism in this study accepted their condition, in that they could not imagine themselves to be who they were without it. This was alongside the negative external responses to autism that young people and their families sometimes received through their schools and their communities.

This study indicates that young people with autism may often be proud that their condition makes them feel different to others, and behave and think differently to others. However, some young people with autism struggled with feeling and behaving differently to others, especially in the earlier years of adolescence when they began to compare their behaviours to those of people around them. Over time, in the later years of adolescence, these young people developed an acceptance of the condition and the effects it had on them. Most of the young people who were proud were mostly from multiplex families (Sanders, 2013); that is, families with more than one member with autism. Some of these families included mothers or fathers with an autism diagnosis.

This study suggests there was a distinction between two groups of families who participated in this study. First, there were families who reported largely negative effect of external responses to autism. Most of these families had more than one member in the family with an autism diagnosis and had an expectation that others outside the family should work to accommodate them more inclusively into the community. Parents in these families actively pushed back against discrimination and stigma directed at their families and actively coached and guided their children with autism to manage challenging or confronting situations they might face outside the family.

These kinds of families mostly considered autism as a neurodiverse condition of difference instead of a disability with which a person is afflicted. These families mostly provided a positive and strengths-based family environment and showed an awareness of how autism is framed within their families. Parents in these families tended to associate the positive characteristics of their child with the autism itself and to relate the negative effects the condition had on their child to poor external responses that impacted young people. For example, they saw these poor external responses as causing an increase in young people's challenging behaviours and oppositional reactions towards others. Most siblings without autism in these families with more than one member with autism also held a strengths view of autism. Second, there were families who mostly perceived the negative characteristics and effects of autism as core to the condition. These families seemed to minimise or avoid time spent out in the community together as a family for fear of ridicule, or drawing attention towards themselves, or disturbing others in the community.

This contrast between the two groups of families indicates the important role that a family plays, and in particular the role parents play in buffering against negative responses to autism. This "social buffering" (Cohen & Wills, 1985; Wilcox, 1981) may potentially protect young people with autism against negative mental health outcomes, such as depression. Supportive and positive family environments are recognised as effective buffers from adverse events (Manczak et al., 2018), and may reduce the impacts negative events have on adolescents (Ge et al., 2009).

For finding 6, social identity theory and its processes (Tajfel & Turner, 1979) offer a potentially useful lens through which to understand how the family as a unit perceives itself in the context of autism, and how this perception can effect family connectedness (Manzi & Brambilla, 2014) and social and community connectedness (Lee & Robins, 1998; Tomison, 1999). Family connectedness is defined "…as a particular characteristic of the family bond, also referred as family or parental closeness, support, warmth, or responsiveness. This characteristic of the family can be observed when families maintain emotional connections with each other through encouragement of shared family [time together] … [to] provide a way for family members to share affection, to offer emotional support and reassurance in difficult times, and to strengthen family bonds by promoting emotional, open and clear communication, and joint problem-solving" (Manzi & Brambilla, 2014, p. 1). Social connectedness is "…an internal sense of belonging that reflects an individual's subjective awareness of being in close relationship with the social world … [and] encompasses close and distal relationships with family, friends, peers, community, and the wider society" (Lee & Robbins, 1998, p. 338). Community connectedness is "…a sense of identity or feeling of belonging, and good relationships, with several links with people or groups from outside the immediate group" (Tomison, 1999, p. 15).

Connecting and a sense of belonging in interpersonal relationships, in family groups, and in wider social groups is a central human need (Greer et al., 2015). The basis of connectedness is "…positive relationships and experiences with others, and more specifically, relationships and experiences from which [children and] youth garner esteem and competence" (Karcher et al., 2008, p. 9). Social identity theory (Tajfel & Turner, 1979) suggests that social groups and group membership play a role in how we define ourselves. Membership in a group stigmatised by society, such as disability and specifically autism (Cooper et al., 2021), can make it difficult for members to develop a positive identity and develop and maintain meaningful relationships with others (Goffman, 1969; Goldstein, 2002). Stigmatisation of groups has negative outcomes on members' emotional and social wellbeing (Crocker & Major, 1989). A strong sense of affiliation with members in a group and positive views of the group's community (e.g., the "autistic" community) may possibly improve psychological wellbeing, as demonstrated through a reduction in depression and anxiety scores in adults with autism (Cage et al., 2018; Cooper et al., 2017).

Finding 7: Families Lack Access to Suitable Supports and Experience Powerlessness and Exclusion from Their Communities

Families in this study lacked access to suitable supports and most had no access to affordable respite. The study provided insights from the perspectives of parents, siblings, and young people with autism about the supports that would be needed for young people with autism and their families to better cope with family relationship challenges.

Some of the supports identified included support groups for parents and children without autism to develop and nurture the connections with each other; targeted supports to reduce conflict within the sibling relationship; and tailored support groups and mentors for sisters with caregiving duties in families to reduce their sense of isolation and difference from peers in families without caregiving responsibilities. Some of the young people with autism had access to a psychologist who provided emotional and social support and skill building, but some young people felt these professionals lacked an understanding of the distinctiveness of experience that people with autism have.

Based on information provided by the participants in the study, there is evidence that the health professionals lacked understanding of autism. This was a common theme across most families, and an experience they reported as occurring throughout their lifetimes. Insights provided from the perspectives of parents, siblings, and young people with autism in families with older adolescents aged 17 to 19 years suggest that health professionals' knowledge of autism increased just slightly over nearly two decades. Families' reports suggested most health professionals that families interacted with continued to have an outdated view of autism or lacked suitable knowledge of the condition and how to work with young people with autism. Most families identified a small number of health professionals that they recognised as holding adequate knowledge of autism and who had suitable clinical experience with adolescents with autism.

The study provided insights from the perspectives of the young people themselves on how this lack of knowledge of autism makes young people, and their families feel powerless and excluded from their communities. This study found that a broader lack of knowledge of autism existed throughout families' communities, and families faced negative responses about autism in all domains of their lives: in public, at work, in school, and with other families. When each family member experiences negative external responses to autism, the family as a unit withdraws into itself, isolated from people outside the family. The study suggests that social isolation places increased pressure on relationships between family members and contributes to a perception of a negative family identity.

The study's findings showed that school was one of the settings that impacted greatly on most families, and on all members in these families. Families in the present study faced extended wait times to access funding from the NDIS to purchase supports, and thus relied on schools to help their young person with autism. The families received inadequate or no support from schools, and some young people themselves experienced exclusion from school activities when their autism diagnosis was disclosed. The study revealed the school environment to be a high sensory setting that some young people with autism struggled in. Despite some parents' attempts to work with the school to make changes to classroom settings, schools responded poorly and did not act on these requests and suggestions from parents. The study found that these poor experiences at school translated to challenging behaviours within the home, which impacted on family relationships.

The influence of the environment on different groups of people with disabilities, including childhood disabilities, is recognised (Kriegar et al., 2018) but has rarely been studied in the context of neurodevelopmental disabilities, such as autism, in adolescence. Scholars have recently turned to young adults with autism to identify the barriers they face to social inclusion and participation in their communities (e.g., Anderson et al., 2018; Buckley et al., 2020; Goodall, 2018; Griffith et al., 2012a; Mattys, 2018), however at present, there is limited knowledge to help make sense of the multitude of factors that contribute to the social disadvantage and exclusion young people with autism face in their communities. While research is yet to determine which families face the greatest risk of experiencing the negative effects of autism, this study indicates that families who lived in advantaged areas and who experienced a multitude of negative relationship and wellbeing impacts could not access the supports they needed and wanted.

Summary of Discussion

This section of the chapter discussed the key findings from the study, highlighting new insights from the perspectives of young people with autism, siblings, and parents, and suggested patterns of behaviour that occurred within these families. The experiences described by the study participants included the disruptive factors in families that have a member who is a young person with autism, and the connective factors that create buffers against these, reducing their impact. These connective factors also had a direct and positive impact on family members, increasing family members’ overall sense of connectedness and strengthening their relationships between one another. Key concepts such as ambiguous loss, boundary ambiguity, enmeshment, resilience, and traumatic growth were drawn upon from the literature to interpret the findings and deepen our understandings of the impact of autism within families.

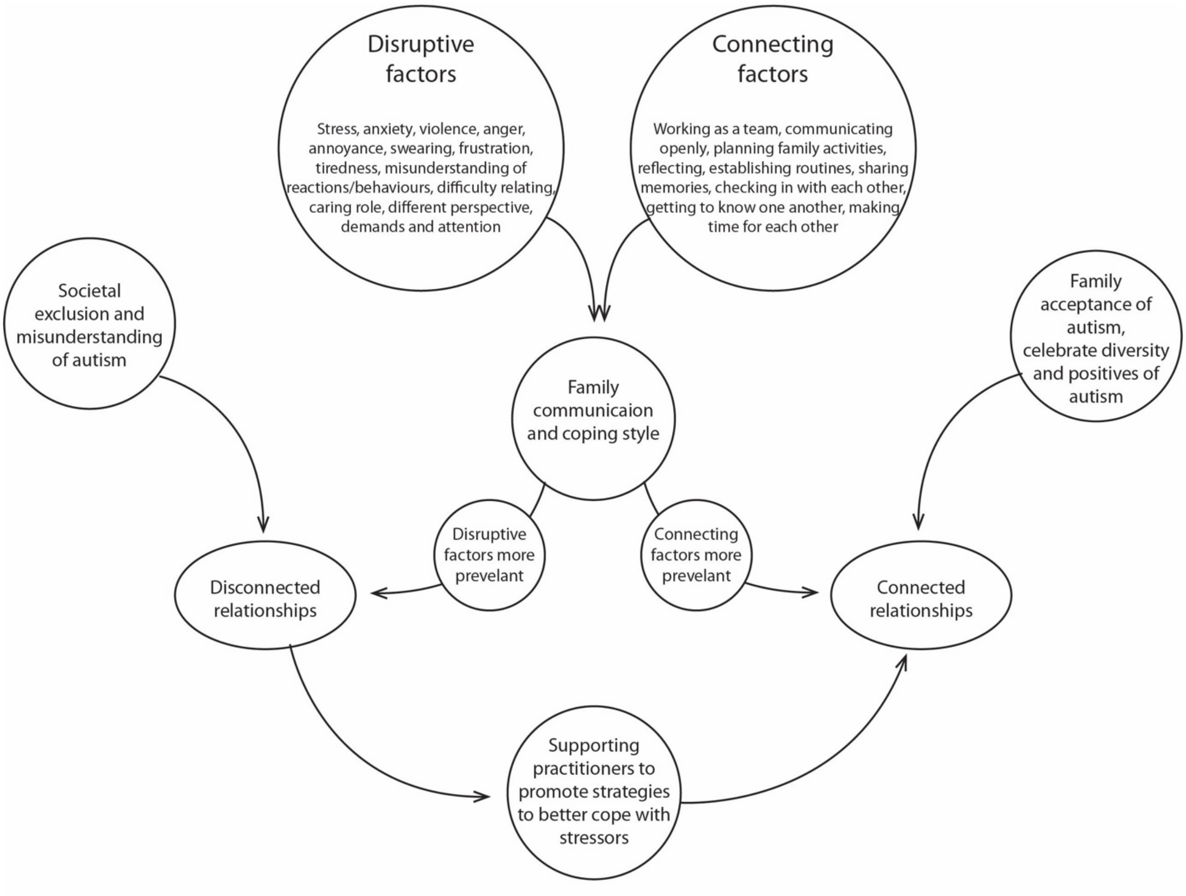
The following section provides further interpretations of the key study findings. It conceptualises how these behaviour patterns (the identified disruptive and connective factors) that this study suggests occurring in families drive underlying social processes (Strauss & Corbin, 1990) that disrupt family and social connectedness and impact on families’ relationships. A detailed description of this process is provided, and a visual of the process is constructed in Figure 8, which is proposed as the conceptual framework.

Conceptual Framework for Understanding how Autism Impacts Family Relationships

A conceptual framework was generated from the key study findings to indicate how autism impacts on relationships between family members, and the family as a unit. The conceptual framework offers new insights and ways of understanding the factors that have an impact. It is a tentative and indicative framework and has the potential to contribute to future theoretical developments in discussions about directions for future research with families that have a member who is a young person with autism. The conceptual framework is presented in Figure 8, illustrating the outline of ideas that help to make sense of what is happening in these families, understood through their experiences.

Figure 8

Conceptual Framework for Understanding how Autism Impacts Family Relationships



First, the framework suggests that the process by which autism impacts the relationships between family members, and the family as a unit, is driven by several disruptive factors and behavioural patterns in families that have a member who is a young person with autism. These have a direct impact on individual family members and a bidirectional effect on the interactions between family dyads. The presence of these factors facilitates a physical withdrawal and emotional distancing between family members, which results in impeded family relationships. Impeded relationships between multiple family members creates disrupted connections across the family as a unit and a sense of disconnectedness within families' relationships.

Second, this process is buffered by several connective factors that positively impact on family members directly and on their interactions with each other. The presence of these factors creates a togetherness in families, a greater understanding of each family member by the others, and a sense of closeness and security within the family as a unit; together, these result in bonded and strong family relationships. Bonded and strong relationships between family members creates positive connections and a sense of connectedness within families.

Third, the framework suggests that societal exclusion and misunderstanding of autism reinforces a family relationship situation already characterised by interpersonal distancing and relationship disruption. The impact of these factors on group formation and cohesion may be an important factor in the intensity and continuation of disconnectedness and detachment within families.

Fourth, the framework indicates that whether families have a greater positive connection or a greater disconnect in their relationships is related to how they respond to autism, and to external responses to autism—those outside of the family as a unit. Linking to the theoretical orientations presented in Chapter 3 to see what distinctive understandings of the data these bring to the conceptual framework, a systems perspective complements childhood studies by recognising children's agency and influence when interacting with their social environments and the systems affecting them and their family (Connolly & Harms, 2012; Walsh, 2011). A systems perspective with a disability studies perspective shaped the data analysis and findings by focusing attention to instances in the data which suggest or affirm how the social and physical environment might dictate or influence the agency of a person with disabilities, and the disadvantages people with disabilities can experience without a strongly positioned voice to influence broader systems. In other words, the systems perspective highlights how social structures and the physical and social environments can oppress, dominate, and constrain people with disability and the people who care for them, such as family members (Cologon, 2016; Jackson, 2018; Mitra, 2018; Oliver, 2013).

Fifth, practitioners supporting families could work collaboratively with them to achieve a balance in the patterns of behaviour that can lead to dysfunction within family relationships and promote strategies that help families to better cope with stressors. This could help to establish bonded, close, and strong relationships between family members, and might assist in establishing family connectedness and social connectedness within families. The implications of these findings—how they contribute knowledge to inform policy and guide practice with families—is presented in Chapter 7.

Finally, it is important to acknowledge that the idea that the ‘prevalence’ of disruptive/connecting factors determine whether relationships are connected or disconnected is an oversimplification, and a visual display of the process cannot capture the complexities involved. While some specific factors wash out the effects of others, it is the combinations and interactions of certain factors that swings the balance from connected to disconnected relationships. The dichotomy in and of itself is problematic, as there are degrees and quality of connections that cannot be captured by such a dichotomy. A description of a continuum might capture this relationship more aptly. Furthermore, the point of support from practitioners is reactive, rather than proactive, as positive outcomes are more likely to occur when the point of intervention is earlier on before relationships become disconnected or engrained.

Chapter 7: A Recommended Practice Model and Conclusions

Introduction

This study provides a conceptual framework that was informed by the key study findings. The framework illustrates how autism impacts on relationships between family members, and the family as a unit; this could then be translated into and used as principles of practice to inform and guide interventions with families. The principles of practice discussed in the following sections might assist practitioners to reflect on what steps they could take to structure an intervention. A practice model informed by the principles might assist practitioners to reflect on what steps they could take to action change in families, with an emphasis on enhancing and strengthening family relationships and promoting connectedness. Family practitioners might use the knowledge generated from this study in a way that sits within a person-centred approach, which considers the people who use human services as equal partners in planning, developing, and monitoring services to make sure they are meeting their needs (de Natris, 2018).

The practice model is proposed to address the recognised shortages of a holistic family support intervention that meets individual family needs, and which works towards improving and strengthening relationships in families that have a member who is a young person with autism (Factor et al., 2019; Spain et al., 2017). It suggests practice strategies and approaches and is aligned with the guiding practice principles. The model and its components bring together multiple forms of knowledge to bridge the gaps between theory, research, and practice.

The Practice Model

The model presented is a situated family-based practice model for practitioners working with families with a young person 12–19 years of age with autism and their parent/s (mother and father or caregiver), and siblings (brother and sister). It has the dual aims of enhancing family relationships and promoting connectedness in families (Figure 9). The significance of a *situated* model is its contextualisation within a particular practice space (e.g., Ash, 2016; Held, 1990; Hugman, 2005; Tronto, 1993). Most often a practice model develops out of actual experience or experimentation rather than evolving from a particular theory of behaviour (Sheafor & Horejsi, 2008). In Chapter 6, the discussion of key findings indicated several impacts that autism had on the study participants' family relationships. In recognition of these impacts, a model for practice (Figure 9) and principles of practice (Figure 10) were developed to provide suggestions and guidance as how to practitioners working with families might address these impacts.

The development of the principles of practice and the identification of the elements that make up the model were guided by and derived from the key study findings and the conceptual framework of the study and were further developed by drawing on findings from previous research to provide evidence-informed approaches and strategies. The central tenet of the model is a collaborative approach to practice, which enables families to have choice and control over how they receive intervention, what the intervention will address, and the kinds of supports practitioners implement or source for the families to engage with (de Natris, 2018). It is important to note that this idea of a collaborative approach to practice is not novel and many service providers would argue that they are already adopting such an approach.

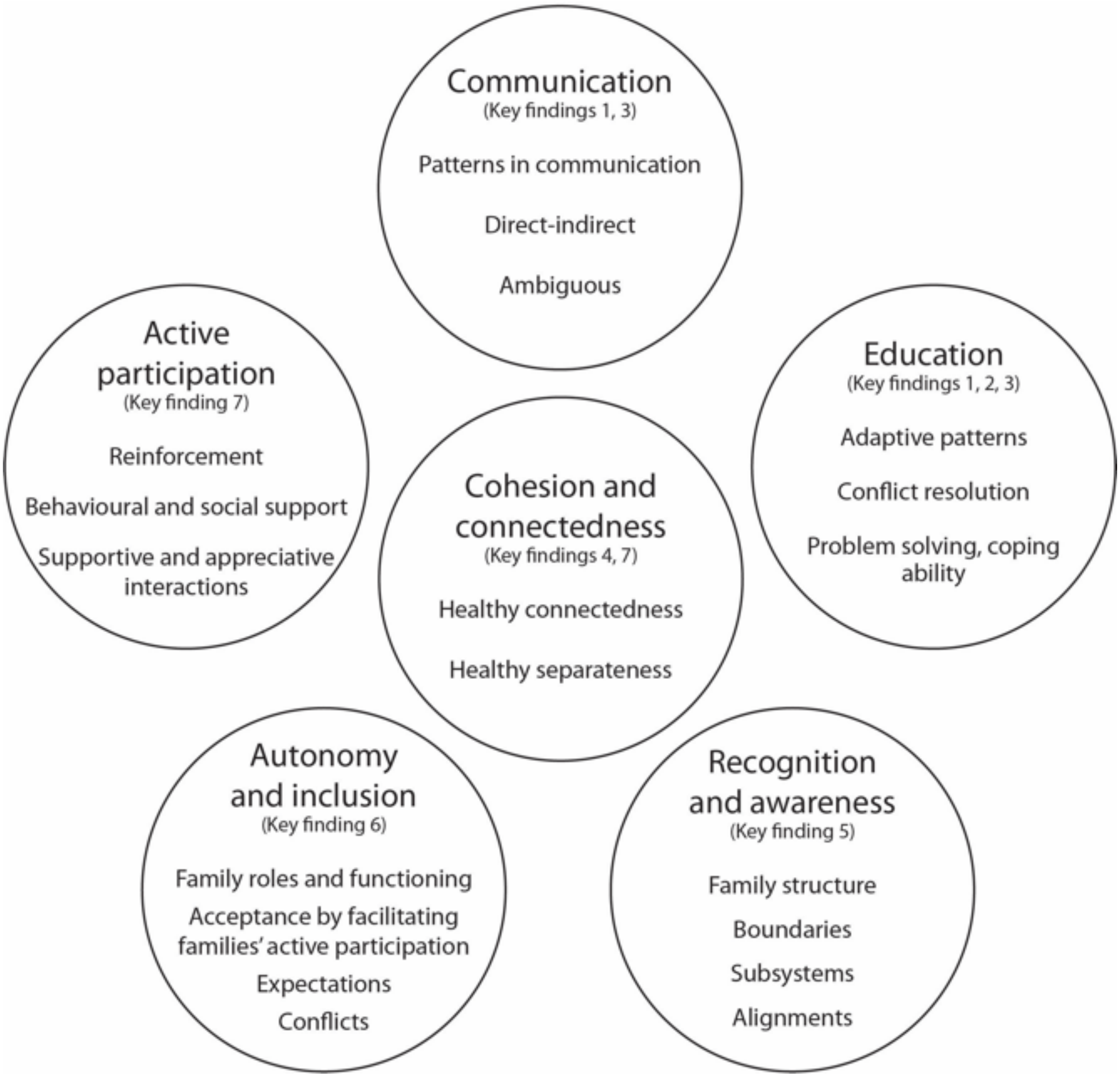
Service providers are, however, often constrained by restrictive service provision models, such as the individualised, therapeutic interventions funded by the NDIS.

Informed by the key findings, six broad elements for practice were generated that address some of the recognised impacts autism has on family relationships. These could assist practitioners who work with families that have a young person with autism as a member to develop their openness and *communication* with each other; *educate* families on adaptive patterns, such as coping and conflict resolution skills*; encourage recognition and awareness* of the issues impacting on the structure of the family and on relationships between family members; and promote *cohesion and connectedness* amongst family members. Practitioners working within families' systems of supports could work towards promoting family members' *autonomy* and encourage the *inclusion* of autism and disability throughout all family domains, and persistently strive to reduce the powerlessness and exclusion families experience external to the family as a unit by reinforcing families' *active participation* in the community.

The practice model (Figure 9) illustrates which of the key findings inform and support the development of each element for practice in the model. Information about how these elements respond to the key findings—that is, how they can be incorporated into intervention with families to reduce the impacts of autism on relationships—is interspersed throughout a description of how the model might be applied for practice with families, presented in the sections below.

Figure 9

A Situated Family-Based Practice Model for Intervention With Families That Have a Member Who is a Young Person With Autism



Given the heterogeneity of autism presenting in young people, and the diversity inherent in families, an exact hierarchy of principles, approaches, and the strategies used to guide family interventions and inform practice are not proposed. Rather, a reflective, flexible, and dynamic model is proposed as a blueprint for action, describing what happens in practice in a general way to guide decision-making and to assist practitioners in articulating key concepts and principles with families. Consequently, the practice principles or *action steps* in an intervention are not tied to any one explanation of problem situations a practitioner may encounter when working with families.

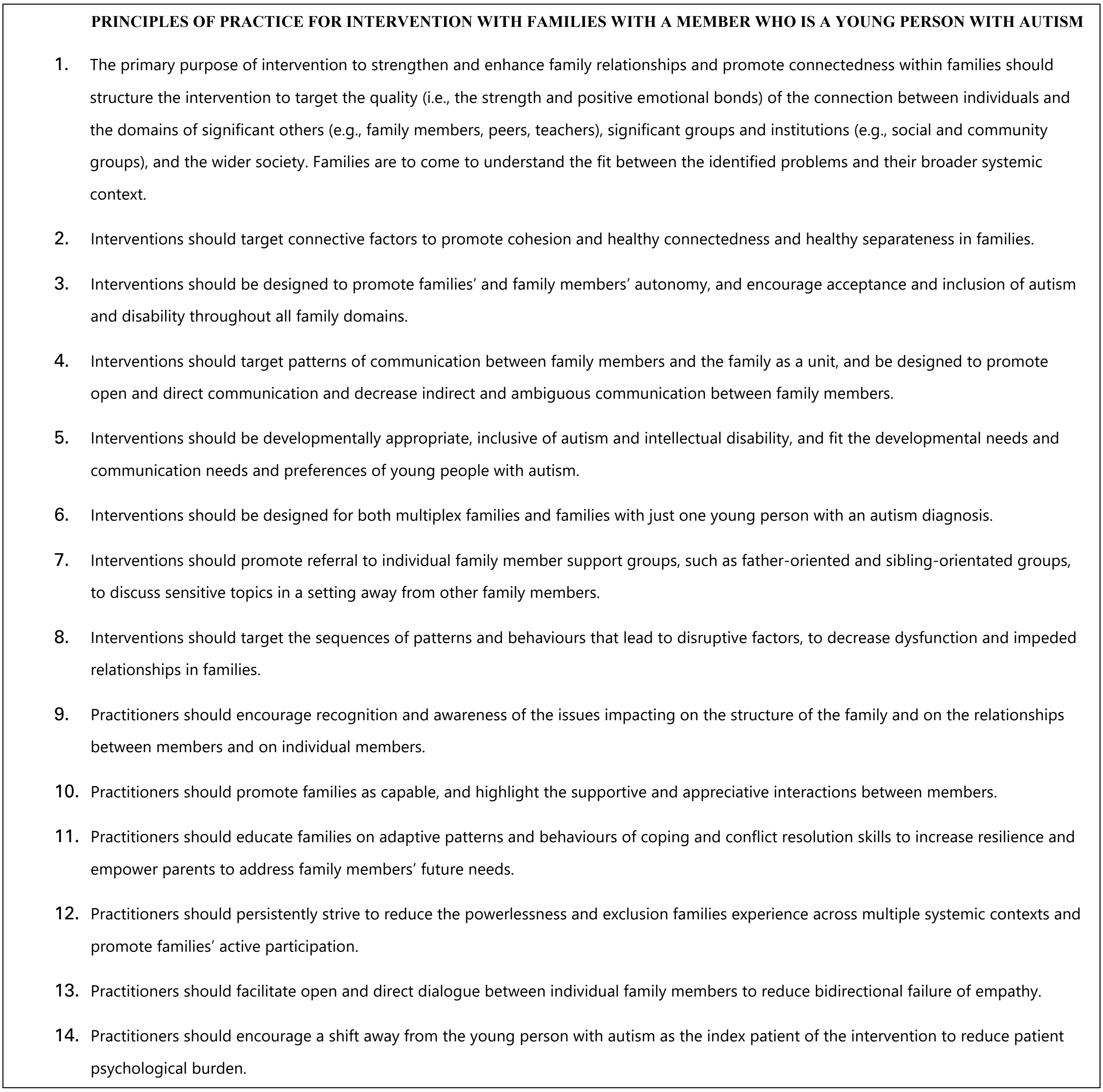
The principles of practice and the practice model are positioned from a social view of disability, recognising that the social environment an individual with autism is in can disable or enable them to participate as fully as possible (Altman, 2001; Hall, 2019). In practice, this means that the family practitioner might create an encouraging and therapeutic practice space to enable full involvement of the adolescent with autism in the intervention and accommodate the young person's communication preferences as fully is possible. It is recommended that practitioners throughout an intervention consistently draw upon professional ethical commitments to uphold disability rights and justice, and respect for persons with disability (Hiranandani, 2005).

Principles of Practice

The proposed principles (Figure 10) that align with the practice model were generated from the conceptual framework, constructed from the key findings of this study, and further developed by drawing on findings from previous research. They could be used to inform and guide interventions with families with the aim of limiting the disruptive factors impacting family relationships and promoting the connective factors, to enhance and strengthen family relationships and promote family and social connectedness.

Figure 10

Principles of Practice With Families With a Young Member With Autism



PRINCIPLES OF PRACTICE FOR INTERVENTION WITH FAMILIES WITH A MEMBER WHO IS A YOUNG PERSON WITH AUTISM

1. The primary purpose of intervention to strengthen and enhance family relationships and promote connectedness within families should structure the intervention to target the quality (i.e., the strength and positive emotional bonds) of the connection between individuals and the domains of significant others (e.g., family members, peers, teachers), significant groups and institutions (e.g., social and community groups), and the wider society. Families are to come to understand the fit between the identified problems and their broader systemic context.
2. Interventions should target connective factors to promote cohesion and healthy connectedness and healthy separateness in families.
3. Interventions should be designed to promote families' and family members' autonomy, and encourage acceptance and inclusion of autism and disability throughout all family domains.
4. Interventions should target patterns of communication between family members and the family as a unit, and be designed to promote open and direct communication and decrease indirect and ambiguous communication between family members.
5. Interventions should be developmentally appropriate, inclusive of autism and intellectual disability, and fit the developmental needs and communication needs and preferences of young people with autism.
6. Interventions should be designed for both multiplex families and families with just one young person with an autism diagnosis.
7. Interventions should promote referral to individual family member support groups, such as father-oriented and sibling-orientated groups, to discuss sensitive topics in a setting away from other family members.
8. Interventions should target the sequences of patterns and behaviours that lead to disruptive factors, to decrease dysfunction and impeded relationships in families.
9. Practitioners should encourage recognition and awareness of the issues impacting on the structure of the family and on the relationships between members and on individual members.
10. Practitioners should promote families as capable, and highlight the supportive and appreciative interactions between members.
11. Practitioners should educate families on adaptive patterns and behaviours of coping and conflict resolution skills to increase resilience and empower parents to address family members' future needs.
12. Practitioners should persistently strive to reduce the powerlessness and exclusion families experience across multiple systemic contexts and promote families' active participation.
13. Practitioners should facilitate open and direct dialogue between individual family members to reduce bidirectional failure of empathy.
14. Practitioners should encourage a shift away from the young person with autism as the index patient of the intervention to reduce patient psychological burden.

Whilst the principles were formed within this project, and therefore directly informed by the perceptions and experiences of the families involved in this study, they may also apply to other families with similar characteristics and experiences. They might be useful as a guide to inform interventions as to what this study suggests might work in families to effect positive change to address the recognised impacts of autism on family relationships. How the principles could be actioned through the practice model (Figure 10) for intervention with families, is interspersed throughout a description of intervention and suggestions as to how it might work.

The principles of practice, the practice model and suggested strategies and techniques together, are constructed from this study - the study participant's perspectives on how autism impacts relationships between family members and on the family unit, the issues and processes presenting in the study families as interpreted and described in the discussion of key study findings and illustrated in the conceptual framework and with what evidence in the literature suggests might work best to effect positive change within these families, towards strengthening their relationships and promoting family connectedness and social and community connectedness.

Therefore, the following sections provide suggestions for intervention, what it might look like and how it might work, for families that have a member who is a young person with autism, that are participant informed, evidenced informed and theoretically grounded.

Description of Interventions

Some authors (Spain et al., 2017) note that approaches, design, and methods for family intervention for families with a member who has autism vary (e.g., Goepfert, 2015; Helps, 2016; Ramisch, 2013; Solomon, 2012), with most evidence recognising social, cognitive-behavioural (Fletcher-Watson et al., 2014; Lang et al., 2010; Spain, 2015; Sukhodolsky et al., 2013), and skills-based approaches for intervention with families (Reichow, 2013; Spain, 2015) as being most effective. These studies have tended to identify effectiveness for groups with defined characteristics (e.g., age ranges and autism level of index patient). Spain et al. (2017) suggests a drawback of these approaches is that they do not target intervention for relationship and communication issues between family members and do not seek to develop family connectedness (Manzi & Brambilla, 2014) or social and community connectedness (Lee & Robbins, 1998; Tomison, 1999), or to improve family coping strategies or resilience factors (Spain et al., 2017).

Although the concept of connectedness is firmly recognised in literature (Foster et al., 2017), it has not been considered for families that have a young person with autism as a member. Most studies of connectedness have based their processes in Bowlby's (1969) attachment theory, defined as "…lasting psychological connectedness between human beings" (p. 194; Barber & Schluterman, 2008). However, attachment alone does not consider other key socio-developmental influences (Hassall et al., 2021). Consequently, an intervention designed for families that have a young person with autism as a member should consider a holistic conceptualisation of connectedness, such as those informed by Bronfenbrenner's (1986) ecological domains of influence, alongside those of Manzi & Brambilla, 2014 and Resnick et al. (1997) conceptualisation of family connectedness and Lee and Robins's (1998) and Tomison's (1999) conceptualisations of social connectedness and community connectedness, respectively.

Relationship dynamics which involve closeness and distance are issues for all dyads and family units (McCann & Pearlman, 1990). Practitioners working with family members can assess cohesion in the family to ensure that the level of social interaction, healthy connectedness, and healthy separateness is balanced and accepted by all members (Broderick, 1993). If patterns of behaviour are unbalanced, family members will most likely act in a dysfunctional way (Broderick, 1993). As such, practitioners working with families with the aim of strengthening and enhancing family relationships and promoting connectedness in families can structure the intervention to enhance the quality (positive emotional bonds) of the connection between family members and significant others, including peers, teachers, colleagues, and friends, and significant groups and institutions, including social and community groups, and the wider society.

There are a variety of interventions and associated strategies available for practitioners to apply with families. These include, for example, psychoeducation (Butler, 2008), narrative techniques (Carr & White,1998), and questioning styles, such as circular, and reflexive questions (Hayes, 1991). Family therapies are recognised as an effective and inclusive intervention approach suitable for a wide range of clinical populations (Carr, 2009; Varghese et al., 2020). Oriented by systemic theories, family therapy aims to understand and enhance family members' communication, relationships, sense of closeness, and strength of connections between each other, for greater functioning of the family (Dallos & Draper, 2010).

Family therapy is recognised by authors (Spain et al., 2017) as a potentially suitable approach to intervention with families who have a member in the family with an autism diagnosis, provided that core symptoms of the condition contribute significantly towards family dysfunction. Practitioners implementing family therapy provide a means for the family to make sense of challenging and difficult situations and circumstances, by helping the unit work together (Hayes, 1991). In therapeutic practice, sessions might include some or all members in the immediate family unit. Family members included in the intervention should be encouraged to decide who is able and open to engage in sessions, and the combination of members attending can vary each session. Prescription of intervention duration and length of sessions will vary between families and is dependent on the unique presenting factors of each family, the service model, and the practitioner's theoretical orientation and approach to therapy (Spain et al., 2017).

The current study's findings suggest that adapting the structure and content of family therapy for young people with autism and their family members is one way to accommodate the unique grouping and presentation of the behavioural patterns that may be present in these families. These are factors that are impacting on family relationships and driving underlying social processes that disrupt family connectedness and social and community connectedness, as illustrated in the conceptual framework (Figure 8). Informed by the study, the suggestions below describe how intervention might work for families with a member who is a young person with autism.

Family-Based Practice Model for Intervention with Families and Young People with Autism

Embedded in the findings of this study, guided by the principles of practice (Figure 10), and actioned through the six elements of the model for practice (Figure 9), a description of how intervention might work for families that have a member who is a young person with autism is proposed. This is a model that is tentative; its suggestions could guide practice in the future or be trialled and tested in practice into the future. Practitioners i.e., speech language pathologists and occupational therapists and social workers, operating from a person-in-environment perspective will need to assess what may be helpful in different family contexts. These practitioners recognise that all families, individuals, and contexts are different, and can best be understood within the multifaceted context of their environment (Kondrat, 2008). Practitioners will need to have suitable skills to assess what is appropriate for each family; this will include a process of building relationships with families and evaluating the appropriateness of interventions.

The Australian Association of Social Workers [AASW] note that clinical social work, "…is a distinct area of practice that includes a formal role in a counselling or therapeutic context of working collaboratively on issues identified by the client or clients" (Australian Association of Social Workers [AASW], 2019, p.1), and is aligned with a person-centred approach. These practitioners work from a broad knowledge base and skills; central to their practice is working with individuals or families and their intimate interpersonal experiences and relationships to "…enhance or maintain the socio-emotional functioning of individuals and families within their social and physical environment" (González & Gelman, 2015, p. 257). The following suggested capabilities—that is, the strategies and skills practitioners might have and employ in an intervention with families that have a member who is a young person with autism—are guided and informed by various approaches, including the AASW (2019) clinical social work context. Some of these elements in a clinical context might depend on a practitioner's experience, practice setting, and role in working with families.

Active Participation

It may suit young people with autism and their family members to be supported to understand autism through psychoeducation with a trusted family health practitioner, someone who holds clinical experience practicing with young people with autism and their family members. The study findings indicated that many participants did not have access to a health professional with suitable autism knowledge and expertise (key finding 7). Practitioners, working alongside a health practitioner, could facilitate discussion with families to make sense of the core symptoms of autism and family members' preferences for terminology to describe the condition, for example, autism or autism spectrum condition or disorder. Practitioners in a formal counselling or therapeutic context could, alongside families, facilitate family dialogue around the meaning that terminology might have for young people with autism and the family as a unit collectively. Practitioners might utilise their well-developed empathy and emotional skills to listen and attend to members in the family and remain sensitive to the emotions that discussion of these topics might generate for family members and implications that might arise from this (e.g., feelings of shame, guilt, or remorse surrounding disability and diagnosis). Practitioners might want to consider their ability to manage emotional regulation when families are discussing these topics.

Autonomy and Inclusion

Participants in the study who were members of families that had more than one member with an autism diagnosis mostly used similar terminology to describe autism and had similar understandings of autism and disability, such as having a neurodiverse view of disability (key finding 6). Members in a group or family as a unit with similar attributes and who hold similar viewpoints and outlooks can have increased psychological wellbeing (Haslam et al., 2012) and enhanced group cohesion and connectedness (Sønderlund et al., 2017). Practitioners might encourage and guide open dialogue between young people with autism and their parents who hold dissimilar views of the condition, in efforts to promote understanding and acceptance of the condition. They will most likely engage in advanced active listening and ask open-ended questions of family members in a sensitive, respectful, and non-judgemental way to achieve this.

The study findings also indicate that in families with more than one member with autism parents played an important role to buffer against impacts to the family as a unit from external responses to autism (key finding 6). To enable family buffering, parents need to feel supported and confident in themselves. Practitioners might provide behavioural and social supports to parents to reinforce their own capacity to support their families. This could mean practitioners working collaboratively with families to develop, implement, and adapt current service delivery for parents through an evolving practice framework to suit the family’s changing needs.

For families who hold dissimilar or deficit views of autism, attention might be focused on the connections these families have to their community and to others outside the family. This is because these families might feel excluded from their communities and at times might minimise or avoid spending time out in the community as a family for fear of disturbing others in the community, or because they fear ridicule from others by drawing unwanted attention towards themselves. The study findings showed this was the case for many families (key finding 6). Strategies developed to support parents might include a focus on developing inclusive and strengths-based environments in the family to increase awareness of how autism or disability is perceived, helping to positively re-orient attitudes. Practitioners might frame an understanding of contributing factors to some of these presenting problems in families who do not engage with the broader community, such as interpersonal dynamics, social determinants, and cultural influences.

Consideration should be given to family members without an autism diagnosis in families where most of the members have autism, and the potential impact this could have on these members' sense of belonging and connectedness with the family as a unit. Practitioners sensitive to this might recognise the potential difficulty for these members to develop a positive identity and to develop and maintain meaningful relationships with others in the family (Goffman, 1969; Goldstein, 2002). They could work collaboratively with these members to identify and navigate supports to help promote a sense of belonging to the family as a unit. Practitioners could use their expert knowledge to provide advice to families on how to access a suitable service, or, with the family's agreement and consent, could take an active role in engaging with other service providers to meet this need, such as recommendations to external supports groups for parents with neurodivergent family members.

Communication

The study findings showed the impact of autism symptomology on young people with the condition included difficulty with socio-emotional reciprocity; misreading and misinterpreting body language, expressions of emotions, and social cues; and restrictive and repetitive interests (key finding 1). These difficulties might be explored with the young person with autism and their family members, alongside an autism specialist service or professional if the practitioner engaged with the family is not familiar with autism. The practitioner, in collaboration with an autism professional, might work the young people with autism and other family members to reduce the frustration or annoyance caused by miscommunications and to address the increased tension or conflict the miscommunicating might create between family dyads.

Young people with autism and their family members could be supported to develop their problem-solving skills and patterns of communication with each other with open, as opposed to closed, communication (Bowlby, 1973). Such support would aim to help families move towards a collective understanding of what are clear and accepted communications about emotions, needs, and behaviours in the family. Although there may be similarities in how individual members communicate with each other, how they use language to describe and share their experiences, and how they understand their own and their family members' experiences, subtle differences in how individuals communicate can lead to misunderstandings between members. This can generate ambiguity, which can lead to conflict or disengagement. Family members in the study shared an experience of communications being indirect and ambiguous or misinterpreted.

Practitioners with families might use advanced active listening skills and display an understanding of non-verbal communication to increase deeper understanding and fuller communications within families of factual and emotional content. This could facilitate more open and direct dialogue between individual family dyads and the family as a unit in efforts to reduce bidirectional failure of empathy (key finding 3), consistent with the double empathy problem theory. This might encourage a shift away from a focus on the young person with autism as the index patient of the intervention and towards an awareness that it is not just the member with autism who can misunderstand others, but that other family members can misunderstand the member with autism (Heasman & Gillespie, 2017; Mitchell et al., 2021).

Whilst individuals with autism do exhibit distinct personalities and traits relative to people without an autism diagnosis, they are likely to have equivalent levels of awareness and insight into themselves (Schriber et al., 2014). However, a more recent review (2017) of the literature about individuals with autism and their perceptions of the self and their understanding of others' perceptions suggests that these levels of awareness and insight are reported mostly in individuals with higher IQ, when compared to those with lower IQ or an intellectual disability (Huang et al., 2017) Whilst, fostering levels of awareness and insight in individual young people with autism has important implications for reducing distress and conflict in families, additional considerations for families with young people with autism and intellectual disability are needed. Practitioners with these families might explore protective factors such as resilience and coping (Clark & Adams, 2022). For example, Clark & Adams (2022) highlight that the 'family resilience model' has been used to explore factors that protect against family risk and the stress of parenting a child with autism and intellectual disability, (Bitsika & Sharpley, 2014; Gardiner et al., 2019; Suzuki et al., 2018) and promoting psychological resilience and reduced mental health difficulties for parents (Bayrakli and Kaner 2012; Crnic et al. 2017; Halstead et al. 2018; Lloyd and Hastings 2009) and improving the systems of interactions between family members, and increasing relatedness (Varghese et al., 2020).

Psychoeducation

Interventions might be put in place to address emotional distancing and physical withdrawal between family members through a facilitated discussion about the behaviours and patterns in families that contribute to ambiguous relationships, unclear communications, and stresses (key finding 3). Practitioners with appropriate skills might draw on theoretical and research knowledge for clinical intervention that explores with families the associated sense of loss and grief that arises for individual members. Family practitioners with the required knowledge and skills, and who remain alert to the behaviours, pattens, and responses within families, might be able to use the construct of ambiguous loss (Boss, 1977, 1999, 2006) to guide intervention and to support the identification of strategies to promote adaptive patterns, such as conflict resolution, problem solving, and coping ability (Verghese et al., 2020).

An ongoing sense of loss and grief within families can impact on members' ability to cope (Hillegas, 2012). Practitioners might promote reflective thinking, feeling, and acting to help families work through periods of reframing expectations in their relationships as part of the grieving process of the loss of normative family experiences. Practitioners might also promote cognitive restructuring (Gladding, 2009) as an adaptive coping strategy, which involves an individual learning to identify and challenge irrational or maladaptive thoughts to change negative thinking pattens. This cognitive-based therapy can be implemented with families in which members are using avoidant actions or strategies (Rodriguez & Thompson, 2014), such as social isolation from the family or emotional withdrawal.

The findings indicated that these types of avoidant strategies and actions were used by adolescents with autism and their siblings in response to challenging behaviours, miscommunications, or a general lack of relatedness (key finding 2). Practitioners might encourage other adaptive coping strategies such as approach or action strategies, problem-focused strategies, and cognitive and meaning-making strategies (Meadan et al., 2009; Marshall & Long, 2009; Mount & Dillon, 2014). This could help families develop the skills to respond to and manage stressors in a way that does not reinforce the kinds of patterns and behaviours that contribute to disrupted relationship connections.

The intervention might consider grief and loss from the perspectives of young people with autism in the relationship with their parents. The study findings indicated (key finding 3) that young people can experience a sense of social and emotional disconnectedness in the relationship with their parents despite a strong desire and need to connect with them. Practitioners aware of some of these sensitivities and complexities could support the identification of strategies to promote a reciprocal awareness and understanding of this potential unifying experience of ambiguous loss between parents and young people with autism.

Family intervention to manage conflict typical of the sibling relationship might be supported through strategies that focus on teaching behavioural and social skills and self-regulatory skills to siblings (Kothari, 2017). Practitioners could encourage open dialogue to explore feelings of guilt, stress, and anxiety for parents trying to manage challenging behaviours and sibling conflict whilst they attempt to keep relationships balanced in the family. They could also promote strategies that could develop or enhance resilience. Enhanced resilience in families might be developed by promoting supportive and appreciative interactions. The study findings showed that some families were already engaging in these interaction styles (key finding 1). For example, some families showed open and positive patterns of communication, supportive and committed relationships, teamwork, problem solving, and flexibility with each member's needs; they spent time together as a family, had a positive outlook on life, and established routines. Similar interaction styles that enhance resilience in families are recognised in the literature (e.g., Bayat, 2007; Davis & Carter, 2008; Greef & Walt, 2010; Kapp & Brown, 2011; Kuhaneck et al., 2010; Kuhn & Carter, 2006; Lickenbrock et al., 2010; Luong et al., 2009; Seligman & Darling, 2007).

Recognition and Awareness

Role conflict in families and uncertainty or lack of clarity in family member roles increase the likelihood of individual family members experiencing depression and anxiety (Boss & Couden, 2002). This is a particular concern given the global prevalence of higher levels of depression and anxiety in families who care for a young person with autism (Dababnah & Parish, 2016; Dabrowska & Pisula, 2010; Dale et al., 2006; Davis & Carter 2008; Estes et al., 2009; Gray, 2003; Ludlow et al., 2011; Sharma et al., 2013; Spain et al., 2017). Family interventions that address role conflict in family relationships may reduce the risk of psychological distress (Holm et al., 2008). Practitioner sensitivity around ambiguous roles or boundary issues between family members would facilitate the labelling and discussion of difficulties without attributing individual blame (Berge & Holm, 2007). For example, siblings could explore their concerns about their present and future role as carers without feelings of guilt (Spain et al., 2017).

The findings of this study indicate that the provision of this type of support is especially important for sister siblings in families with a young person with autism and intellectual disability (key finding 5). As suggested earlier, sisters in these families may be particularly involved in caring for their sibling because parents of a child with autism and intellectual disability may have increased needs for support and rely on the sister sibling for this additional support. Practitioners who are cognisant of the gendered nature of caring in families could closely monitor sister siblings increased caring load and the associated pressure this has on sister siblings. Practitioner sensitivity around role acceptance, coupled with strategies to enhance resilience, might be used as a central component in a therapeutic setting for enhancing sister siblings' ongoing ability to cope.

Practitioners might advocate for regular respite for sister siblings away from their caring duties and caregiver role expectation in the family. With their knowledge of suitable agencies, they could also support applications for funding for household support and respite for parents. Consideration might also be given to the functioning of the family as a unit in single parent families, where siblings' caring duties are possibly increased further when there is only one primary carer in the family (key finding 5).

The intervention might encourage exploration of each family member's responsibilities and roles in the family, and practitioners could facilitate an open dialogue between parents and siblings to address family structural issues, such as boundary issues or ambiguities in the role of caring for the young person with autism (key finding 5). Practitioners with the theoretical knowledge who remain alert to boundary issues or role ambiguities within families might use the construct of boundary ambiguity (Boss & Greenberg, 1984) to guide intervention and to support the identification of strategies to promote alignment in family subsystems to a balance between *open* and *closed* boundaries within family relationships. One goal of such an intervention could be to reduce uncertainty about relationship roles and expectations in families. By drawing attention to boundaries in the family that might be too open, practitioners might be able to assist family members to distinguish more clearly between family roles, such as the blurred division between being a sibling and being a carer (Cridland et al., 2014). Practitioners could work to address the complexities of the emotional entanglement which may potentially occur between the primary caregiver and child with autism in the parent-child dyad due to emotional boundaries that are too open.

Cohesion and Connectedness

The intervention might be set up to support a need for father-oriented supports that acknowledge fathers as primary caregivers of children with autism. Practitioners might facilitate open dialogue between fathers of children with autism in father-focused parenting groups. Practitioners could work collaboratively with fathers to develop strategies to strengthen relationships within the family as a unit and to learn the necessary skills to address emotional and physical challenges they face in parenting their child with autism. The study findings (key finding 4) support a need for interventions that promote a balance between healthy connectedness and healthy separateness in the father-child with autism relationship, which may be important in families where fathers adopt multiple roles in the parent-child relationship (e.g., care giver, friend, teacher, and caseworker/advocate). These multiple roles may be associated with a potentially increased prospect for emotional entanglement and psychological fusion between parent and child.

Practitioners might support cohesion in families by choosing strategies to address enmeshment and emotional entanglement in the parent-child relationship. These strategies could include, for example, encouraging more independence and autonomy for the young person with autism in the relationship, and working towards a balance of healthy connectedness and healthy separateness. Practitioners might use their knowledge of suitable agencies to provide referrals to external peer support groups for young people and to carer support groups for parents. This recommendation connects with study participants' suggestions for the kinds of supports they need and want (key finding 7). External support groups can be helpful outlets for family members' emotional and social needs. They are considered important for families who have a member with autism, as these families are an identified group with limited formal and informal support networks, and often rely greatly on extended family members for this kind of support (Luong et al., 2009).

Whilst there are challenges associated with raising a child with autism, and families can be assessed to be at risk of poor mental health and wellbeing outcomes, practitioners could encourage families to see themselves as capable, strong, and successful in the ways they exhibit resilience and growth as they manage diverse and multiple stressors. Practitioners might choose to draw attention to positive changes in families; for example, they could highlight a newly acquired outlook or appreciation of life, increased family cohesion, and development of stronger family relationships.

Summary of Practice Model

This section proposed a tentative situated family-based practice model for enhancing and strengthening family relationships and promoting connectedness between family members and the family as a unit in families with a member who is a young person with autism. This model fills a gap in knowledge regarding approaches to intervention specific to strengthening and enhancing family relationships in these families, thus far not addressed in the literature. Drawing on the findings of this study, the model has potential to inform client-centred practices involving families and young people with autism.

The suggested strategies throughout the intervention description, roughly aligned with the six elements of the practice model (Figure 9), target various family domains. These include family structure (e.g., boundaries, subsystems, alignment); role structure and functioning (e.g., role expectations, role conflict, role acceptance); communication (e.g., patterns of communication, direct-indirect communication, ambiguous communication); reinforcement (e.g., behavioural and social skills, supportive-appreciative interactions); cohesiveness (e.g., enmeshed to healthy connectedness, healthy separateness to disengaged); and adaptive patterns (e.g., conflict resolution, problem solving, coping ability).

The model and suggested strategies for practice could be used to inform assessment, case management, and therapeutic work with families and with individual family members. It might also be used to develop group work programs, such as groups with fathers, groups with siblings, and groups with adolescents with autism.

Study Limitations and Recommendations for Future Research

The research is not without challenges and limitations relating to study design and methodology. The main limitation of the study is that it reflects a singular and specific point in time amongst a relatively small group of families drawn from a single geographic area. The span of time involved, with data collected from early 2019 to final write up in late 2021, means the research is not generalisable outside the specific scope of the project. It is likely there have been many changes in study participants' lives since interviews were conducted over 2 years ago, and thus findings specific to these participants may no longer apply. However, a recent (2022) review of the literature (Chapter 2) has shown that gaps remain in understanding the impacts autism has on family relationships in families that have a young person with autism as a member. The perspectives and experiences of children and young people with autism and their families remain mostly unknown, with the questions of "What is it like?" and "How is it so?" largely unexplored. Also, gaps remain in evidence for interventions for this group, informed by their perspectives to strengthen and enhance family relationships.

Several other study limitations exist. First, young people with autism and their family members demonstrated an interest in the study through their participation; thus, the accounts and insights they provided are not necessarily the views or experiences of other young people with autism or other family members. Second, many families in the present study were white, university educated, and living in one of the most advantaged local government areas (LGAs) in Australia (ABS, 2018). Third, for many participants, it is likely that a single interview might not have captured the complex and varied experiences of families. Single interviews may not generate rich descriptions for meaningful findings (Polkinghorne, 2005), and for some participants these interviews were very short.

Fourth, in the description of findings in the current study, individual participants are discussed as mothers, fathers, siblings, and young people with autism. Sometimes the different views of participants within a family are compared, but it is not always clear. Given there are multiple family members present it could have been relevant and interesting to consider how we can understand differences of perspective within a family. In the presentation of the findings, it could be made clearer when comparisons are being made between the views of participants from within families. However, a decision was made to not make the different views of participants within a family obvious or to draw attention to these for purposes of understanding differences of perspectives within a family, due to concern about participants anonymity and internal confidentiality (Tolich, 2004). This issue was raised both in the ethics process and methodological literature when members from within a family are included in data collection processes, analysis of data and in the presentation of findings.

For future research, studies looking at how we understand differences between family members could be interesting and an area where delving further into childhood studies and disability studies could be helpful. Methodologically, collecting data for this purpose might be achieved through family case studies or family group conferencing (Bredewold & Tonkens, 2021), with considerations given to the method to minimise the potential for participant responses to be influenced by others in the family (Eisikovits & Koren, 2010). Finally, when collecting these kinds of data from families, it is suggested that careful attention be paid to families' openness and willingness to explore differences in perspective, and that members understand and are prepared for the possibility of family issues being exposed or relationships being threatened.

Fifth, it is plausible that families experiencing greater difficulties, challenges, or impacts to their relationships would not participate in this type of study. All these factors limit the generalisability of the study findings.

Sixth, including more families who had a young person with both autism and intellectual disability to account for their unique perspectives and experiences would have further benefited the study. Given the premise of the current study is that the voices of young people with autism often goes unheard in research, this is a significant limitation. Given the substantial weighting of transcribed verbal interview data as findings in the study, this might have meant that deeper exploration with young people with autism and intellectual disability, including one young person who was non-verbal, was not able to occur. Whilst the design of the research attempted to account for a range of communication preferences and needs, time constraints, and resource constraints, hampered some of these efforts.

There remains a great need for significant improvement in methodologies and methods for including children with disabilities in qualitative research, including guidance for appropriate research tool selection according to disability or impairment type (Courchesne et al., 2021; Jenkin et al., 2015; Tesfaye et al., 2019). Findings in relation to this subgroup of participants in the current study (those with autism and intellectual disability) is therefore almost exclusively from the perspective of other family members, rather than the young person with autism themselves. Whilst qualitative researchers have a large selection of nonverbal behaviour that can be collected that would generate thick descriptions and interpretations compared to just the use of verbal data (Denham & Onwuegbuzie, 2013), the learnings from the current study suggest there is a scarcity of typology of nonverbal communication for autistic children with intellectual disability. To address this limitation in future studies, one suggestion is for research to investigate the non-verbal behaviours and cues displayed by autistic verbal and non-verbal children and young people with and without intellectual disability.

A framework with this information might assist researchers with the analysis and interpretations of these kinds of data to translate into meaningful findings for these groups. For example, future research collecting these types of data from this group could be guided by Gorden’s (1980) typology of nonverbal communication comprised of the following indicators: kinesics (i.e., behaviours reflected by body displacements and postures), proxemics (i.e., behaviours denoting special relationships of the interviewees/interviewers), chronemics (i.e., temporal speech markers such as gaps, silences, and hesitations), and paralinguistics (i.e., behaviours linked to tenor, strength, or emotive colour of the vocal expression). However, learnings from the current study (described in the Methods section) suggest that for individuals who are either a verbal or nonverbal autistic child or young person with an intellectual disability, they display a unique and novel typology of communication, one that might not be able to be collated into a description or summary of shared behaviours and meanings.

This observation poses a consideration and a challenge for future research collecting data from these groups, however, as documented in the current study, when researchers include a young person’s network of supports including family members and allied health professionals such as speech therapists and occupational therapists, these kinds of data analysis and interpretation challenges can be addressed. It is recommended that future studies look to involve these young people’s family members and allied health professionals more actively and collaboratively in the analysis and interpretation phases of the research, than the current study did, so that the voices of autistic young people with intellectual disability including those who are nonverbal are suitably represented and heard.

Finally, despite that the aim at the onset of the study was to develop a model for practice, due to time and resource constraints, the Advisory group did not have representation from service providers and professionals to make sense of findings against current practice. As such, practitioners and/or service providers were not explicitly included in the development of the practice model. Future studies should look to address this by including service providers and professionals in an Advisory group. The balance is suggested to lay in the need for reciprocity between people with autism and professionals to jointly develop a practice model that takes account of factors both within, between and outside service providers and people with autism as recipients of services. Practice models differ between countries and even between states within countries such as Australia. The data collected from the sample does not account for that and does not recognise the potential for co-design of practice models with service providers.

This study did, however, demonstrate that involving families in consultation about the research design and data collection processes is one way to work towards improving and refining collaborative research methods. It also generated new insights into the dynamics of family relationships, and the patterns of behaviour that may occur in these families, which can guide research and interventions with families with a young person with autism.

Chapter Summary

This chapter provided an account of the unique study findings in the context of the overall aim of this study, to investigate *how autism impacts the relationships between family members, and the family as a unit.*

The key findings of the study, with a focus on the new insights from the perspectives of young people with autism, siblings, and parents, were interpreted to further understand the patterns of behaviour within families impacting on relationships between family members, and the family as a unit. The behavioural patterns identified were understood to be shaping both a *togetherness* and a *detachment* between each family member and for the family as a unit. A conceptual framework informed by the key findings helped to organise and assist with understanding how these behavioural patterns that are suggested to occur in families drive social processes (Strauss & Corbin, 1990) that disrupt family members' sense of connectedness with each other and the family as a unit, and impact family relationships.

Practice principles informed by these findings were applied in the development of a situated family-based practice model with a dual focus on enhancing and strengthening family relationships and promoting connectedness in families with a member who is a young person with autism. The principles of practice and the practice model could potentially inform client-centred practices involving families and young people with autism. In addition, evidence-informed techniques and strategies roughly aligned with the practice model were provided as suggestions for practitioners to use when seeking strategies for strengthening relationships in families with a member who is a young person with autism.

Concluding Comments

To conclude this thesis, the author firstly acknowledges the 44 participants from 18 families who participated in this study, and who provided their perspectives on how autism impacts their family relationships. With a focus on the new insights provided by the study participants, key study findings were generated and then interpreted further to construct a conceptual framework for understanding the behavioural patterns and social processes behind this impact. The remainder of this concluding chapter provides a reflection on the study and its strengths.

To the best of the author's knowledge this is the first Australian study to explore how young people between 12 and 19 years of age with an autism diagnosis perceive and experience their condition within their family. The design of the study was also novel, being the first study in Australia and internationally, to the best of the author's knowledge, to qualitatively investigate relationships within families with young people with an autism diagnosis and the ideas espoused by disability studies, childhood studies and a systems perspective have particularly influenced the methodology adopted in the study. The study demonstrated how these can be merged effectively in research to study a topic from a lived experience, first-person perspective, with consideration of the broader context.

The study is one of only a few interpretivist studies conducted on the subject, and the first that has gone beyond description and provided a conceptual framework to indicate how autism impacts on relationships between family members, and the family as a unit, and that provides a practical application of the findings. The conceptual framework offers new insights and ways of understanding the factors that impact family relationships. The conceptual framework has the potential to contribute to future theoretical developments when considering directions for further research. Employing hermeneutic and transcendental methods and concepts to address the research question and research aims, this study drew from a diversity of existing knowledge from across disciplinary boundaries. This has been integrated with the grounded findings to develop a new conceptual framework and practice model. In keeping with the qualitative phenomenological approach guiding the analysis, this ensured the focus remained on participants' subjective experiences and sense-making, while grounded theory methods drove the analysis to generate findings grounded in the new insights of the study participants' perspectives that has deepened our understanding of relationships in these families.

The conceptual framework fills a gap in knowledge, providing a deeper understanding of how autism impacts family relationships than was available in previous research, as presented in the literature review in Chapter 2. The conceptual framework developed, based on the findings, moves beyond description to provide an interpretation of processes that disrupt family and social connectedness and impact family relationships. The practice model fills a gap regarding an approach to practice for enhancing and strengthening family relationships in families with a member who is a young person with autism, thus far not addressed in the literature. The conceptual framework and practice model have direct relevance to practitioners working with young people with autism and their family members in a therapeutic setting.

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Appendices

Appendix A: Comprehensive Literature Review Key Terms and Subject Headings

EBSCOhost research platform used to search in

- CINAHL
- PsycInfo
- SocINDEX
- ERIC
- Medline (PubMed)

Subject headings

*autism spectrum disorders *Autistic Disorder
*Asperger's syndrome * Family Relations

Limiters

Academic Journals
Dissertations
Language English

Subject terms > "autism"

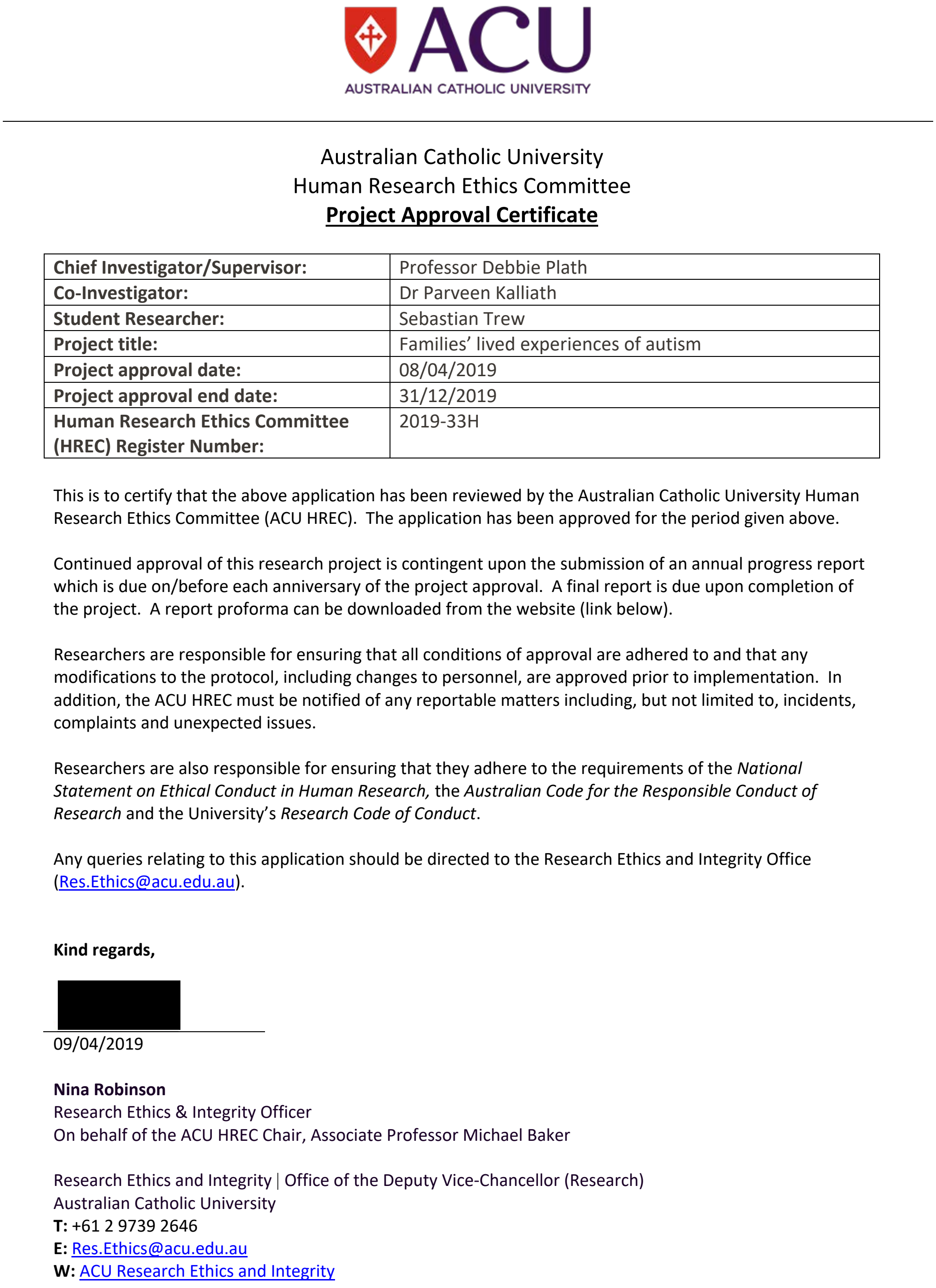
DE "AUTISM" OR DE "Autism Spectrum Disorder-- Social aspects" OR DE "AUTISM in adolescence" OR DE "AUTISM in children" OR DE "autism spectrum disorder" OR DE "autism spectrum disorder in women" OR DE "AUTISTIC children" OR DE "AUTISTIC youth"

Subject terms > "Family relationships'

DE "Structural Family Therapy" OR DE "Dysfunctional Family" OR DE "Family Work Relationship" OR DE "Relationship Quality" OR DE "Co-dependency" OR DE "Family Relations" OR DE "Relationship Termination" OR DE "Relationship Satisfaction" OR DE "Interpersonal Relationships" OR DE "Family Intervention" OR DE "Family and Parenting Measures" OR DE "Biological Family" OR DE "Family Systems Theory" OR DE "Relationship Therapy" OR DE "Strategic Family Therapy" OR DE "Family Therapy" OR DE "Dual

Relationships” OR DE “Domestic Violence” OR DE “Marriage and Partner Measures” OR DE “Family Structure” OR DE “Family Size” OR DE “Family Members” OR DE “Family Conflict” OR DE “Family” OR DE “Intellectual Development Disorder” OR DE “Marriage Attitudes” OR DE “Male Female Relations” OR DE “Intergroup Dynamics” OR DE “Couples” OR DE “Attachment Theory” OR DE “Attachment Behavior” OR DE “Associative Processes” OR DE “Social Support” OR DE “Caregiver Burden” DE “FAMILY relationships of caregivers” OR DE “FAMILY relationships of children with disabilities” OR DE “FAMILY roles” OR DE “FAMILY systems theory” OR DE “FAMILY therapists” OR DE “FAMILY values” OR DE “FAMILY violence -Research” OR DE “FAMILY violence -- Social aspects” OR DE “FAMILY violence risk factors” OR DE FAMILIES

Appendix B: Study Approval



Australian Catholic University
Human Research Ethics Committee
Project Approval Certificate

Chief Investigator/Supervisor:	Professor Debbie Plath
Co-Investigator:	Dr Parveen Kalliath
Student Researcher:	Sebastian Trew
Project title:	Families' lived experiences of autism
Project approval date:	08/04/2019
Project approval end date:	31/12/2019
Human Research Ethics Committee (HREC) Register Number:	2019-33H

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above.

Continued approval of this research project is contingent upon the submission of an annual progress report which is due on/before each anniversary of the project approval. A final report is due upon completion of the project. A report proforma can be downloaded from the website (link below).

Researchers are responsible for ensuring that all conditions of approval are adhered to and that any modifications to the protocol, including changes to personnel, are approved prior to implementation. In addition, the ACU HREC must be notified of any reportable matters including, but not limited to, incidents, complaints and unexpected issues.

Researchers are also responsible for ensuring that they adhere to the requirements of the *National Statement on Ethical Conduct in Human Research,* the *Australian Code for the Responsible Conduct of Research* and the University's *Research Code of Conduct*.

Any queries relating to this application should be directed to the Research Ethics and Integrity Office (Res.Ethics@acu.edu.au).

Kind regards,

[redacted]

09/04/2019

Nina Robinson
Research Ethics & Integrity Officer
On behalf of the ACU HREC Chair, Associate Professor Michael Baker

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W: ACU Research Ethics and Integrity

Appendix C: Study Information Letter

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: Families' lived experiences of autism

APPLICATION NUMBER: 2019-33H
INVESTIGATORS: Professor Debbie Plath and Dr Parveen Kalliath
STUDENT RESEARCHER: Sebastian Trew
STUDENT'S DEGREE: Doctor of Philosophy

Dear Parent/Guardian,

You are invited to participate in the research project described below. You have been approached to participate in this study as a:

- father of a young person 12-18 years of age with an Autism Spectrum Disorder diagnosis;
- mother of a young person 12-18 years of age with an Autism Spectrum Disorder diagnosis.

What is the project about?

The project is about families, including young people on the autism spectrum, their mothers, fathers, and siblings. The project is looking to develop a better understanding as to how these families experience and think about their identity, relationships and interactions, and how services can better support families. Previous research that looks at families with a young person on the autism spectrum has usually focused on the challenges of their family lives, without talking to families about other experiences. Research is unclear how these families experience and understand their identity, relationships and interactions and how these may nurture and sustain positive family experiences. The findings of the project will provide researchers, practitioners, service providers, schools, and policy makers a better understanding of these families and a greater knowledge of how best to support them. This will help inform future research, supports, services, and policies to better support families with a young person on the autism spectrum.

Who is conducting the project?

This project is being conducted by Sebastian Trew and will form the basis for the degree of Doctor of Philosophy at Australian Catholic University. Sebastian has 12 years professional practice experience in family support work, youth work and disability work, working with families who have a child or young person on the autism spectrum. Sebastian has 1-years' experience conducting research with vulnerable young people and families in his current position as Research Officer at the Australian Catholic University's Institute of Child Protection Studies. Sebastian is under the supervision of Professor Debbie Plath and Dr Parveen Kalliath. Debbie and Parveen have broad experience in social work practice, education, research and consultancy.

What will you be asked to do?

To develop a better understanding as to how families with a young person on the autism spectrum experience and define identity, relationships, and interactions, you will be asked to share your story and your experiences with Sebastian. Participation will consist of one digitally recorded interview, lasting up to 1 hour conducted at a time and place convenient to you. If you run out of time, or decide to finish the interview later, Sebastian can arrange a second interview with you. First, some brief background information will be collected. Then you will be able to share and explore what is important and relevant to you and your families' identity, relationships and interactions. Sebastian will also ask you about the services and supports your family receives. Sebastian will ask you some questions to start the conversation but what you want to share and talk about is up to you. There are no right or wrong responses or answers to the questions, they are there to help you tell Sebastian about your experiences and you do not have to answer them. Interviews will be informal and conversational, and you will have the opportunity to talk about other areas that are important to you. If you become tired, or change your mind, or do not wish to continue, you can stop as soon as you like. You can choose to complete the interview another day at another convenient time and place.

Questions to start may include:

Identity

1. In what contexts would or wouldn't you use the term "autism"?
2. How do you talk about autism with your family?
3. How do you talk about autism to people outside the family?
4. In what ways does autism make your family unique or distinct?
5. How does autism play a role in who your family is?
6. In what ways does your family identify with autism?

Supplementary questions for young person on the autism spectrum

a) In what ways do you identify with the term "autism"? (What does autism mean to you?)
b) In what ways does autism make you unique or distinct?

Relationships

7. How do you all get on as a family?
8. In what ways does autism influence family relationships? Positive and negative influences?

Interactions

9. What does your family do together?
10. In what ways does autism influence what your family does together?
11. In what ways does autism influence family interactions? Positive and negative influences?
12. Does your family have some respite or relaxation time? What do you do during this time?

Services and supports

13. What supports and/or services does your family currently receive/access?
14. What are your support needs as a family?
15. In what ways do services fit with your family identity, relationships and interactions?
16. In what ways do services meet your needs as a family?
17. Could you tell me about any unmet support needs?
18. In what ways can these services better support your family?
19. If a new service was created for families with a young person on the autism spectrum, how should it provide support?

Finishing up: the future

20. Is there anything else you would like to mention regarding your family identify, relationships and interactions, something I haven't asked you about?

How much time will the project take?

Participation in the project will include one digitally recorded interview. The interview will last for about 1 hour and can be at a time and place convenient to you. You can choose to meet or talk on the phone with Sebastian and ask him any questions before deciding to take part in an interview. This can be at a time and place convenient to you.

What are the benefits of the research project?

You probably won't see any benefits for yourself. The findings will help improve services and supports for families. However, you may benefit from the opportunity to contribute your views about your family identity, relationships and interactions while offering your knowledge on how to nurture and sustain positive family experiences, and how services can provide improved supports. You will be provided with a shopping voucher to thank you for your time and contribution to the project. If you choose to be involved, you may benefit from:

- the opportunity to tell your story.
- contributing to building a better understanding of families with a young person on the autism spectrum.
- what you share could contribute to improving services and supports for families with a young person on the autism spectrum.

Are there any risks associated with participating in this project?
Interviews, particularly on sensitive topics, which for some people may include family relationships and family interactions, may bring up unsettling memories. You will have choice and control during your interview, and the choice to stop any time, or not to answer questions or discuss issues you feel uncomfortable to explore and share. If you want to be involved, but do not want to be interviewed alone with Sebastian, you can bring a support person along for the interview. After the interview is finished Sebastian will provide you with contact details for support services. Sebastian will be available to discuss concerns following the interviews and can provide direction to support and referrals if needed.

Can you withdraw from the study?
Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without any consequences. If you decide to withdraw from the study after Sebastian has interviewed you, you may choose if you wish to have your data included in the study or deleted.

Will anyone else know whether you have participated?
You will have received this information letter from a support service or a school. While there is a possibility that the person who gave you this information letter will know you are interested in participating, Sebastian will not be notifying any person or service of you or your family's agreed involvement.

You and your family are invited to participate in this project. You and your family can choose if you all want to be involved, or if only some of you want to be involved, or if only you want to be involved. If you and your family decide to be involved, apart from Sebastian, no one else will know whether you have participated, unless you choose to have a support person present. With your permission, Sebastian will digitally record the interview with you. This is so Sebastian can later carefully review and transcribe what you have shared with him. All recordings will be transcribed and kept on a secure password protected server as a digital audio file and a Microsoft Word file on the ACU Canberra campus and will only be accessible to Sebastian and the research team. All files will be deleted at the end of the research project.

Sebastian has the intention to write for publication in national and international journals and present at conferences. To protect you and your family's confidentiality, names will not be used in anything available to the public, pseudonyms will be used instead. Although direct quotes will be used in reports, all identifying features will be removed to ensure you and your family cannot be identified.

If you or your other family members choose to be involved, you will each sign a separate consent form, and you will each be interviewed separately. There is a risk that some information contained in a publication could be recognized by another member of your family. Sebastian will take all efforts to ensure the reporting does not identify you. After your interview Sebastian will provide you with a copy of the interview transcript. This is your opportunity to review your interview and to let Sebastian know if you do not want something you said written about.

Will you be able to find out the results of the project?
You will be sent a copy of your own interview and a summary of the issues raised by all other participants. Again, you and your family's confidentiality will be protected at all stages of the project. After Sebastian has transcribed and reviewed your interview with him, he will show it to you for you to check it and confirm it is accurate.

Once the project is completed you will be sent a summary of the findings of the project.

Who do you contact if you have questions about the project?
Please contact Sebastian on 02 6209 1228 or sebastian.trew@myacu.edu.au if you would like to:

- ask any questions
- organise to meet Sebastian
- discuss you or your family members' involvement in the project
- withdraw from the project
- anything else

Alternatively, you may contact Professor Debbie Plath, School of Allied Health, Australian Catholic University, on (02) 9701 4757 or debbie.plath@acu.edu.au

Professor Debbie Plath (BA, BSW, MSW, PhD) is an experienced, internationally recognised social work researcher who has published widely in high quality peer reviewed journals such as the British Journal of Social Work. Debbie has expertise in qualitative and participatory research.

Alternatively, you may contact Dr Parveen Kalliath, School of Allied Health, Australian Catholic University, on (02) 6209 1125 or parveen.kalliath@acu.edu.au

Parveen has over thirty years social work practice experience in countries including India, USA, New Zealand and Australia. Parveen has Qualitative Methods expertise and published works on family satisfaction, social support and psychological strain.

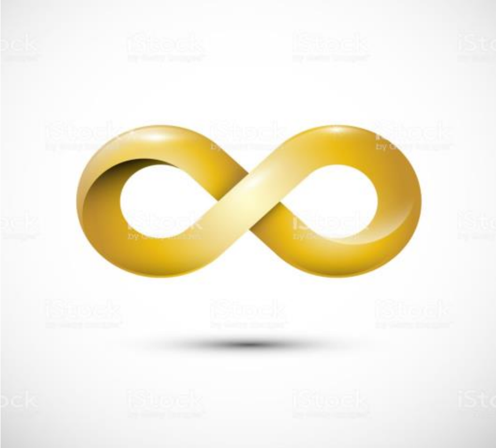
What if you have a complaint or any concerns?
The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2019-33H). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics and Integrity Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics and Integrity
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968
NORTH SYDNEY, NSW 2059
Ph.: 02 9739 2519
Fax: 02 9739 2870
Email: resethics.manager@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Do you want to participate? How do you get involved?
You may contact Sebastian directly on 02 6209 1228 or sebastian.trew@myacu.edu.au Alternatively, if you received this information letter from your support service, you may have the support service contact Sebastian and, with your permission, provide Sebastian with your contact details, and he will make contact with you.

Appendix D: Sample of Recruitment Pamphlet for Young Person With ASD



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FAMILIES’LIVED EXPERIENCES OF AUTISM

National School of Allied Health

Hello, you are invited to be part of a research project.

What is the project about?
The project is about you and your family and autism spectrum disorder. You may know it as autism, ASD, or the spectrum.

Who is doing the project?
This project is by Sebastian, a student at the Australian Catholic University.

What will I be asked to do?
You will be asked to talk with Sebastian about:

- who you and your family are,
- what you like to do with your family,
- how you get along with your family, and
- who helps you and your family to have fun or relax

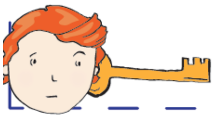
If it is OK with you, what you say to Sebastian will be recorded. This is so Sebastian can write about it later for this project. What you tell Sebastian, no one else will know about. Your name will not be used in what Sebastian writes. Talking with Sebastian will take about 1 hour.

Are there any risks?
No, but if you get upset or worried while talking to Sebastian you can stop and see your parent or carer or support worker. You can choose to have someone with you when you talk with Sebastian.

Why should I talk with Sebastian?
You don’t have to talk with Sebastian. You get to choose. If you want to stop talking that is OK too. What you tell Sebastian might improve the support you and your family gets.

You have the right to be informed
We will help you understand what you're being asked to do. We'll use child-friendly words and activities.

You have the right to confidentiality
If you tell us that you aren't safe, that you are being hurt or if we are worried about you we will need to tell someone about it. Otherwise people won't know which specific things you told us.



Do you want to be in the project? If you would like to or want more information you can ask your parent/s or guardian or worker to call me on 6209 1228 or email me on sebastian.trew@myacu.edu.au

If your support service or school gave you this pamphlet, you can have them contact me or, with your parent's or guardians OK, Sebastian can call you and your family.

Anyone who gets involved can STOP or change their mind at **ANY** stage.

You will need to sign a form and then you can talk with Sebastian.

You will get a **shopping voucher** for talking with Sebastian.

You have the right not to be hurt
We will not hurt or tease you and we will stand up for you if others do.

You have the right not to be discriminated against
We will not treat people badly because of who they are or where they come from.

If you become upset talking with Sebastian, Sebastian will help you to access supports and you can see your parent or guardian or worker. Sebastiancan help you call: Lifeline (ph.) 13 11 14 or Kids Helpline (ph.) 1800 55 1800

The study has been checked by the Human Research Ethics Committee at Australian Catholic University (review number 2019-33H). If you have any worries about the project, you may write to the Manager of the Human Research Ethics and Integrity Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics and Integrity
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968
NORTH SYDNEY, NSW 2059
Ph.: 02 9739 2519
Fax: 02 9739 2870
Email: resethics.manager@acu.edu.au

Any complaint or concern will be confidential and taken care of. You will be told what happens.

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THANK YOU. I HOPE TO TALK TO YOU SOON!

Images sourced from the Institute of Child Protection Studies (ICPS) store of images developed for use in ICPS research or practice by Fuzz Illustrations.

You have the right to complain
If you're not happy you can tell us or our supervisors and we'll take it on board.

You have the right to stop participating
If you want to stop working with us you can at any time.

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Recruitment Pamphlet young people on the autism spectrum (intellectual disability and non-verbal) Example

Hello, you are invited to join a research project.

The project is about you and your family and autism spectrum disorder You may know it as autism, ASD, or the spectrum.

This project is by Sebastian

, a student at the Australian Catholic University

Appendix E: Consent and Assent Forms

AUSTRALIAN CATHOLIC UNIVERSITY

CONSENT FORM

Copy for Researcher / Copy for Participant to Keep

TITLE OF PROJECT: **Families' lived experiences of autism**

APPROVAL NUMBER: **2019-33H**

(NAME OF) PRINCIPAL INVESTIGATOR (or SUPERVISOR): **Professor Debbie Plath**

(NAME OF) STUDENT RESEARCHER (if applicable): **Mr Sebastian Trew**

I .... *(the participant)* have read (*or, where appropriate, have had read to me)* and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this digitally recorded interview for about 1 hour, realising that I can withdraw my consent at any time (without adverse consequences). I have the option to participate in a second interview, if I run out of time or if I would like to finish the interview another time. I agree that research data collected for the project may be published or may be provided to other researchers in a form that does not identify me in any way. I understand that I can choose to have my data deleted if I decide to withdraw from the project.

NAME OF PARTICIPANT: ....

SIGNATURE: .... DATE:
....

SIGNATURE OF PRINCIPAL INVESTIGATOR (or SUPERVISOR): ....
DATE:
....

(and, if applicable)
SIGNATURE OF STUDENT RESEARCHER: ....
DATE: ....

Copy for participant to keep

INTERVIEW ASSENT FOR YOUNG PEOPLE

(this might be read by young person, or it might be read to them by an adult)

PROJECT TITLE: Families' lived experiences of autism
PRINCIPAL SUPERVISOR: Professor Debbie Plath
STUDENT RESEARCHER: Mr Sebastian Trew

I ____ (please print name) agree to take part in an interview for a project exploring family identity, relationships and interactions.

I know that:	**Please tick if you're OK with this**
I will participate in a recorded interview for about 1 hour. If I would like to, I can participate in a second interview.	☐
Sebastian will ask you questions about you and your family, such as what you like doing with your family, how do you get along with your family, and the supports you and your family get.	☐
I don't have to answer any questions that I don't like or don't want to answer.	☐
I am free to change my mind and decide not to take part at any time.	☐
To say thanks, I will be given a voucher for shops. I will get the voucher even if I decide not to answer some of the questions or if I change my mind later on and I don't want to take part any more.	☐
If anything we talk about makes me feel upset, I can choose to take a break or finish the interview. Sebastian, can tell my parent/carer/support person if I want them to. Sebastian can help me find someone I can talk to about anything that makes me upset.	☐
What I say in the interview is confidential and belongs to me. Sebastian won't tell anyone else that I took part.	☐
What I say to Sebastian will be used in presentations and written reports, but Sebastian will make sure that nobody will be able to tell who I am.	☐
The only time Sebastian would have to tell someone else is if they were worried that I, or someone else, wasn't safe.	☐

It is OK for me to ask questions if I don't understand anything.	☐
It is OK for me to complain if I'm not happy about the way I've been treated, or anything else.	☐
Sebastian will contact me again in the future to see if I'd like to read, have read to and/or comment on what Sebastian has written from the interviews. I can decide at any time whether or not I'd like to take part	☐
If I change my mind and don't want what I said to Sebastian used in the project, I can choose to have it deleted.	☐

Your name: ______________________ Your signature: ___________________________
Date: ____________________ (Indicate if verbal consent ☐)

Researcher's name: ____________________ Researcher's signature: ________________

Any Questions?

If you have any questions about the project you, or someone on your behalf can talk to:

Professor Debbie Plath
Australian Catholic
University
School of Allied Health
25A Barker Road
Strathfield NSW 2135
Phone: 02 9701 4757
Email:
debbie.plath@acu.edu.au

If, during the course of the research, you have any complaints about the way that you have been treated or if you think something has not been dealt with by the researchers, you can talk to a safe adult, and you or they can contact the ethics committee to have your complaint fully investigated:

Manager, Ethics
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University
North Sydney Campus
PO Box 968, NORTH SYDNEY, NSW 2059
Ph.: 02 9739 2519

Appendix F: Interview Guide

Identity

1. In what contexts would or wouldn't you use the term "autism"?
2. How do you talk about autism with your family?
3. How do you talk about autism to people outside the family?
4. In what ways does autismmake your family unique or distinct?
5. How does autism play a role in who your family is?
6. In what ways does your family identify with autism?
7. Autism as negative and autism as positive?
8. Diagnosis period – want kids to feel "not different" – do you see autism as being different or not?
9. What do you think about the label "autism?"

Supplementary questions for young person on the autism spectrum

a) In what ways do you identify with the term "autism"? (What does autism mean to you?)
b) In what ways does autism make you unique or distinct?

Relationships

10. How do you all get on as a family? Do the children get along well with one another? Do the children get along well with the parents – ASD child
11. In what ways does autism influence family relationships? Positive and negative influences?

Interactions

12. What does your family do together?
13. In what ways does autism influence what your family does together?
14. In what ways does autism influence family interactions? Positive and negative influences?
15. Does your family have some respite or relaxation time? What do you do during this time?

Services and supports

16. What supports and/or services does your family currently receive/access?
17. What are your support needs as a family?
18. In what ways do services fit with your family identity, relationships and interactions?
19. In what ways do services meet your needs as a family?
20. Could you tell me about any unmet support needs?
21. In what ways can these services better support your family?
22. If a new service was created for families with a young person on the autism spectrum, how should it provide support?

Finishing up: the future

23. Thinking about your family's future, what would help to reach your hopes and expectations?
24. Is there anything else you would like to mention regarding your family identify, relationships and interactions, something I haven't asked you about?

Appendix G: Sample From Interview Guide for Young People With ASD

- Can you tell me a little bit about your family? **(Draw them if you like)**
    - Who do you live with? (including pets etc)
    - What do you like most about your family?
    - What is your family good at?
    - Who has autism in your family?
    - Do you talk about their autism?
    - How do you talk about?
    - Who do you talk about it with?
    - In what ways does autism make your family different?

ARE YOU OK TO KEEP TALKING WITH ME? Do you need your (parent/guardian/support worker)? Do you have any questions?

- How do you get along on as a family?
    - Do you like spending time with your family?
    - What is the best thing about your family?
    - What is difficult about your family?

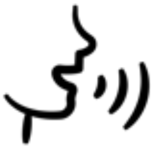
ARE YOU OK TO KEEP TALKING WITH ME? Do you need your (parent/guardian/support worker)? Do you have any questions?

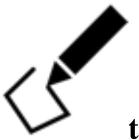
- What activities do you like doing together with your family?
    - What do you do with:
    - Dad
    - Mum
    - Sibling with autism
- How do you and your family have fun and relax?

ARE YOU OK TO KEEP TALKING WITH ME? Do you need your (parent/guardian/support worker)? Do you have any questions?

Services and supports

- Do you or your family get any help from any other services or people?
    - Who is it?
    - How do they help?
    - Do they talk to you much?
        - What about?
    - Do you like them/going there?
        - What do you like about it/them?
        - What don't you like about it/them?
    - How could they help you better or more?

- Can you  tell me  about your  family  ?

  (Draw  **them**  **if you like**  **)**

    - Who  do you  live  with  ?

      (including pets )

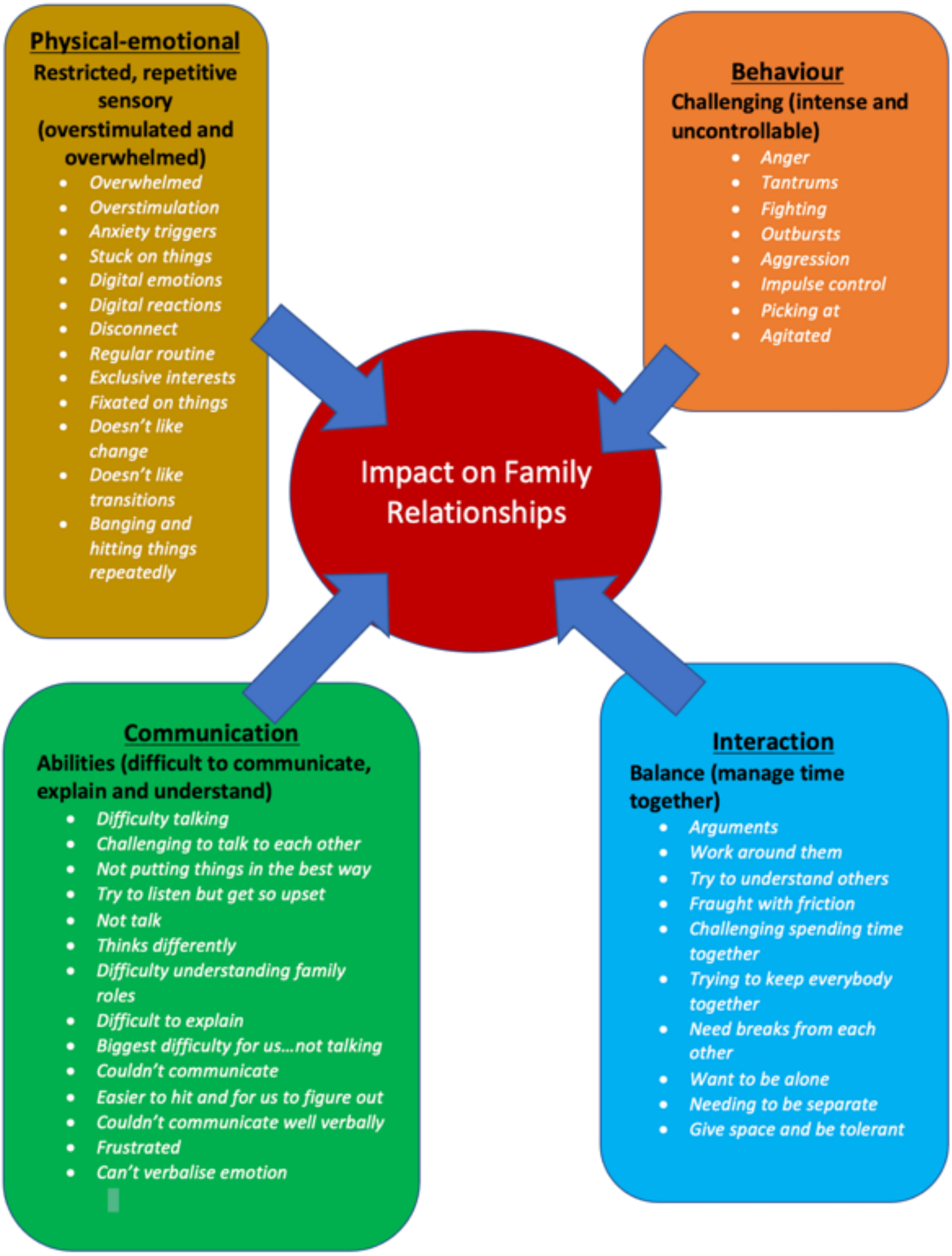
- What  do you  like  most  about your  family  ?

- What  is your  family  good  at?

- What  do you  like  most  about you  ?

- What  are  you good  at?

Appendix H: Sample Basic Theme Maps



Impact on Family Relationships

Physical-emotional

Restricted, repetitive sensory (overstimulated and overwhelmed)

- *Overwhelmed*
- *Overstimulation*
- *Anxiety triggers*
- *Stuck on things*
- *Digital emotions*
- *Digital reactions*
- *Disconnect*
- *Regular routine*
- *Exclusive interests*
- *Fixated on things*
- *Doesn't like change*
- *Doesn't like transitions*
- *Banging and hitting things repeatedly*

Behaviour

Challenging (intense and uncontrollable)

- *Anger*
- *Tantrums*
- *Fighting*
- *Outbursts*
- *Aggression*
- *Impulse control*
- *Picking at*
- *Agitated*

Communication

Abilities (difficult to communicate, explain and understand)

- *Difficulty talking*
- *Challenging to talk to each other*
- *Not putting things in the best way*
- *Try to listen but get so upset*
- *Not talk*
- *Thinks differently*
- *Difficulty understanding family roles*
- *Difficult to explain*
- *Biggest difficulty for us…not talking*
- *Couldn't communicate*
- *Easier to hit and for us to figure out*
- *Couldn't communicate well verbally*
- *Frustrated*
- *Can't verbalise emotion*

Interaction

Balance (manage time together)

- *Arguments*
- *Work around them*
- *Try to understand others*
- *Fraught with friction*
- *Challenging spending time together*
- *Trying to keep everybody together*
- *Need breaks from each other*
- *Want to be alone*
- *Needing to be separate*
- *Give space and be tolerant*

Impact on Sibling Relationships

Physical-emotional

Restricted, repetitive, sensory (difficult to deal with)

- *Hyper empathic*
- *Highly emotional*
- *Stuck on things*
- *Not fun*
- *Difficult*
- *Sensory seeking*
- *Quickly get out of hand*

Behaviour

Atypical (mean and unusual)

- *Hit and kick*
- *Hit back and fight*
- *Verbal stuff (swearing)*
- *Being mean*
- *Not like a normal sibling*
- *Couple of other things going on – not annoying on purpose*

Communication

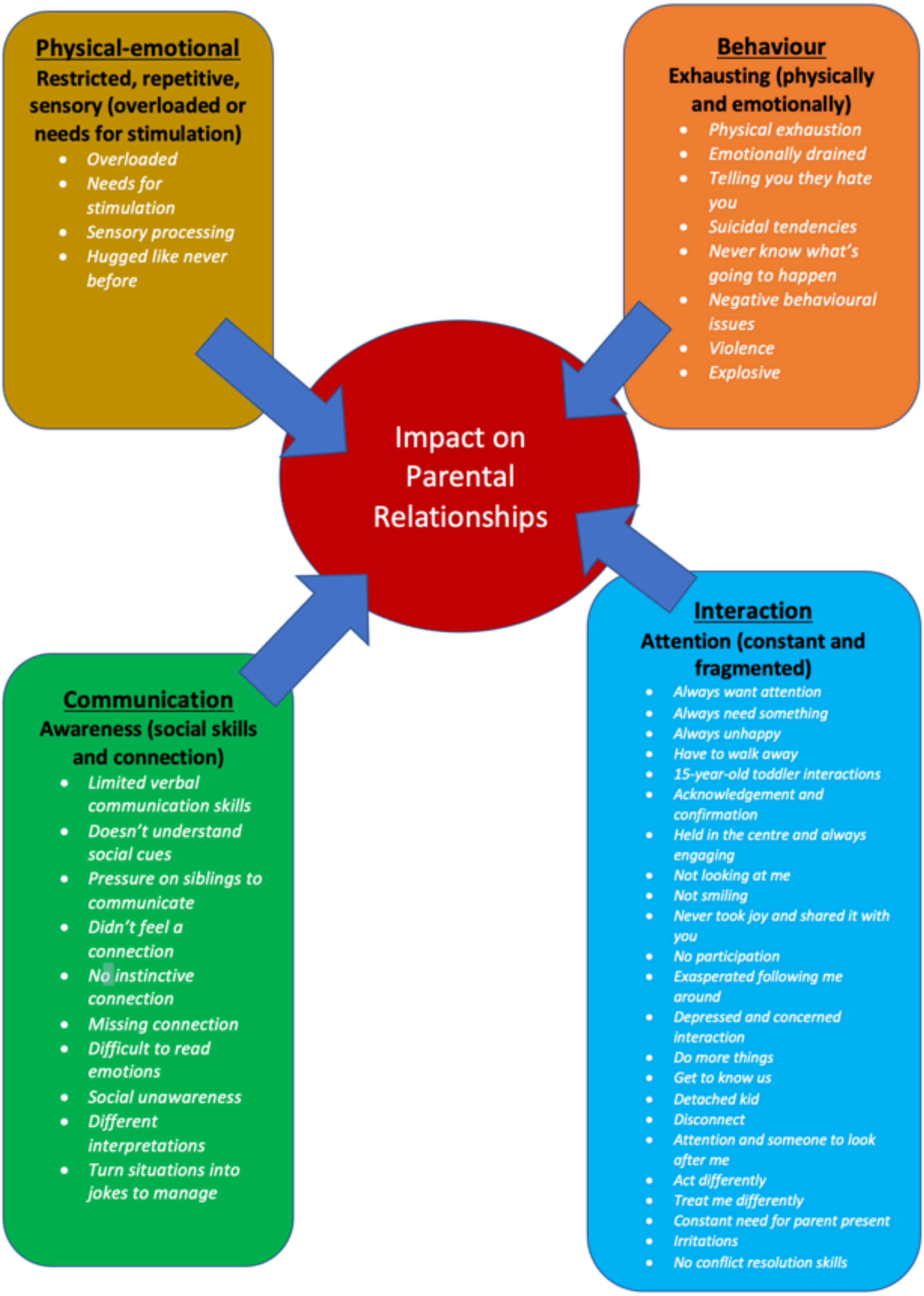
Connecting (problem solving and bridging an understanding gap)

- *Don't get that perspective*
- *Looking for another way to explain something*
- *Very different thinking*
- *Understanding gap*
- *Struggled to connect*
- *Language insufficient*
- *Hitting himself*

Interaction

Friction (hesitant and unusual)

- *Scared to say anything (anger)*
- *Loud and rude*
- *Scared going to yell*
- *Afraid*
- *Arguing*
- *Mother and look after him*
- *Annoy*
- *Forgive poor choices*
- *Just exist with him*
- *Strange relationship*
- *Telling him off but he's older*



Impact on Parental Relationships

Physical-emotional

Restricted, repetitive, sensory (overloaded or needs for stimulation)

- *Overloaded*
- *Needs for stimulation*
- *Sensory processing*
- *Hugged like never before*

Behaviour

Exhausting (physically and emotionally)

- *Physical exhaustion*
- *Emotionally drained*
- *Telling you they hate you*
- *Suicidal tendencies*
- *Never know what's going to happen*
- *Negative behavioural issues*
- *Violence*
- *Explosive*

Communication

Awareness (social skills and connection)

- *Limited verbal communication skills*
- *Doesn't understand social cues*
- *Pressure on siblings to communicate*
- *Didn't feel a connection*
- *No instinctive connection*
- *Missing connection*
- *Difficult to read emotions*
- *Social unawareness*
- *Different interpretations*
- *Turn situations into jokes to manage*

Interaction

Attention (constant and fragmented)

- *Always want attention*
- *Always need something*
- *Always unhappy*
- *Have to walk away*
- *15-year-old toddler interactions*
- *Acknowledgement and confirmation*
- *Held in the centre and always engaging*
- *Not looking at me*
- *Not smiling*
- *Never took joy and shared it with you*
- *No participation*
- *Exasperated following me around*
- *Depressed and concerned interaction*
- *Do more things*
- *Get to know us*
- *Detached kid*
- *Disconnect*
- *Attention and someone to look after me*
- *Act differently*
- *Treat me differently*
- *Constant need for parent present*
- *Irritations*
- *No conflict resolution skills*

Appendix I: Additional Participant Quotes

How do young people with an ASD diagnosis perceive and experience their condition within their family?

Global theme: Feeling different and being different

> Jim: I think that there's a lot of [people] that don't know much about it [autism], and so instead of living with the unknown, they give it their own logical reason, not thinking, instead of it being more about, "that's their mental journey." For me, I know what autism is, but it's our own definition. It's different for everyone.
>
> Ken: It doesn't bother me that I'm different … it used to bother me that I was different, and it made me really upset, but it doesn't really anymore because I think I really wanted to be like everybody else. … I found that I am smart, I just think differently … I think it [autism] plays a positive role. Sometimes I don't do things as quickly as other people might like. It might take me a little bit longer to understand something.

Organising theme: Intense emotions

> Joanne: I get just randomly, extremely anxious about nothing in particular.
>
> Joanne: I try to see the best in most things even if sometimes my brain goes silly and gets angry at me, and then after trying to calm down, I walk through and fix it, and slightly deal with it. It's still an ongoing thing, beating myself up mentally.
>
> Joanne: I like to be around people to make sure that I have a secure connection and support group, otherwise I'm not 100% sure if I would be OK. Because I do need a lot of reassurance with a lot of things because I'm quite anxious, unless I've got a lot of help pushing me to do it and encouraging me. I don't want to be a burden on my family.

> Samantha: With autism, you get overwhelmed with overstimulation which can happen frequently for those on the spectrum.
>
> Lance: I needed my parents around me because I needed attention and somebody to look after me and I didn't want to be on my own. Now, I want to develop a form of emotional self-reliance, not depending on other people's behaviours to affect my emotions. For me that's become a very important thing, not depending on [my dad] looking happy for me to feel happy. To control that within myself and learn to relax.
>
> Ken: We sometimes find it challenging to talk to each other in a nice way. Sometimes you want to be alone and someone else wants to do something, and you get angry about it, then we get angry at each other. Everyone in our house has Asperger's, so we all knew it's going to happen. It's hard on relationships having one Asperger in the house, let alone four. One thing we can do to help each other with our Asperger's is listen to each other. We try to listen, but we can get so upset.

Joanne described autism as feeling like, "an overwhelmingness that pushes me back … I think that's for the whole family because any overwhelming situation for me translates to everyone else."

Organising theme: Disconnected and blocked off

Lance described how the focused love on his interests made everything else, which included noticing and connecting with others, seem so meaningless: "That's one thing about being a kid and on the spectrum, my ability to have a single mind and passion for things. That my love of things is very intense and very focused I didn't notice other people. Part of that disconnect is that I was so focused on the love of my interests, that everything else seemed so meaningless."

Lance: When I was a little kid, I wasn't getting on too well with them, a lot of the time I wasn't very happy. My parents weren't happy because they were concerned about me. They figured I didn't have a future, that I'd be stuck in a regress state forever and for the rest of my life I'd probably need assistance of some sort. I think I could sense that they were a bit disappointed about that.

Nina: I do think that this world is still a puzzle to me, like how people act and how rules are, and for my world it's easy to go there and understand it because it's my world and stuff like that, but this world is still quite a puzzle to me. It's good too because I can just go off my own world. I think it plays a positive role. I'll be sad, but I won't stay upset for long. I'm also very resilient, I'll just pick myself back up and I won't stay upset for long.

Mother of young person: sometimes when we are out do you feel like people are looking at you

Young person: yes

Mother of young person: how does that make you feel? (young person pointed to "happy" visual on the language board) Happy?

Young person: Yes

Mother of young person: Do you like that people help you?

Young person: Yes

What are family members' perspectives on how ASD impacts relationships between family members, and the family as a unit?

Organising theme: Closer and stronger

Douglas (male partner) and Francene (female partner) shared the personal qualities that brought them together through their approach to parenting their child with autism:

> Douglas: Communication is why it works for us.
>
> Francene: Communication would be paramount. But also, it works because you're very accepting.
>
> Douglas: I've had a lot of growing to do; you've been such a stalwart in educating, and we communicate.
>
> Francene: But you've also been opened to listening which is hard because you get frustrated sometimes. So, it's me having to push back a bit and say, "But you're asking for what you can't have."
>
> Douglas: That's how it's been. If the parents aren't willing to adapt and learn you need to change.
>
> Francene: Your expectations, you've got to change your expectations

Jim (young person with autism) commented on his condition as a problem that contributed to great stress on the relationship between his parents and shared that, "I wish I never had this problem, because I think it would put a lot less stress on my parents' relationship."

Organising theme: Getting Along

For example, Monica (mother) described the interactions between her children as part of a "typical family":

> Monica: [Child not with autism] is just a seven-year-old girl. She floats around, does her thing. [Brother with autism] is constantly in her way, it's his way to interact with her. She [can be] standing talking to me, and as he walks down the hall past her, he just whacks her, and then he walks away. We're a typical family like that, the big brothers pick on the little sister.

Organising theme: Not just a sibling but a carer too

In some families, the sibling-caregiver role was considered a liability for the sibling with autism and governed the sibling relationship dynamic. Lance (young person with autism) reported that "the neurotypical sibling often gets short-changed. They have to wear some of the burden of care of the person on the spectrum, if not directly supporting them. Yes, they're a brother or sister, but indirectly in that way."

Organising theme: Challenging behaviours

In one family, physical behaviour impacted the sibling relationship when a young person with autism and limited language skills resorted to hitting themselves. Nairi (mother) shared about her son with autism:

> Nairi: [His] language is insufficient, so when he is sitting there, hitting himself, and she [sibling] is sitting there saying, "sorry," when she's [sibling] had no part of causing his distress, she [sibling] gets really, really upset by that. His behaviour sincerely impacts

> them.

Reported by a few families, the sibling with autism did not always purposely act out physical behaviour on their brother or sister. Tamara (mother) reported:

> Tamara: [Child with autism] ended up not only kicking [her sister] with big Doc Marten boots on the forehead, but also almost broke [her sister's] ankle as she [child with autism] sat down on [her sister], and [child with autism] was giggling so much she couldn't get off [her sister's] foot, which was twisting at the same time. Her self-awareness and self-control, not so much.

Sarah explained: "Sometimes my sister [with autism], she's angry, so sometimes I'm scared to say anything to her." Kate shared that there are many times her brother with autism:

> Kate: … will get frustrated at something, or something that [his other sister] does, or something that's not quite going right, like he can't get something to fit the way he wants it to, and they'll be a bit of anger or frustration. I don't want to deal with it, but we're sort of working around that, "Maybe if we tried this, or if we tried that." This is something that other siblings wouldn't have to do without being forced really, to take other approaches.

Amandi reported on her need to automate her responses when stressed out by or interrupted by her brother with autism:

> Amandi: I feel myself losing my patience, due to stress, or if he's interrupting me when I am trying to work, I definitely lose my patience a lot. I really need to work on giving out automated responses without losing it.

Organising theme: Time together and time apart

Martina explained that she went to her room as a means of avoiding potential conflict:

> Martina: When [my brother with autism] is not in the right headspace it's hard to talk to him and try to get him in the right headspace. I usually go to my room, so he doesn't think that I'm a part of it.

Organising theme: Managing autism

For example, Colin (father) reported on his daughter's echolalia:

> Colin: She started doing other things which I think are very usual for autism where she would say something over and over again, echolalia, for a while it was very annoying to cope with and also do the same playthings over and over which you can do for a while before it becomes a bit of a drag.

Francene (mother) reflected on her son's sensory needs: "The sensory processing did make sense afterwards because when we reflected back, [my son] had always been a child who when he hugs, he hugs like you've never been hugged before."

Nairi (mother) described the need to be "three steps ahead" in order to learn how to manage her son's communication and behaviour. Nairi explained, "I say [to my son] 'What do you want?' I don't know what he's looking at and what's going on. If he doesn't name it, I've got no idea. It's having that ability to try and be three steps ahead."

A few families noticed differences in perception for their young people with autism. This included reports of different interpretations of social situations, events, and cues. Tamara (mother) considered that her daughter "might be looking at it a little bit differently. She'll miss so many social cues. Her interpretation is totally different."

Tamara (mother) described her daughter's need for constant attention:

> Tamara: [Young person with autism] seems to always want attention, always need something, always unhappy, always the one that whinges, always the one that I have to walk away [from]. As if she was one of 20 that [had] never been looked at. A lot of me, me, me, me, and the thing that gets me is it's never enough.

Gary (father) reported on his son's violent tendencies as, "this frustrated element and he used to hurt himself. He pulled his hair out, he'd bang his head, he would smash his head on the ground." For Francene (mother), moving through meltdowns meant she could get on with the rest of the night's routine:

> Francene: You've got to have the meltdown before you can then move on to the next part, which is dinner, bath, bed. If you don't deal with these things and just go, "Mate, not now." There's no moving on. You have to throw yourself at it before we can move on.

Half of all parents described their child's challenges with emotional regulation as a lack of awareness of their emotions. Greg described his sons' emotions as "digital":

> Greg: The boys have "digital emotions" and can react in a microsecond. The only time he knows he's in a problem is when he's hit meltdown stage. This is where the issues often come up. His reactions are different in the way he doesn't realise that he was in a sense of stress or sense of something like that. He's doing something, the stress builds up, and he explodes.

Tamara (mother) shared that her daughter's autistic traits influenced her behaviour and contributed to the unawareness of her actions; this included a need for acknowledgement, attention, confirmation, and belonging:

> Tamara: For her, a lot of it is awareness and a lot of it is that need for me confirming that I know her, that I see, that I hear, that I acknowledge. It's that need of belonging and always being held in the centre.

As the majority of parents reported on their child's difficulty in acknowledging and registering their emotions and behaviours, Douglas (father) reported on his own growth and adjustment, whilst he continued to struggle to understand his child's behaviour:

> Douglas: I've struggled in understanding his behaviour. I've always wanted to treat him as a normal kid. I've had a lot of growing to do, adapt and learn, but I still struggle with it. Understanding all types of his behaviour, I had a lot of adjustment to do.

All parents reported that their child with autism struggled to understand their own emotions. Two of the parents reported that their children with autism struggled to understand their own and others' emotions. Described as "dyslexia of the emotions," Dwayne (father) described his stepchildren's limited internal and external emotional awareness:

> Dwayne: Whereas [the young person with autism], they're more dyslexia of the emotions. They don't have that level of internal awareness and by default, they don't have the external awareness. [Young person with autism] asked me a question and he looked at my face and thought, "he's mad." He has no idea what I'm feeling on the inside because he can't picture how he looks when he's angry. Whereas I'm just in visible pain. Which can come across as anger, but they don't understand the difference.

Cassie (mother) reported on her adolescent daughter's recent achievement to understand and accept her emotions as: "She's now started understanding what her emotions are and has also accepted that she has a moderate level of anxiety."

Margaret (mother) shared her and her male partner's disappointment during the time they tried to build a connection with their child. Frustrated and upset, she and her male partner struggled to communicate with their child:

> Margaret: It was a very disheartening time for us as parents. Trying to build that connection with our child, you couldn't see that progress in your kid. It was really frustrating and upsetting because we were trying our best to get words out of him, but we couldn't, and we didn't know how to.

Organising theme: Mostly work and little play

Maya (mother) listed the amount of mental and physical work required to keep the home running smoothly:

> Maya: A lot of patience from me makes things go smoothly at home. Physical work from me, cook food and have that available, clothes washed and dry and clothes folded away, housework being done, mainly me who is doing all these things.

Dwayne (father) reported: "You've got to learn each of your kids' characteristics. You've got to learn when they're overloaded versus when they have needs for stimulation."

Lance (young person with autism) described the support his parents had to implement around him and the impacts this had on them: "It started badly because my parents, they are often exasperated having to follow me around, cleaning up after me."

> Dwayne: We're building one of those whiteboard type things. We're going to have magnets for the chores and things they've got to tick off, each one has their own pigeonhole. We're spelling out every job that they've got to do to look after themselves, and their behaviour is listed as well. Just because everything being spelled out seems to really help the kids, because they know where they stand, they know what they've got to do. It alleviates the anxiety because they know what's expected of them.

Some mothers shared investigating problems that occurred between their children with autism was a regular and stressful event:

> Cassie: There is a lot of issues we have very little control over. A lot of times their behaviour … we often have to spend the evening trying to get to the bottom of what happened. It involves working on it and a lot of research. We decided to select one day to deal with all of these issues, because otherwise it gets too overwhelming in the sense that every single day, something happens, so if you spend every evening discussing what happened and what we could have done differently, we're just stressed out.

Tamara (mother) shared that: "you always have to be engaged. It is tiring." Maya (mother) echoed this sentiment: "It's tiring and it's draining because I know there's no end to this in my lifetime. There is a lot of burden as his parent, and I feel a lot that I'm not free."

Some families commented on the different experiences of raising a child with autism and one without. Tamara (mother) explained: "Parenting a kid with autism is tremendously more difficult than parenting a kid without autism. There's a big difference in terms of motivation and communication."

In addition to feeling tired and frustrated, some parents, such as Debbie (mother), reported feeling stressed, as her daughter's "speech was characterised by a lot of echolalia, that used to drive me mad. When I was spending time alone with her, it would be extremely stressful." Whilst parents mainly reported on the impacts to their mental health and wellbeing, Adam (father) shared a story that captured his son's awareness of the burden of care he placed on his father:

> Adam: We were watching a television program last night, the actor who was playing the part of his elder brother was talking about the burden of looking out for this younger sibling with schizophrenia and how difficult it was and how terrible it was. He turned to me and half-jokingly said, "Do you feel that way about me, dad?" He can't ask that question unless there's some recognition that what he's saying might have an element of truth.

The demands of "work" on parents left some feeling the need to make time for themselves. Stephanie (mother) shared that "as I got older, I was really spending a lot of time with them, which was hard for me because I need my alone time too." Some parents, such as Cindy (mother) disclosed: "I get really worried about my own health, I am sleep deprived. Once they've finally gone to bed then I stay up late because I want that non-caring time, non-parent time."

Colin (father) reported on the extra difficulties experienced with the limited flexibility of his child with autism:

> Colin: There's a balance between doing what I, or [female partner] and I, like and what [young person with autism] likes. It's great when the interests align but this isn't always

> the case of course. I suppose all families have to find this balance, but the limited flexibility of a child with autism makes this more difficult. Negotiating jobs is harder. Changes to routine aren't ideal for her. Holidays are often a bit tricky. We have a conflict sometimes; we would like to go away, and she would rather stay at home. With experience we've learnt to manage this fairly well, not moving around too much and making sure to do at least some things that [young person with autism] enjoys; finding a balance.

Stephanie (mother) reported on the management and negotiation of her child's and husband's differing interests:

> My husband does a lot with him because they have very similar interests with war gaming. The trickiest one is him and our daughter [have] very divergent interests. What they do like to do is go out to lunch together, or on occasion watch a movie, but that's the trickiest one. Saying to her, you're both the same, neither of you really wants to talk to the other about your other interests, so you both have to bend.

In a couple of families, parents described negotiation and management as "a battle." Dennis (father) described the negotiation and management of his and his female partner's preferences, and his son's conflicting preferences as, "a battle of differences and exclusion":

> Dennis: It's a big birthday, it's an emotional thing for me. I could have arranged something that was in a park or something that was shorter, something he could have been more capable of participating in, but I chose an event that was more focused around my preferences. It's a battle, in a sense that sometimes you find this is not going to work for [our son] so we're going to have do it differently, or we're going to have to exclude

> him. If he didn't have a disability, this would be a normal thing for a 16-year-old teenager to participate [in] with his parents.

For another family, Margaret (mother) described the negotiation and management of her son's behaviour as "a battle worth fighting for":

> Margaret: I've made a lot of allowances for his behaviour, but at times I've also not let him get away with things where I can see a potential. For example, like if he says he's very screen dependent, he uses that [autism] as an excuse to say, "Look, I need the screen I'm a screen boy," and I say, "OK, I think this is a battle worth fighting for."

In another family, Maya (mother) described how autism had impacted the dynamic between her and her child as she remained on "high alert" and conscious of her son's needs:

> Maya: I think what disability has done is to try to address what [my son] is doing, I have to stop what I am doing, stop and respond to him, and with escalations from him I am on high alert. If he were normal, he would not be doing that. I am very conscious about what [my son's] needs are and what he tells me, even though it is really repetitive stuff I try not to lose patience.

In a third family, Francene (mother) reported that "routines and remaining calm helped" manage her son's need to know what was happening, as "routines are essential for him. He always wants to know what's going on, but he has no time management." In a fourth family, Tamara (mother) shared her approach to the management of her daughter's "rigid thinking":

> Tamara: When she does certain stuff, like with the shorts for work, it's three degrees. I say, this might be an example of that rigid thinking. I'm not saying you are being rigid. I'm trying to say perhaps you could work differently with this because this is that rigid

> thinking that we know that sometimes happens to you.

In another family, Kate described how management and negotiation played a role between her parents as they worked together for their child with autism despite their different approaches:

> Kate: To work together as a parent with a child that has autism. Definitely Mum and Dad take very different approaches when it comes to him [child with autism]. They're both doing their best. I think communication with the child, and then communication with each other, would probably be really good.

Organising theme: Mastering Diverse Roles

Stephanie (mother) commented that she was "constantly coaching and guiding them, educating them, the development of their character."

Monica (mother) strongly emphasised that parenting her children with autism was not extra hard, it was just done differently:

> Monica: Having autism in the family does not mean parenting is extra hard. It just means we parent differently. We have different expectations of our children. … We think about what skills our kids will need as adults, and we start building those skills from a young age, so they can live as normal a life as possible.

Stephanie (mother) shared she had lots of conversations with her children to ensure they understood the social and behavioural rules of the "neurotypical world" and emphasised the need to fit in with that world:

> Stephanie: It was important for them to know how to navigate the neurotypical world. We have lots and lots of conversations about this. I want them to understand that there are some rules of engagement about being in this world, behaviourally. I really love you

> and I think you're fantastic and special to me, but you know, you need to fit in here.

Mothers reported on a range of areas they focused on when they interacted with their child. Tamara (mother) described using good-humoured storytelling as an approach to highlight to her daughter her past actions:

> Tamara: My way I suppose is to turn a lot of things into joke. I try to illustrate other people's examples. "Oh my gosh, look at this, what they have done?" When I'm really talking about what you did yesterday, so that it's not always a dig at her.

Cassie (mother) reported she focused on communication and language skills when she interacted with her daughter, and lessons around positive emotional management to help build trusting and close relationships:

> Cassie: We're focusing on how we phrase things and language we use when interacting. … Taking the time to practice active listening, to understand our children's feelings, and to help our children understand ours are wonderful and highly practical ways to build relationships of trust and closeness.

As well as mothers' desire for their children to have positive relationships, they expressed the importance of finding opportunities that allowed their children to develop independence and a positive self-image. Francene (mother) described balancing the need to protect her child and finding moments that allowed her child to develop important life skills:

> Francene: They want to do what their peers can do, but they don't have the inbuilt safety mechanisms that the peers do. Therefore, as parents you are just that little bit more protective because you know they can't be self-protective. Any opportunity you can try and give them to grow some independence and some self-worth and self-importance and

> decision-making for themselves is really valuable.

Stephanie (mother) emphasised her wish for her children to understand and embrace who they are, and to consider and accept themselves:

> Stephanie: I really want my children to know and like who they are, the unique and wonderful individual that they were always meant to be—to embrace themselves fully. There's nothing wrong with being on the spectrum. It's all about neurodiversity.

Organising theme: Off Balance

"Naturally we have different expectations of Sigrid than other children" (Cassie, mother). Some parents had to explain and discuss the differences to their child without autism but commented on the difficulties of explaining to their child not with autism the differential treatment: "One of the things is forever explaining to [child not with autism], 'But your sister is different,' so that's a big one" (Tamara, mother).

> Daryl: The only time that she's been unhappy with his autism would be when he's got something she hasn't, or we've had to accommodate things. We'll say, "Look, he can't do those activities," because of his autism, and she would get upset that we would make allowances for him, but not for her.

Other parents chose methods such as redirection: "Sometimes the younger one would say, 'But Sadib is doing it, Sadib is holding a knife.' Then we say, 'Sangeeta, let's do something else.' It's difficult to explain to her why we would deal with him a bit differently" (Mikel, father).

> Kate: We have a lot of discussions. … Sometimes the patience runs low some days, and there's a bit of frustration there every now and then … Mum and Dad talking about,

> "This is him you, this is how he works, we need to work with him around this." We have discussions to try to understand all sides of the story, and how everyone's thinking, how everyone else is going.

Additional support and care for the needs of the child with autism meant time spent together between parents and their child/ren not with autism was impacted. Cindy (mother) explained that "the focus was definitely on [child with autism] needs. The others had to suck it up. Trying to carve out any time for the other two boys, I was very conscious of the siblings." James (father) explained the difficulty of he and his female partner attending their daughter's activities together, as mother and father:

> James: [Our child not with autism] has all her pursuits. She does dance and drama, she's got quite a lot of after school commitments. We both try to be in for that and go and witness those kinds of things. But what can be quite difficult is going and supporting her together, as like having Mum and Dad there at the same time, because we've got to get someone to come and care for [child with autism]. We try to do that for special occasions

Monica (mother) explained the differences in her children's behaviour and demeanour caused difficulties in her family:

> Monica: One was hyper, and one was hypo, which caused a lot of issues in the family because [child with autism] is totally hyperactive, screams all the time, and has absolutely no play skills other than throwing stuff up in the air and watching it bounce. [Child not with autism] would go off to his room and would stay in his room for hours looking at books and I was so swamped by everything that was going on with [child with autism], that if [child not with autism] wants to sit in his room and read books, isn't he a

good boy.

In one family, Dennis (father) shared that his daughter thought he, and her mother, were too accepting of her brother's behaviours and focused too much on his needs: "She thinks we've erred too much on the side of focusing on his [our son with autism] needs. She has her views on us being too accommodating to [his] preferences or misbehaviours."

Organising theme: Loving Connection

Some parents shared other positive impacts related to autism, which for a mother and father across two families included a reduction in worry for where their child was and who they were with. Nairi (mother) stated "I never have to worry about where he is going out to or who he is; with autism he doesn't go out on his own." Adam (father) described the benefits of his son being the way he was:

> Adam: There are benefits to him being the way he is because at least I know where he is. Most of the times I'd not know if he's driving around with friends being drunk and high, doing whatever teenagers typically do.

Janette (mother) reported on the positives of a shared feeling of happiness and mindfulness created from her son's focus on his interests:

> Janette: The really nice thing about [my son with autism] is he does very much live in the moment. When he's happy, he's doing things that he enjoys, his sense of happiness is infectious. He can be really fun to be around and helps bring you into the moment, because he's focused on the buses and the trains and the dogs.
>
> Daryl: He has made me a better dad. It was about me learning how to manage my behaviour, not his behaviour, which has been the journey to try and be a lot calmer. He's

> made me calmer, he's made me more understanding, more forgiving of problem behaviour.
>
> Janette: He's very affectionate, and even though it's hard for [my son with autism] to articulate it, I very much feel that he loves his family and that we have a really important role, in many ways a lot more important than for another child. With that kind of a responsibility, we help give [him] as many opportunities as possible.

Some parents also reported on their protective and caring role as a positive dynamic in the parental relationship. Gary (father) shared about his son, "He melts my heart. He's a really endearing kid and there's an element of vulnerability. I'm his protector. It's hard to explain, I gush over him even now." For Maya (mother), her son with autism positively impacted her relationship dynamic between her daughter not with autism, as she reported: "We are the carers of him. We feel like we really need to protect him. It is super positive. It makes me feel closer to his sister. We've got a mutual connection there."

Organising theme: Rising to the challenge of autism as a family

Stephanie (mother) shared the "hardest" challenge for her family was to balance each family member's needs:

> Stephanie: [We are] really trying to understand and learn about the various personalities in the house, giving each other space, trying to make sure people feel loved and supported, even though someone needs to be separate. If things don't work out, we address why and try again.

As well as managing challenges, families described how they used strategies that helped form closer relationships between each other. A father, mother, and sibling across three families reported on the importance of routine in their lives, as they made checklists, worked to understand each other's needs, and recalled memories as a family. Dwayne (father) shared that his daughter with autism has "got it really down pat; we've documented in a checklist form her entire day and all the things that we need her to do. It's been a fun learning experience and family rituals definitely help." Kate highlighted her family took "the time to make sure we all understand each other, it's sort of being really passionate with everyone else's differences and all of our different needs."

> Lance (young person with autism): It's taught me the value of family, the value of family not being some happy family where everybody gets along and stuff, that is not what it's about. It's about learning to manage and deal with people, learning how to negotiate the things that annoy the shit out of you and things that you absolutely love about them.

Organising theme: Held Back by autism

Nairi (mother) shared the impacts of her son's frustration and violence on the family:

> Nairi: In terms of the emotional toll on family relationships, it is too hard for him to say, "I'm hungry. I want some food." It's easier for him to hit himself and for us to figure out he's hungry, which is nasty, and she (his sister) gets really, really upset by that. There are times when she is in her room crying, he's sitting out here hitting himself, and I'm in my room crying. It's a huge emotional investment.

Adam (father) described how through the process of managing and focusing on the needs of the child in the family with autism:

> Adam: The family of a person with autism becomes autistic themselves because they adapt their pattern [of] living to the preferences and comfort level of their family

> member. If you have a child that has poor socialisation, who doesn't like change, who doesn't like transitions, you protect that child. In the process of doing that, your own social life shrinks. Your own interactions become more limited. They become more inward looking, more focused on that person's needs. Social connections start to fall away because it's more difficult. It's more difficult to go out to dinner. It's more difficult to attend family functions because of the amount of intensive management that's required to get the child out of the house, keep the child occupied, prevent the child from getting distressed, prevent the child escalating in some way or doing things that are inappropriate. Your behaviours and relationships become more autistic. I think that observation certainly holds true in our lives.

Organising theme: atypical family life

A mother, Helen, shared that "sometimes we're just a family, and sometimes we realise we're not like other families."

What are family members' perspectives on how external responses to ASD impact on their family relationships?

Bullying and stigma and stress at school

> Lance (young person with autism): Part of it is that I do one-on-one tuition, which is really good for me. But also, the main thing I've noticed is I was left with no real knowledge [of] how to complete tasks because completing tasks, doing work, organising my time, schools managed to stigmatise that so much that I associated it with nagging and fighting with my parents and misery. ... I believe this is a struggle for many parents, especially with kids on the spectrum.

Parents’ insights supported young people’s recollections of their poor school experiences, and parents shared the impact this had themselves:

> Karen (mother): High school’s been a lot harder … a major factor is [my child] hasn’t made close enduring friendships from school. … You do tend to feel a bit, “trapped here being the mother of a 15-year-old who’s totally dependent, and I don’t have a life.” … It just tends to reinforce a sense of being very isolated.

Isolation meant most families felt different to other families; Cindy (mother) stated: “We’re not just another family.” Family life was described by most parents as “really hard”:

> Jannette: It depends on the context. Sometimes we’re just a family and I think during the summer holidays is the time where it’s really easy to just think of ourselves as, “We’re just a family.” Then you hit school, and you hit all the problems that school entails for them, and you go, “Oh yeah, we’re not just another family. It’s really hard.” As soon as you start any kind of comparison, that’s when you realise that you’re not at all like any other families.

Fitting in as a family

As families deliberated on what being a family meant, as well as trying to remain as truthful to themselves as they could, they faced barriers and restrictions to how they spent time as a family in the community:

> Dennis (father): It’s a bit of a battle in a sense that sometimes you find this is not going to work for [son with autism] so we’re going to have do it differently. We’re going to have to exclude him … but all the other families are bringing all their kids, so why wouldn’t we bring all our kids? …And it’s always on the inclusion, exclusion line. You have to do

> something quite different to include [son with autism] and that's difficult for other people.

When families planned to spend time together outside the home, as well as wanting to fit in and to not stand out, they faced multiple barriers which limited what they could do in the community. Monica (mother) explained: "We're in this disability world … autism does limit the places we can go as a family. But we compensate for this by creating our events within our own community at our home". Francene (mother) explained that cost was a prohibitive factor her family faced due to her children's medical needs, as well as finding an event that was fun for all but was not too stimulating:

> Francene: If we are having an outing, we have to plan how we will manage if [child with autism] becomes upset or isn't coping so that it doesn't mean the other children miss out on the fun outing promised … It would be great to be able to offer our children visits to live theatre, not things … too loud … too overwhelming in stimuli, but to things like musicals. But the costs are prohibitive when medical costs are factored into living expenses. Also, so many of these opportunities are held in Sydney or Melbourne—this means overnight accommodation for Canberra families, which adds to costs.

Another area that families faced a restriction or barrier to was the social norm of eating out together as a family. Cassie (mother) shared they would never take the kids out to a restaurant due to their behaviour around others at the restaurant: "We would never take the kids out to eat because they wouldn't behave appropriately. You wouldn't take them near older people or couples that are trying to have a nice quiet evening." James (father) mentioned that his family missed out on attending important family events together:

> James: Missing out on those really important events like weddings and funerals. An example would be an Anzac Day dawn service as well. … I think it would be very disrespectful for us to bring him along … from a respectful level, the day is about them, and we wouldn't want him to go to the ceremony and then something to happen and then that's what people remember.

Parents reported they and their children with autism received judgement from others when their child found the sensory input of the environment they were in, overwhelming:

> Stephanie (mother): for example, taking Nina out when she was younger and taking her to shopping centres, where you've got the most amount of sensory input. It'd make her go nuts. I got a lot of judgement from people in shopping centres.

Amandi (sibling) shared her experience of feeling judged by others: "I don't like the stigma against it. That it's like a really negative thing and it's kind of something to be almost ashamed of. It really catalysed the whole like wanting to fit in thing." Families also felt they could not have the same experiences as families without autism in their lives, such as family holidays and travelling. Karen explained, "We just don't get those experiences … it tends to reinforce my sense of being very isolated." Cindy (mother) reflected, "There are lots of families like ours, isolated just getting by in life and doing their thing."

> Dennis (father): You don't know whether other people have seen these super narratives of triumph in the face of disability and autism. How do you compare yourself when your situation is so atypical to others? It's comparing yourself to the neurotypical family and comparing yourself to the narratives that come out because they are quite amazing and that's why you hear about them. But there's plenty more of that boring, old story of

> disability which are probably more typical and is more like you.

How autism was portrayed by others, including the media, affected almost all young people with autism.

> Ken: If you see some things about portrayals of Aspies or autistic people, it's not like what the real thing is. They act like normal people. Some people make us different, really different. It's not that nice because we are normal people. … When autistic people act weirdly, everyone is like, "Oh, this is weird, these people, there's something wrong with them." It's not like that, it's just different.

Lance and Joanne provided an example of one common depiction of people with autism in television shows:

> Lance: I understand it's a media thing, but people with Asperger's are depicted as being completely socially distant. … That's what I really enjoy, is having good people I'm able to make friends with and talk to and stuff like that. There are people on the spectrum out there who are like that.
>
> Joanne: The stereotype, what I've seen, is we're all a bunch of Sherlocks and Sheldons … Sherlock, highly intelligent, non-emotional. Sheldon, highly intelligent, especially with their specified interest areas, and focused, a huge nerd.

Jim listed the many different perspectives of autism and noted the limited understanding amongst the general public of what autism is and how a person with autism might act outside social norms or expectations:

> Jim: Everyone has a lot of different perspectives. Some people with autism that tend to act funny, or erratic, or something that people wouldn't deem as usual. Some often fear it,

> or see it as, “Get your child under control and give it some manners,” because they don’t really understand. I think others think that autism is kind of like being a bit mentally retarded, where you’re not fully capable, when you can have autism and still be fully capable.

Joanne explained there needed to be educational services for families to learn about autism, as well as greater information available about what autism is from the perspectives of those with autism:

> Joanne: educational services for the parents and other relatives and family friends to learn about what autism is, and just more research on autism because there’s a lot of things that are misconstrued about autism. People with autism aren’t all emotionless and don’t have empathy at all. That’s the biggest one ever. Autistic people do not want to be sexual in any way. The stereotype is absolutely asexual. There needs to be more information about those on the spectrum, so autistic people can explain it to someone.

Stephanie (mother) reported how social pressures played a role in her daughter acting out a stereotype:

> Stephanie: People say, “They don’t communicate well, they’re not very good socially, they don’t have an imagination, they can’t handle emotions. They’re not really emotional people.” My children are very affectionate, and loving, and kind. But in particular [my daughter] put under a lot of social pressure, she becomes what we jokingly refer to, and she laughs at it, a robot. I am the stereotype because that is where you’ve pushed me.

Most siblings did not talk about autism to others outside of the family. Eileen shared: “I don’t really know to be like, ‘Oh yeah, my brother has a disability’ because I don’t know how they'd react." Mothers Francene and Janette shared that they did not refer to their child as having autism or chose to not talk about their young person with autism, as others did not know what autism was. Francene commented, "He doesn't have autism, because people don't know what autism is. So, we really don't refer to it in that way."

Parents who chose to talk about their child with autism were faced with comments that demeaned the person with autism as well as who they were as a family. Cindy (mother) shared one of the comments she received from a person at her workplace that autism was a "trend" or a "fad":

> Cindy: I don't talk about my family to other people because they don't get it. And I don't like people's reactions. You have to be careful who you talk to in the first place because there are autism deniers out there, I don't have time to deal with you. Full stop. You're not worth my time … just the other day I said to this person, "I've got a little boy with autism." She said, "Oh, everybody has autism nowadays". Like it's a trend, or a fad.

Many parents and most siblings did not speak with others about autism and their family. Janette (mother) said, "There's lots of conversations at school, at work, around the kids and it's very hard to interject with your child when they're so different. No one really can understand that."

Most young people with autism disclosed that they spoke about being on the spectrum or having autism to others outside the family, but on a need-to-know basis. Lucy would mention her autism diagnosis to others if she said something that was considered outside of social norms, or if she behaved differently to those around her: "There'll be certain social situations where I'm just like, 'I'm on the spectrum,' not really feeling comfortable talking about it. I usually will say to the person, 'Sorry, I didn't mean to say that. I'm on the spectrum.'" Joanne thought it was important that a person knew them as “Aspy” (Asperger’s) if they needed to know, which included for official documents or when trying to get a job: “Sometimes, if people need to know because I’m very subtly presenting myself. Official documents, trying to get a job or something because they need to know what your capabilities are.” Others, such as Will, Jim, and Nicki shared that they didn’t talk about their autism to others as they said, “It’s not important.”

Organising theme: Support families want and need

> Jim: First services should try and interview the child. They can bring a parent, or whoever they want to be with them. I would run it so whoever was conducting the program, in the first interview the child would get their view. Then they’d interview the parents. Then, I’d bring both of them back in and talk about each other’s definitions.

Ken shared: “Well, one thing is everyone who sees people with Asperger’s or autism they shouldn’t wipe them just because they’re different.”

> Lance (young person with autism): Even though I’m on the spectrum, even though I’m different, there’s a huge amount of people who I can’t communicate with because they’re just not able to do that. There are people on the spectrum out there who are like that. Their difficulties are too much … somebody who’s on just on a very different world than I am. I can’t have a person-to-person conversation like we’re having.

Parents highlighted the importance of unique and individualised supports, such as workers fitting in with the family dynamic and unique needs of the family. For Monica, this was a support worker who felt like an extension of their family:

> Monica (mother): When I choose my support workers, I try to choose somebody that I’m quite happy to have in the house. … I want them to feel like an extension of our family

> … if you're out with [the children], you can make decisions regarding them. … Just behave as you would if you were their parent.

Supports identified for siblings, such as sibling groups or mentors, were suggested as a way to help limit the factors of isolation and caring responsibilities in the sibling-dyad. Amandi shared her idea for a sibling group with mentors:

> Amandi: I think it would be really helpful. I wanted a siblings' group because it's very weird and I would have very much appreciated if someone, growing up, told me like, "Hey, it's OK." … Cause it's very different talking to someone about caring who has no idea what's going on, because they understand the condition [autism], but they don't understand the actual experience of it, and that's a game changer. … If someone was feeling isolated, I can help, I can be a sort of mentoring guide to someone who's got a sibling [with autism or another disability]. Because I know I never had anyone to talk to about that stuff growing up and so I wonder what would have changed if I did … maybe I wouldn't have felt so isolated and an outlier … it would be nice to have that sort of commonality between me and someone else.

Arguments between siblings were a main factor in the sibling dyad relationships that caused significant impacts on quality of time shared amongst siblings. Siblings had trouble coping with these arguments, which occurred on a daily basis. Sarah stressed the importance for service providers to help with arguments:

> Sarah: First people could ask them what it's like at home for them, getting to know the family. I would ask them, are there many arguments at home? … I would help with that. Because I know arguments are a really big thing in this house … like I said before, we

cannot go one day without an argument.