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Living with autism: The experience of developmentally healthy adolescents and youths who have a sibling diagnosed with autism spectrum disorder

Jessica Michel

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**Living with Autism: The Experience of Developmentally
Healthy Adolescents and Youths who have a Sibling
Diagnosed with Autism Spectrum Disorder**

Jessica Michel

This thesis is submitted in partial fulfilment of the requirements for the award of

Doctor Philosophy (Clinical Psychology)

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School of Arts and Humanities

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Abstract

Researchers have proposed that typically developing siblings of individuals diagnosed with autism spectrum disorder (ASD), or target siblings, are at increased risk of experiencing psychological distress particularly when compared to other clinical and community sibling groups. To date, evidence drawn from quantitative studies, utilising the target siblings' mothers as the primary informants has been mixed. These studies have primarily focused on risk factors, while the role of protective factors in the experiences of target siblings remains unexplored in quantitative investigations. However, qualitative studies utilising target siblings as informants have emerged providing insights regarding the processes of coping and adaptation that target siblings and their families employ. Therefore, this mixed methods (quantitative and qualitative), multi-informant study sought to explore the role of risk and protective factors in the experiences of target siblings aged between 12 and 24 years ($M = 16.58$ years, $SD = 3.10$ years) utilising a two stage design.

The two purposes of Stage One were to examine if target siblings were more distressed than community siblings as reported by the siblings themselves and their mothers on measures of psychological distress, and the protective factors of psychological resilience and family functioning; as well as to determine the role of psychological resilience and family functioning on the level of psychological distress in the target siblings. In the first part of Stage One 52 target siblings reported significantly lower levels of psychological resilience (large effect) when compared to 34 community siblings. No significant differences were detected on the measures of psychological distress (small effect) and family functioning (small effect) between the two groups of siblings. The mothers reported that target siblings displayed significantly lower levels of psychological resilience (medium effect) and significantly greater levels of

psychological distress (medium effect) when compared to the reports of the mothers of the community siblings. The mothers of the target siblings reported similar levels of family functioning (small effect) when compared to the mothers of the community siblings. Using a hierarchical regression analysis family functioning and psychological resilience were identified as significant predictors of psychological distress in the target siblings. Greater family dysfunction was associated with greater psychological distress in the target siblings while higher levels of psychological resilience in the target siblings were associated with lower levels of psychological distress. In sum, the degree of discrepancy between the experiences of the target siblings and community siblings seemed to vary based on the domains measured as well as on the type of informant (i.e., siblings vs. mothers). However, the psychological distress experienced by target siblings was influenced by their psychological resilience and degree of family functioning.

In Stage Two, a qualitative methodology employing a phenomenological approach was adopted in order to investigate the lived experiences of target siblings and the factors that shaped these experiences. Twelve target siblings and their mothers, who had participated in Stage One, were interviewed separately and two set of themes emerged from the analysis; one from the interviews with the target siblings, and one from the interviews with their mothers. The narratives of the target siblings clustered around three main themes: (i) the evolving natures of the target siblings' experiences; (ii) the challenges experienced by the target siblings; and (iii) the role of target siblings as carers. The narratives of the target siblings' mothers yielded four main themes: (i) the impact raising children with ASD had on the family unit; (ii) the impact living with children with ASD had on the target siblings; (iii) the nature of the target siblings' interpersonal experiences; and (iv) the developmental maturation of the target siblings.

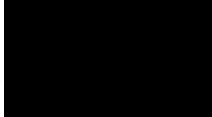
Thus, the main factors that shaped the target siblings' experiences based on the narratives of the target siblings and their mothers were the target siblings' developmental stage, the target siblings' interpersonal experiences, the role of the target siblings within the family unit, and the needs of the family unit.

In conclusion, the results of Stages One and Two indicated that living with brothers or sisters with ASD had a pervasive impact on the target siblings, influencing the experiences of target siblings in psychological, interpersonal, and familial domains. Given that target siblings appeared to have limited psychological resources to cope with the various challenges they encounter the results of the present study are of clinical significance. The complex, multi-faceted, evolving nature of the target siblings' experiences indicate that clinicians supporting target siblings can benefit from conceptualising the experiences of this population within a risk and protective factor framework that considers psychological resilience, as well as familial and developmental factors as influential aspects that shape the psychological adjustment of the target siblings.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. incorporate without acknowledgement any material previously submitted for a degree of diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or
- iii. contain any defamatory material.

Signed 

Date ..03.10.2018.....

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Chapter 1

Introduction: Setting the Context

Chapter Overview

This chapter introduces the impact that Autism Spectrum Disorder (ASD) can have on typically developing siblings and their families. A description of the characteristics of ASD, the diagnostic criteria, prevalence, and aetiology of ASD are summarised in the chapter. The ways in which typically developing siblings and their parents can be affected by the disorder along with the theoretical frameworks that informed the study are then introduced. Following this, the aims of each stage of the research study are discussed. The structure of the thesis is presented at the conclusion of the chapter.

Chapter 1

Introduction: Setting the Context

In the last few decades interest in the experiences of families of individuals with Autism Spectrum Disorder (ASD) has increased (Bebko, Konstantareas, & Springer, 1987; Kuhn & Carter, 2006; Noh, Dumas, Wolf, & Fisman, 1989). ASD, a developmental neurobiological disorder with an early onset, has been argued by some researchers to create unique circumstances that can shape the experiences of the members within the family unit (Lubetsky, McGonigle, & John, 2009). With time, researchers' interest has shifted from the experiences of the parents to the experiences of the typically developing siblings, at times referred to as 'target siblings' (e.g., Tomeny, Barry, & Bader, 2012; Trent, Kaiser, & Wolery, 2005; Verte, Roeyers, & Buysse, 2003). The increased prevalence of ASD in the last few decades has led to a rise in the number of target siblings, and this has further driven the research concerning the experiences of typically developing siblings whose brothers or sisters have been diagnosed with ASD (Ferraioli & Harris, 2010; Frith, 2003; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009).

The prevalence of ASD in Australia varies depending on the source of the data (MacDermott, Williams, Ridley, Glasson, & Wray, 2007). The Australian Advisory Board on Autism Spectrum Disorders estimated the prevalence of ASD in Australian children aged between 6 and 12 years to be 62.5 per 10,000 in 2005 (MacDermott et al., 2007). In more recent estimates it has been reported that 164,000 Australians, about 0.7% of the Australian population, had been diagnosed with ASD in 2015 (Australian Bureau of Statistics, 2016). This is an increase of 49,000 individuals from 2012 when 0.5% of the population had been reported to be diagnosed with the disorder (Australian Bureau of Statistics, 2014). A global increase in the prevalence and incidence rates of

ASD have been reported since the 1960s (Ratajczak, 2011). Holburn (2008) has stated that based on the available estimates there has been a 100-fold increase in the prevalence of ASD in the United States since the 1970s. Some researchers argue that the global increase in the prevalence of the disorder is due to changes in the diagnostic criteria and methods of diagnosis rather than an actual increase (Frith, 2003; Parner et al., 2011). Other researchers argue that these factors alone do not account for the drastic increase in the disorder, and thus the true nature of the rise in ASD remains unclear (American Psychiatric Association, 2013; Ratajczak, 2011).

Associated with the increase in prevalence of the disorder is the economic cost of ASD in Australia which has been calculated to range from \$8.1 to \$11.2 billion per year (Synergies, 2011). These figures are comprised of direct costs (e.g., healthcare, education, and social services), reduced productivity (e.g., reduced employment of carers and individuals with ASD), as well as the burden of disease, which has been calculated at \$3.9 billion (Australian Institute of Health and Welfare, 2011a). Important factors that have not been included in the calculations, due to a lack of data, are the costs of early intervention programs and the costs of informal care, such as that provided by family or friends (Synergies, 2011). In 2015 it was reported that 2.7 million Australians provided informal care for a family member, and out of these informal carers 1 in 10 were under the age of 25 years (Australian Bureau of Statistics, 2016). While not all of these informal carers would provide care for individuals with ASD, it can nevertheless be argued that a sizeable portion of adolescents and youths, and their families would bear this responsibility, thus making it a significant issue for Australian families and target siblings.

The increase in the number of individuals diagnosed with ASD also signifies a proportionate increase in the number of typically developing target siblings and families

who live with individuals diagnosed with the disorder. Not only do target siblings have to learn to adjust to the needs of their brothers or sisters but families also have to find ways to cope in order to meet the unique demands created by the disorder. The two key features of ASD according to the Diagnostic and Statistical Manual (DSM) are impaired social interactions, and repetitive or restricted behaviours, interests, or activities (American Psychiatric Association, 2000, 2013; Carcani-Rathwell, Rabe-Hasketh, & Santosh, 2006; Kasari, Chang, & Patterson, 2013; Mandy, 2013). However, symptoms of ASD lie on a continuum of severity; that is, cognitive and language impairments vary amongst individuals and are dependent on the timing of diagnosis, as well as the amount of support and treatment received (American Psychiatric Association, 2013; Lord, 2011; Rapin, 1997; Vismara & Rogers, 2010). Children with ASD are often also diagnosed with some degree of intellectual disability (ID; Ghaziuddin, 2000; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004).

The recent changes in the diagnostic criteria in the DSM-5 (American Psychiatric Association, 2013) have caused concerns amongst some experts in the field who have argued that up to 40% of individuals previously diagnosed with ASD will no longer meet the diagnostic criteria for the disorder (Mayes et al., 2014; I. C. Smith, Reichow, & Volkmar, 2015; Young & Rodi, 2014). The most significant implication of this change in the threshold of diagnosis relates to the ability of individuals and their families to acquire services and support to address the needs created by the disorder, as well as to comprehend the reason for the difficulties they experience (McPartland, Reichow, & Volkmar, 2012). Oftentimes, a clinical diagnosis can be important as it can validate the challenges the individuals and their families experience (O'Sullivan, 2016). Consequently, the changes in diagnostic criteria can lead to a significant number of individuals and their families being at risk of not being eligible for support to meet their

unique needs. While more research is necessary in order to critically evaluate these arguments and implications this is beyond the scope of this research study. However, this may prove to be an important factor in the experiences of individuals with ASD and their families in the future.

Aetiology of ASD

ASD has no known aetiology and although numerous factors have been associated with the disorder none of these factors account for more than a small fraction of all cases (Geschwind, 2011; Inglese & Elder, 2009; Posthuma & Polderman, 2013). Most of the research regarding the aetiology of ASD has focused on genetic factors and, and so far, genetic predisposition has been found to be the best-established risk factor associated with the disorder (Rutter, 2005). Concordance rates in monozygotic twins have been reported to be as high as 90% compared to 23% for dizygotic twins (DeFrancesco, 2001). While the recurrence of ASD in siblings ranges from 3% to 18% (Goin-Kochel, Abbacchi, Constantino, & Autism Genetic Resource Exchange Consortium, 2007; Lauritsen, Pedersen, & Mortensen, 2005; Ozonoff et al., 2011; Ritvo et al., 1989) siblings of individuals with ASD can be at risk of a range of related impairments, referred to as broader autism phenotype (BAP; Bauminger & Yirmiya, 2001; Orsmond & Seltzer, 2009). These figures indicate there is an important genetic component to ASD including gene mutations, gene deletions, or other genetic anomalies (Sutcliffe, 2008).

Additionally, environmental factors are also believed to play a role in the development of the disorder (Landrigan, 2010; Ratajczak, 2011). The most significant environmental risks for ASD have been identified to occur during the prenatal period as the developing foetal brain is very sensitive to toxic environmental exposures or intra-

uterine infections (Madsen et al., 2002; Medical Research Council, 2002; Rodier & Hyman, 1998). What can be concluded from the data available is that the aetiology of ASD is complex; no one risk factor has been linked to the majority of cases of ASD, and it is most likely that a combination of genetic and environmental factors interact to cause the disorder.

In sum, the reported increase in prevalence of ASD indicates that a growing number of target siblings and their families are living with individuals who have unique needs created by the clinical features of the disorder. Thus, gaining a comprehensive understanding of the risk and protective factors that impact the experiences of typically developing siblings whose brothers or sisters have been diagnosed with ASD can aid professionals in providing these siblings and their families with the adequate support to manage the psychological and social difficulties they may encounter during the course of the target siblings' development.

Living with ASD: Target Siblings and their Families

Researchers' interest in the experiences and psychological adjustment of typically developing siblings whose brothers or sisters have been diagnosed with ASD has increased in the last few decades (M. Gold & McCabe, 2012; Kaminsky & Dewey, 2002). To date, the research findings, mostly drawn from quantitative studies primarily utilising mothers as the informants, are diverse; some researchers have reported that target siblings experience mostly challenges and negative outcomes while other researchers have reported that target siblings can experience opportunities and positive outcomes (N. Gold, 1993; Macks & Reeve, 2007; Yirmiya, Shaked, & Erel, 2001). In particular, there has been some recognition that the experiences and outcomes of target siblings are not static and they are complex, being impacted by developmental factors,

as well as influenced by issues pertaining to the family unit (Benson & Karlof, 2008; Downwy & Coyne, 1990; Haefner, 2014).

The research focused on the experiences and outcomes of target siblings is an extension of the studies conducted on parents of children diagnosed with ASD and consequently, it has generally been guided by the assumption that having brothers or sisters with ASD is a stressor that can increase the risk of negative outcomes for all members within the family unit (M. Gold & McCabe, 2012). However, positive or neutral outcomes for target siblings have also been reported by some researchers (M. Gold & McCabe, 2012). The impact on the outcomes of target siblings can be summarised into three broad areas: intrapsychic, interpersonal, and systemic effects (Randall & Parker, 1999; Rodrigue, Geffken, & Morgan, 1993; Strohm, 2001). Intrapsychic issues can be precipitated by feelings of responsibility for the brothers or sisters with ASD, and feelings of distress caused by behaviours associated with the disorders, such as aggression or atypical behaviour in public (Mascha & Boucher, 2006). Feelings of guilt for being healthy or feelings of responsibility for the disorder diagnosed in their brothers or sisters, known as survivor's guilt, have also been documented in this population (Strohm, 2001). Target siblings may also experience interpersonal problems inside and outside the family unit such as social isolation, limited relationships, and reduced affection from their parents and brothers or sisters (McHale, Sloan, & Simeonsson, 1986; Orsmond & Seltzer, 2009; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Seltzer, Greenberg, Orsmond, & Lounds, 2005). However, target siblings can also develop prosocial traits such as empathy (Hastings, 2007; Kaminsky & Dewey, 2001). Lastly, systemic issues within families, including changes in roles, reallocation of resources, parents' adjustment, and changes in the quality of relationships can also influence positively or negatively the psychological

adjustment of target siblings (Bellin & Kovacs, 2006; Downey, 2001; Kaminsky & Dewey, 2001). Researchers have proposed that there are individual as well as familial factors that can influence the experiences of target siblings, however, no consensus has been reached regarding the influential factors (Benson & Karlof, 2008; Giallo, Gavidia-Payne, Minett, & Kapoor, 2012; Hastings, 2003b).

There is a significant amount of research regarding the impact of raising children with ASD on the parents (Abbeduto et al., 2004; N. Johnson, Feetham, & Simpson, 2011). Researchers have generally proposed that parenting children with ASD is considerably more challenging than raising typically developing children and while the data support this premise few studies have been designed to explore positive aspects of parenting individuals with ASD (Estes et al., 2013; Taunt & Hastings, 2002; Weiss, 2002). Furthermore, it has been proposed that the increased demands on the parents influence the experiences of the target siblings (Dellve, Cernerud, & Hallberg, 2000; Lutz, Patterson, & Klein, 2012). There is also evidence to suggest that families do experience a number of changes in order to adapt to the unique needs of children with ASD (Opperman & Alant, 2003). As the family changes and adjusts to meet the demands precipitated by the children with ASD target siblings are impacted by these changes (Lutz et al., 2012; Mackintosh, Goin-Kochel, & Myers, 2012; Opperman & Alant, 2003).

Developmental factors have also been identified as impacting the experiences of target siblings with some evidence suggesting that the effect on the outcomes of target siblings can vary throughout the target siblings' developmental journeys (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Lloyd, et al., 2009). That is, each stage presents individuals with unique developmental tasks and these developmental factors can help shape their experiences as target siblings (N. Gold, 1993; Hastings, 2007; Holder &

Blaustein, 2014). However, researchers rarely explore the role of developmental factors on the outcomes of target siblings; therefore it is difficult to draw robust conclusions about the unique factors that affect target siblings at different developmental stages.

In sum, it has been proposed that having brothers or sisters diagnosed with ASD is a risk factor for target siblings that can impact on the target siblings' psychological wellbeing. In addition, it has been proposed that other factors, such as developmental factors, can contribute towards the psychological wellbeing of target siblings. However, the understanding of the experiences of target siblings and the factors that impact these experiences remains complex and diverse. Therefore, a comprehensive insight into the experiences of typically developing siblings of individuals who have been diagnosed with ASD would aid professionals: first, in adequately understanding the challenges and opportunities encountered by target siblings, second, in understanding the factors that promote the target siblings' psychological adjustment, and third, in providing these siblings and their families a framework for appropriate support and interventions.

Theoretical Frameworks

The research regarding the experiences of target siblings is at times atheoretical (McHale, Updegraff, & Feinberg, 2016). That is, it has been suggested that studies investigating the experiences of target siblings are not driven by specific theoretical frameworks; and, as such the hypotheses and results are not contextualised within any given theoretical understanding. Theoretically driven research studies facilitate the interpretation of the data by identifying underlying processes that influence the experiences of target siblings and their families. Moreover, theoretically driven studies can assist in the development of interventions that promote the wellbeing of target siblings and their families. In order to provide a theoretical grounding for the

examination of the experiences of adolescents and youths as siblings of individuals diagnosed with ASD a number of theoretical frameworks were used. These frameworks were the risk and protective factor framework, the family systems framework, and the developmental framework.

Risk and Protective Factor Framework

Researchers have reported that the outcomes of target siblings can be impacted by a number of risk factors, while limited attention has been given to the identification of protective factors (N. Gold, 1993; Macks & Reeve, 2007; Walton & Ingersoll, 2015). The risk and protective factor theory proposes that outcomes are influenced by the presence and interaction of risk and protective factors (Frankford, 2007). Risk factors can be defined as factors that either maintain or increase the probability of poor outcomes for individuals (Coleman & Hagell, 2007). Risk factors can be found in the individuals, their families, or the environment (Wikstrom & Loeber, 2000). On the other hand, protective factors have been described as assets that decrease or remove the negative effects of being at risk, and consist of individual, familial, and environmental attributes that exert a positive influence on individuals (Bynner, 2001). Risk and protective factors do not have to be static, consequently they may change over time (Baker et al., 2003; Costello, Swendsen, Rose, & Dierker, 2008; Rutter, 1985). The risk and protective factor framework is commonly adopted by researchers examining mental health in children, adolescents, and youths (Bogenschneider, 1996). In the context of the present study researchers have argued that having brothers or sisters with ASD can lead to psychological distress for target siblings. However, in order to understand the psychological adjustment of target siblings it must be noted that other risk and protective factors, whether relating to the target sibling themselves, their families, or

their environment, are likely to influence the psychological adjustment of the target siblings.

Family Systems Framework

Researchers exploring the impact of living with children with ASD have generally reported that the presence of the children can have both positive and negative impacts on all members of the family unit (Dąbrowska & Pisula, 2010; Lutz et al., 2012). The family systems framework posits that in order to understand the emotional and behavioural functioning of individuals it is necessary to understand their family units since it is argued that family members are emotionally interdependent (Bowen, 1978). The emotional interdependence signifies that the response to stressors is transmitted from one member to another within the family system; consequently, an individual's ability to adapt is in part dependent on the relationship system he or she belongs to and the level of stress within the system (Bowen, 1978; Bregman & White, 2010). When individuals, particularly children and adolescents, display emotional symptoms they are reflecting the emotional symptoms of the family system and thus it is important to understand the familial context when investigating the experiences of individuals (Haefner, 2014). The family's emotional system also creates certain roles that specific members of the family unit will adopt (Titelman, 2013). These roles and their associated expectations tend to occur subconsciously yet they have a significant impact on the behaviour of the individuals as well as their interactions with other members of the family system (Kerr & Bowen, 1988). Consequently, family systems provides a framework to view target siblings and their functioning as an integral part and reflection of their families of origin (Haefner, 2014).

Developmental Framework

Little investigation has been focused on the impact of developmental factors on the experiences of target siblings. From a developmental perspective, each developmental stage presents individuals with unique tasks, risk, and opportunities (Erickson, 1963; Holder & Blaustein, 2014; Neyer & Lehnart, 2007). Adolescence, defined as the period of development spanning from ages 12 to 18 years (Peterson, 2004), is a phase that is characterised by significant changes in the biological (Ellis, 2004; Holder & Blaustein, 2014; Hurwitz et al., 2016), cognitive (Casey, Jones, & Hare, 2008; Eisner, 2002; Haworth, Davis, & Plomin, 2013; Piaget, 1972; Sisk & Foster, 2004), and psychological domains (Erickson, 1963; Hankin et al., 1998; Neyer & Lehnart, 2007) of an individual. While adolescence is characterised by significant and rapid changes in all areas of development, in early adulthood youths, that is, individuals aged under 25 years (Chavez, 1999; Prause & Dooley, 2011; United Nations, 2005), experience a slower continuation of these changes, culminating in the peak of physical and cognitive skills (Arnett, 2000; Artisticco, Cervone, & Pezzuti, 2003; Baltes, Lindenberger, & Staudinger, 1998; Pew Research Centre, 2007; Satterthwaite et al., 2014; Steinberg, 2005; Steinberg & Morris, 2001; Zarrett & Eccles, 2006). The changes associated with both phases of development can have a negative impact on the psychological wellbeing of the individuals (Diamond, 2002; Haworth et al., 2013; Hurwitz et al., 2016; Mendle & Ferrero, 2012).

Psychopathology is more common in adolescence and early adulthood than in other stages of development (Aalto-Setälä, Marttunen, Tuulio-Henriksson, Poikolainen, & Lönnqvist, 2002; McGue & Iacono, 2014). Youths are more likely than older adults to experience every mental disorder with the exception of dementia, and symptoms of psychopathology often first appear during adolescence (American Psychiatric

Association, 2013; Ferdinand & Verhulst, 1995; Steinberg et al., 2006). In fact, it has been reported that the rate of serious mental illness amongst youths is almost double that of adults over the age of 25, with one in four Australian youth having experienced at least one mental health disorder (Australian Institute of Health and Welfare, 2011b, 2018). Moreover, a vast majority of individuals who experience mental health issues during their life will have had mental health issues prior to the age of 25 years (Australian Bureau of Statistics, 2012). Adolescents and youths experience many biological, cognitive, and psychological changes; the stress associated with these changes, combined with genetic vulnerability is one of the key hypotheses proposed to explain the elevated incidence of psychopathology evident in these cohorts (Hooley, 2004; Kessler, Berglund, Demler, Jin, & Walters, 2005). The developmental journey of target siblings thus helps to shape their experiences as siblings of individuals with ASD. Consequently, the developmental tasks associated with adolescence and early adulthood provided the backdrop against which the experiences of target siblings in the present study played out.

The abovementioned frameworks were used in the present study in order to ground the experiences of target siblings within a number of assumptions. The developmental framework was used to contextualise the experiences of target siblings within the developmental tasks associated with adolescence and early adulthood. On the other hand, the family systems framework provided the background against which the experiences of the target siblings played out, highlighting the challenges and resources of the target siblings' families of origin, and how these impacted on the target siblings themselves. Finally, the risk and protective factor framework facilitated the exploration of various factors that increased or decreased the risk of distress in target siblings.

Research Aims

The overall aim of the study was to gain an understanding of the role of risk and protective factors that contribute towards the complex and diverse nature of the experiences of adolescents and youths whose brothers or sisters have been diagnosed with ASD. The research design of the present study is a partial replication of past research studies (N. Gold, 1993; Griffith, Hastings, & Petalas, 2014; Walton & Ingersoll, 2015). That is, past studies have utilised mothers or target siblings to investigate the psychological wellbeing of target siblings. However, the present study adopted a mixed methods, multi-informant approach. The study was divided into two stages, one quantitative and one qualitative, and each stage had a number of specific aims. Also, the study utilised adolescents/youths and their mothers as informants.

The main purpose of stage one was to examine differences between target siblings and community siblings (those who acted in essence as a control group) on measures of psychological distress, psychological resilience, and family functioning to determine if target siblings were more distressed than community siblings. The mothers of both sibling groups also completed the measures of psychological distress, psychological resilience, and family functioning in order to provide additional data from the mothers' perspective on the factors that were measured in this study. To date, data regarding the target siblings' psychological resilience or their perspective of family functioning has not been gathered. Stage one also sought to investigate the role of psychological resilience and family functioning on target siblings' psychological adjustment.

While examining differences between groups of participants can yield information about discrepancies between the groups the purpose of stage two was to

examine the experiences of adolescents and youths as siblings of individuals diagnosed with ASD from a qualitative perspective in order to describe in-depth the lived experience of the participants and the factors that shape these experiences. The experiences of the target siblings were explored from their perspectives as well as from their mothers' perspectives in order to gain an understanding of the developmental and systemic factors that can impact on this cohort of siblings.

Structure of Thesis

The thesis is composed of 9 chapters. In chapter 2 the literature regarding the familial context of the target siblings along with the concept of adaptation are examined. Further, the impact raising children with ASD has on the family unit, and on the parents, particularly the mothers, is explored. The chapter also presents a number of models of how families and individuals can adjust to and cope with the stressors associated with raising children with ASD.

In chapter 3, the literature regarding the psychological adjustment of target siblings is reviewed. The roles of psychological resilience and family functioning on psychological distress are also examined. This is followed by a review of the lived experiences of target siblings. Lastly, the rationale and the research questions of the current study are provided.

In chapter 4 the methodology adopted by the present research study is discussed. The mixed methods approach along with the methodology of each stage is also described. In this chapter the various forms of data collection (i.e., quantitative and qualitative approaches) that were used are also identified. Finally, issues pertaining to rigour are discussed.

The outcomes of stage one of the research study are described in chapter 5. This chapter presents the description of the method, including participants, materials, procedure, and analysis for stage one. The results and a brief discussion of the results in relation to past research are also presented.

The method of stage two is presented in chapter 6. This chapter includes the research questions addressed in the second stage of the research project. In addition, it provides a description of the participants, materials, procedure, and analysis.

Chapters 7 and 8 present the results of stage two. Chapter 7 provides the findings and interpretations of the interviews conducted with the target siblings whereas chapter 8 provides the findings and interpretations of the interviews conducted with the mothers of the target siblings.

The thesis concludes with chapter 9. This chapter summarises the findings of stages one and two. In additions, the significance of the current research study as well as its implications is discussed in this chapter. The limitations of the current study and recommendations for future research are discussed at the conclusion of this chapter.

Chapter 2

Literature Review Part 1:

The Target Siblings' Family: How ASD Impacts on the Family Unit and Its Members

Chapter Overview

In this chapter, the familial context of the target siblings is highlighted and the concept of adaptation is introduced. A review of the impact ASD can have on the family unit and on its members, particularly on the mothers, is provided. In addition, in this chapter a number of models of how families and individuals can cope and adjust to the stressors associated with raising children with developmental disorders such as ASD are outlined. Thus, in this chapter the environment from which the experiences of target siblings emerge is provided.

Chapter 2

Literature Review Part 1:

The Target Siblings' Family: How ASD Impacts on the Family Unit and Its Members

Research regarding the effects of ASD on family members initially focused on how ASD impacted on parents, with mothers typically being utilised as the main informant in these studies (Bebko et al., 1987; Kuhn & Carter, 2006; Pottie & Ingram, 2008; Rao & Beidel, 2009). As the interest of researchers has broadened to include other family members, mothers have generally remained the most frequent informant utilised in these investigations (Rodrigue et al., 1993; Ross & Cuskelly, 2006; Tomeny et al., 2012). Researchers argue that mothers, as the most common primary caregiver, are in a unique position to provide information about the family unit and its members (De Los Reyes & Kazdin, 2005; Richters, 1992). Given that the family is the base of child and adolescent development, the family unit can be considered an important factor underpinning the experiences of target siblings (Cano et al., 2016). Therefore, the challenges and opportunities faced by the families as they raise children diagnosed with ASD provide the backdrop for the risks and opportunities target siblings encounter.

Impact of ASD on the Family Unit

Children diagnosed with ASD can present numerous challenges and stressors that can have a significant impact not only on individual family members but also on the family unit as a whole (Benson & Karlof, 2008; Lutz et al., 2012; Meirsschaut, Roeyers, & Warreyn, 2010). Parents have reported that raising children with ASD is particularly challenging (Baker-Ericzén, Brookman-Fraze, & Stahmer, 2005; Estes et al., 2013). In

fact, it has been argued that parenting children with ASD is not only more difficult than parenting typically developing children, but it also presents more difficulties than parenting children with other disabilities including Down syndrome, fragile X syndrome, and developmental delays not associated with ASD (Abbeduto et al., 2004; Estes et al., 2009; Weiss, 2002). The challenges associated with raising children with ASD can impact family functioning. Researchers have explored family functioning using a variety of measures across studies including questionnaires, surveys, checklists, and scales thus making it difficult to compare results across studies (Meadan, Halle, & Ebata, 2010). Parents of individuals with ASD have reported that they experience less family satisfaction, less family cohesion, lower levels of family adaptation, and poorer family functioning when compared to parents whose children do not have ASD (Gua et al., 2012; Higgins, Bailey, & Pearce, 2005; Sikora et al., 2013; Sullivan, Winograd, Verkuilen, & Fish, 2012). The effects of impaired family functioning affects all family members, including the children (Bregman & White, 2010; Mohammadi & Zarafshan, 2014); consequently, chapter 3 will include a discussion of the impact of family functioning on target siblings' psychological wellbeing.

Researchers have identified that the social and communication deficits associated with ASD, the behavioural difficulties, and the increased levels of dependency are the main sources of stress for families (Benson, 2006; Hastings, 2002; Lecavlier, Leone, & Wiltz, 2006). Furthermore, it has been suggested that the life course manifestation of ASD results in parents experiencing greater uncertainty about the future (Abbeduto et al., 2004). Moreover, the therapeutic and medical needs of children with ASD, which in turn can accompany the loss of parental income, often place a significant financial burden on the families despite the existence of financial subsidies in Australia (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014).

In Australia, services and support for children with ASD and their families can be funded by the families themselves or be subsidised by the Australian Government (Raising Children Network, 2013). The Government provides funding for a number of services with a special focus on early intervention services for children under the age of 7 years (Australian Government Department of Social Services, 2013). Once children turn seven, the Government-funded resources and services decline significantly. In a Western Australian study it was reported that the median cost to a family of having one child with ASD was \$34,900 per annum, well above the funding available to families (Horlin et al., 2014). Consequently, the combination of financial strain and the stress of accessing sufficient services and resources presents as one of the many factors that can impact on the family functioning and the wellbeing of the family members when children are diagnosed with ASD.

Despite some families experiencing increased stress and family dysfunction, other parents of individuals with ASD have reported more positive family functioning outcomes. In a small number of studies families of individuals with ASD have reported similar levels of family functioning as that of families whose children do not have ASD (Rao & Beidel, 2009; van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2013). Parents involved in qualitative studies have also expressed positive consequences for the family unit as a result of having children diagnosed with ASD (Myers, Mackintosh, & Goin-Kochel, 2009; Taunt & Hastings, 2002). Myers et al. (2009) report that parents, 92% of which were mothers, stated that despite challenges, raising children with ASD had brought the family closer together. The perceived presence of positive aspects of family functioning indicates that families can successfully adjust to the demands associated with raising children with ASD (Taunt & Hastings, 2002).

How Families Adjust to ASD

Researchers have sought to understand how families adjust to and cope with the demands created when children have been diagnosed with ASD (Saloviita, Itälina, & Leinonen, 2003). Coping has been defined by Lazarus and Folkman (1984) as the continuous change in behaviours and cognitions in order to deal with internal or external demands that are perceived to exceed the resources of the person. Adaptation is not a one-off event but rather a process that occurs over time and is dependent on multiple factors (Lutz et al., 2012). As families make adjustments in their homes, lifestyles, and future plans in order to accommodate the needs of the individuals with ASD, each family unit, and its members, embark on the process of adaptation (Lutz et al., 2012). Adaptation is evident when the family and its members are able to report positive outcomes and perceptions as a result of their experiences (Taunt & Hastings, 2002). Coping is a complex phenomenon that is dependent on numerous factors within family units as well as in their immediate and wider environment (Bronfenbrenner, 1951, 1979; Hall et al., 2012; Manning, Wainwright, & Bennett, 2011). Moreover, a central premise of adaptation and coping is the notion that family units do not react passively to the stressors they experience; their ability to be flexible in their response to the demands of their experiences by adopting a wide range of responses translates to successful coping (Cheng, Lau, & Chan, 2014).

Understanding the adaptation process of the family unit is important to comprehend the experiences of target siblings for two main reasons. First, it has been argued that in order to assist adolescents and youths who are struggling psychologically the family context that surrounds and informs the adolescent's or youth's behaviour must also be understood, and then modified accordingly (Andolfi & Mascellani, 2013; Bowen, 1978). Second, improving coping and adaptation in any part of the family

system will have an impact on all other components of the system (Hall et al., 2012; Trute, Benzies, Worthington, Reddon, & Moore, 2010). Therefore, as the ability of families to cope is enhanced, positive impacts on the target siblings are more likely to emerge.

The Double ABCX model is commonly used to provide a theoretical framework for researching the adjustment of families whose children have been diagnosed with ASD (Pakenham, Samios, & Sofronoff, 2005). The model was originally based on the ABCX model developed by Hill (1949; 1958) and it has been widely used in family studies. The ABCX model suggests that a family's crisis is produced or prevented (X) based on three factors: the stressor (A); the family's resources available to meet the crisis (B); and the meaning attributed to the stressor by the family (C). The model was expanded by McCubbin and Patterson (1983) who believed the adjustment of families to stress was better predicted by four factors. In the Double ABCX model the outcome of a stressor (XX) can be determined by the pile-up (accumulation) of additional stressors and responsibilities (aA); the resources the families employ in order to manage the stressor (bB); the changes the families make to how they view the situation in order to cope with the stressor (cC); and the coping strategies utilised (BC; McCubbin & Patterson, 1983). Adaptation is conceptualised as occurring on a continuum, ranging from 'bonadaptation' to negative maladaptation (Saloviita et al., 2003).

The Double ABCX model has been used by researchers for a number of purposes including for casual modelling and ordering variables, for its predictive power, and for conceptualising the process of adaptation (Pakenham et al., 2005; Saloviita et al., 2003; Summers, Behr, & Turnbull, 1988). Researchers investigating the experiences of families of children with ASD have frequently utilised the model in their studies (Manning et al., 2011; McStay, Trembath, & Dissanayake, 2014, 2015; Pakenham et al.,

2005; Paynter, Riley, Beamish, Davies, & Milford, 2013; Pozo, Sarriá, & Brioso, 2014; Saloviita et al., 2003). The Double ABCX model thus, offers a conceptual model for understanding the complex process of adaptation plus the numerous factors that can impact on the ability of families to cope with the stressors they experience when dealing with the challenges associated with raising children diagnosed with ASD.

In sum, families raising children with ASD can experience a range of unique stressors. These stressors can increase the probability of the family experiencing greater family dysfunction and dissatisfaction. Although models of adjustment and coping along with empirical research indicate that families can adjust and thus experience positive outcomes, considerable research indicates that the family unit as well as its individual members, including the target siblings tend to be uniquely impacted when children are diagnosed with ASD.

Impact of ASD on Mothers

As previously stated, mothers are most commonly utilised in research studies in order to rate the adjustment of the family unit, as well as that of its members, including the target siblings to living with children diagnosed with ASD (De Los Reyes & Kazdin, 2005; Myers et al., 2009; Richters, 1992). Researchers have indicated that when rating the behaviour of their children diagnosed with ASD, the experiences of the mothers will influence the ratings (Chi & Hinshaw, 2002; Richters, 1992). Factors that can influence the mothers' ratings of their children's adjustment and wellbeing include the mothers' psychological wellbeing, their parenting style, the level of conflict in the mother-child relationship, the level of stress the mothers experience, as well as the level of stress within the family unit (De Los Reyes & Kazdin, 2005; Jensen et al., 1999; Kolko & Kazdin, 1993; Youngstrom, Loeber, & Stouthamer-Loeber, 2000).

Consequently, when mothers are employed to comment on the target siblings' experiences it is important that the mothers' experiences are also understood.

It has been well documented that parents raising children with ASD can experience significant parental stress (Davis & Carter, 2008; Tomanik, Harris, & Hawkins, 2004); psychological distress (Abbeduto et al., 2004; Benson, 2006) including depression, anxiety, and pessimism (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001); coping and adaptation difficulties (Higgins et al., 2005); and marital difficulties (Dunn et al., 2001). Although fathers and mothers have reported that parenting children with ASD is challenging, researchers have generally tended to focus on the experiences of mothers (Abbeduto et al., 2004; Boyd, 2002; Davis & Carter, 2008; Duarte, Bordin, Yazigi, & Mooney, 2005; Estes et al., 2013; Jeans, Santos, Laxman, McBride, & Dyer, 2013; Koegel et al., 1992; Konstantareas & Papageorgiou, 2006; Tomanik et al., 2004). One reason research has focused on mothers is because it has generally been found that raising children with ASD has a greater negative impact on every aspect of mothers' functioning while having a less pervasive impact on fathers (Hastings, 2003c; Hastings & Brown, 2002; Hastings, Kovshoff, et al., 2005; Lutz et al., 2012). Self-reports indeed support this, with mothers of children with ASD reporting lower levels of marital satisfaction and affective expression, more psychopathology, and more stress than fathers of children with ASD (Gua et al., 2012; N. Johnson et al., 2011; McStay et al., 2014).

Arguably mothers are the most affected parent when children are diagnosed with ASD as they tend to be the main caregivers and they are less likely to be employed outside the home, and consequently spend more time directly managing the needs and demands of the children with ASD plus those of any additional children in the family (Davis & Carter, 2008; Gua et al., 2012). It has been observed that the stress mothers

experience is related to the amount of time they spend directly caring for the children with ASD. That is, greater stress has been reported by mothers who spend greater time caring for the children with ASD (Lutz et al., 2012). Mothers of children diagnosed with ASD, when compared to mothers of typically developing children, have reported more negative outcomes in almost every domain of functioning including physical, psychological, and social stress and strain, feeling overwhelmed, as well as experiencing anxiety, fear, and coping difficulties (Abbeduto et al., 2004; Benson, 2006; Lutz et al., 2012). Their psychological distress is often exacerbated by the social stigma, social isolation, and the reduced ability to work outside the home that many of these mothers experience due to the behaviours and needs associated with ASD (Lutz et al., 2012).

The predictability of children's maladaptive behaviours has been found to be strongly positively correlated with maternal stress, depressive symptoms, social isolation, and the use of maladaptive coping strategies (Abbeduto et al., 2004; Benson, 2006; Dunn et al., 2001). In other words, the less predictable the behaviours of the children with ASD are the greater the level of maternal distress. A substantial amount of the adjustment difficulties reported by mothers can be explained by the fact that ASD is a disorder that is characterised by more negative and less positive behavioural features, and in many cases these behavioural problems tend to persist throughout the children's lives (Abbeduto et al., 2004). The relationship between ASD-symptom severity, social isolation, and psychological distress can become a complex cyclical process (Benson, 2006; Dunn et al., 2001). That is, more severe ASD symptoms are associated with elevations in parental distress and reductions in their ability to access social support, the social isolation this creates in turn can intensify the parental distress. In addition to

social isolation and mental health concerns, mothers often have to adjust to their new roles as caregivers of children with a developmental disorder (Meirsschaut et al., 2010).

When children are diagnosed with ASD parents can experience a substantial change in their roles (Benson, Karlof, & Siperstein, 2008). Mothers predominantly, not only tend to become their children's primary carers but often become involved in their learning experiences, acting as therapists, advocates, and even teachers (Benson et al., 2008; Kidd & Kaczmarek, 2010; Stoner & Angell, 2006). Popular interventions for ASD, such as applied behavioural analysis, can cause significant stress to mothers and families (Hastings & Johnson, 2001; T. Smith, Buch, & Gamby, 2000) as they not only require mothers to invest significant amounts of time into the therapy but also money and energy, resulting in mothers having less resources available for other family members including target siblings (Benson et al., 2008; E. Johnson & Hastings, 2002). This, in turn, can provoke feelings of guilt in the mothers as they do not have enough time and resources to devote to the rest of their offspring (Lutz et al., 2012).

Despite the significant challenges and stressors that mothers can experience as they care for children diagnosed with ASD, there is some evidence that mothers, just like family units, are able to adapt to the challenges (Kidd & Kaczmarek, 2010; Taunt & Hastings, 2002). A number of mothers have reported experiencing positive personal and familial changes as a result of having children who have been diagnosed with ASD (Benson, 2010; Moyson & Roeyers, 2011). Mothers have reported an increased level of sensitivity and empathy, often becoming more tolerant as well as more conscious of the needs and struggles of others (Taunt & Hastings, 2002). Other mothers have reported experiencing personal growth, enriched relationships, and having increased opportunities to learn about their children and about ASD (Benson, 2010; Myers et al., 2009). The reports of personal growth indicate that despite significant stress mothers

perceive themselves as having successfully adjusted to the stressors associated with raising children with ASD.

Mothers Coping

Most stress research has been based on the stress and coping model developed by Lazarus and Folkman (1984). The model classified coping strategies into a dichotomy: problem-based coping consists of strategies aimed at altering the source of the stress, while emotional-based coping consists of strategies aimed at controlling the emotional response to the stressor (Benson, 2010). Generally, emotional-based coping is associated with increased levels of psychological distress while problem-based coping is more frequently associated, but not always, with better mental health (Abbeduto et al., 2004; Dunn et al., 2001; Lin, Orsmond, Coster, & Cohn, 2011). Some researchers have proposed that the stress and coping model is too simple to explain how people deal with complex adversities, such as raising children who have been diagnosed with ASD (Skinner, Edge, Altman, & Sherwood, 2003), which has led to the development of slightly more complex models (Benson, 2010).

Benson (2010) proposed four broad coping factors after conducting a factor analysis on the responses of how more than 100 women coped with being the mother of a child with ASD. These four factors were engagement, such as active problem-solving; distraction, for example, self-blame or humour; disengagement which included behaviours such as withdrawing from the stressor or denying the problem; and cognitive reframing, for example, acceptance and the use of religion. Although Benson (2010) presented a broader range of coping styles than previous studies, other researchers have identified more than four distinct coping strategies suggesting that the coping and adaptation strategies used by these mothers might not be as simple as it was originally

theorised (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Hastings, Kovshoff, et al., 2005). However, what can be deduced from the literature available is that mothers can use a range of coping strategies in their attempt to adjust to the demands associated with parenting children with ASD.

In sum, while there is substantial research which indicates that raising children with ASD can cause significant stress and distress particularly for mothers, there is also some evidence that indicates that mothers can experience a variety of gains from parenting children with ASD. Models of stress and coping describe processes that can influence how mothers cope with the challenges they encounter. Given that mothers are most frequently utilised to provide information about the family unit as well the children within the family, understanding the experiences of the mothers can provide some insight regarding the familial risk and protective factors that can impact on the experiences of target siblings.

Impact of ASD on Target Siblings

As it can be seen, raising children with ASD causes disruption within the family unit as the family adjusts to meet the demands associated with the disorder (Hastings, 2003a, 2003c; Higgins et al., 2005; Noh et al., 1989; Sikora et al., 2013; Tomanik et al., 2004). Researchers have indicated that the stressors experienced in the family unit as well as the family's degree of adjustment has an impact on the experiences and outcomes of other family members, including mothers and target siblings (N. Johnson et al., 2011; Shek, 1997). That is, the level of family functioning can be considered a protective factor for experiences of target siblings (Bogenschneider, 1996).

Researchers have argued that since families and mothers of children with ASD tend to report poor outcomes across a number of measures of wellbeing and functioning, target

siblings will also experience greater psychological distress due to the unique stressors they encounter (M. Gold & McCabe, 2012; Kaminsky & Dewey, 2002). A comprehensive review of the literature detailing the experiences of target siblings will be provided in chapter 3.

Summary

ASD is a developmental disorder that has life-long consequences not only for the individuals with the disorder but also for their family members. The needs and demands of children with ASD can precipitate distress in the family unit as it confronts numerous challenges and struggles associated with the disorder. Mothers in particular, can suffer from mental health issues, increased stress, marital difficulties, unemployment, and social isolation. However, neither families nor mothers necessarily succumb to the stressors associated with raising children diagnosed with ASD. Families and their members are able to cope and adapt, and experience positive wellbeing. Adaptation is a complex process that requires on-going adjustments as new challenges are encountered. Adaptation is also dependent on numerous factors. Most importantly, the experiences of the family unit and of the mothers, either positive or negative, provide the critical backdrop for understanding the experiences of target siblings. It is in this familial context that the experiences of the target siblings transpire.

Chapter 3

Literature Review Part 2:

How ASD Impacts on Target Siblings

Chapter Overview

In this chapter, the literature regarding the psychological and familial experiences of children, adolescents, and youths as siblings of individuals diagnosed with ASD is reviewed. In the chapter the current limitations of the literature in this area are identified and the rationale for the present study is provided. Research questions pertaining to the current study are provided at the close of the chapter.

Chapter 3

Literature Review Part 2:

How ASD Impacts on Target Siblings

As the focus in the field of ASD has expanded from the experiences of the parents to those of other family members, aspects of the experiences of target siblings have begun to be explored (Kaminsky & Dewey, 2002; Yirmiya et al., 2001). In this chapter the psychological and familial adjustment of target siblings and the factors that impact on their experiences are reviewed in order to identify what is known about the experiences of typically developing siblings of individuals with ASD. The gaps in the literature are also identified and thus the rationale for the research study that was conducted is presented.

Psychological Adjustment of Target Siblings

A number of studies have been published in the recent past exploring the psychological adjustment of target siblings (Benderix & Sivberg, 2007; Ferraioli & Harris, 2010; Petalas, Hastings, Nash, Hall, et al., 2012; Petalas, Hastings, Nash, Lloyd, et al., 2009; Yirmiya et al., 2001). Research regarding the experiences of target siblings tends to be based on the assumption that having brothers or sisters with ASD is a risk that must lead to some degree of negative outcome in target siblings, particularly when compared to other sibling groups. A review of studies published in peer-reviewed journals between 1990 and December 2017 concerning the psychological adjustment of target siblings in the databases WorldCat.org, SpringerLink, ProQuest Central, ERIC, AcademicOneFile, Emerald Group Publishing Limited, ScienceDirect, SAGE Journals, and IEEE Publications Database yielded 727 results. The database searches were

supplemented by identifying publications referenced in the studies identified in the search. Studies were selected based on the age of the target participants (i.e., sampled participants needed to include adolescents and/or youths), and based on the outcomes of psychological adjustment measured (i.e., measures of internalising or emotional behaviour problems, and/or externalising or conduct and behavioural problems had to be included). The quantitative studies identified utilised mothers, fathers, teachers, and/or target siblings as the informants.

The results of the available literature regarding the psychological adjustment of target siblings can be divided into three broad themes: those that indicate that target siblings experience significant levels of psychological distress, those that indicate target siblings experience some psychological distress, and those that indicate target siblings experience no psychological distress. A summary of the relevant literature can be seen in Table 3.1, while the key aspects of these research studies will be discussed below.

Several studies have found that target siblings experience significant levels of psychological distress (N. Gold, 1993; Griffith et al., 2014; Hastings & Petalas, 2014; Orsmond & Seltzer, 2009; Petalas, Hastings, Nash, Lloyd, et al., 2009; Ross & Cuskelly, 2006). Researchers have reported that significantly higher proportions of target siblings tend to score in the borderline or clinical ranges on various measures when compared to other sibling groups, yet the figures range considerably. In one of the earliest studies investigating the psychological adjustment of target siblings conducted by N. Gold (1993), the author reported that 50% of target siblings aged between 7 and 17 years scored in the clinically depressed range on the Children's Depression Inventory (CDI; Kovacs, 1992) compared to 26% of siblings of typically developing children. Of significance, it was noted that adolescent target siblings (aged 12 years or older) had higher levels of depressive symptomatology than target siblings under the

age of 12. Likewise, Petalas, Hastings, Nash, Lloyd, et al. (2009) reported that a similar percentage of siblings whose brothers or sisters had been diagnosed with ID and children in the normative sample scored in the clinical range on the emotional and pro-social behaviour scales of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). However, the percentage of target siblings in the clinical range was considerably larger. Thus suggesting that the distress of target siblings is greater when compared to other sibling groups whose brothers or sisters have developmental disabilities, or who are typically developing.

Griffith et al. (2014), in an atypical study exploring the reports of both mothers and fathers regarding the target siblings' adjustment, found that on all the subscales of the SDQ except for peer problems and hyperactivity, parents reported that target siblings had significantly greater levels of psychological distress compared to the normative sample. In addition, the percentage of target siblings in the clinical range was significantly greater when compared to the normative sample. However, mothers reported that target siblings experienced more psychological distress in more domains when compared to the reports provided by fathers. The findings of this study indicate that there can be differences in the reports of the psychological adjustment of target siblings based on the informants used. Even though the use of multiple informants increases the richness of the data by providing various perspectives on the same phenomena (Natsuaki, Ge, Reiss, & Neiderhiser, 2009), the use of multiple informants is not a common methodological feature in this area of research. Moreover, studies that utilise multiple informants do not tend to compare the reports of the various informants so that discrepancies in their reports can be examined. Nevertheless, despite the methodological differences between studies, variance in the results regarding the psychological adjustment of target siblings is evident.

Table 3.1

Summary of the Quantitative Studies

Authors	Participating siblings' details	Informants	Measures	Findings
Gold (1993)	<i>N</i> = 22; males Range = 7-17 years Target siblings vs. community group	Siblings	CDI	50% target siblings clinically depressed vs. 26% community siblings. Higher depression amongst 12-year-olds and older.
Ross & Cuskelly (2006)	<i>N</i> = 25 Range = 8-15 years	Mothers	CBCL	40% target siblings in borderline or clinical range on internalising or externalising difficulties.
Hastings (2003)	<i>N</i> = 78 Range = 7-16 years. Target siblings vs. normative sample	Mothers	SDQ	Target siblings more peer problems, lower levels of pro-social behaviour, more overall adjustment problems (when compared to British normative sample). 27% - 37% target siblings scored in abnormal range.
Griffith, Hastings, & Petalas (2014)	<i>N</i> = 168 mothers <i>N</i> = 130 fathers Range = 4-17 years. Target siblings vs. normative sample	Mothers and fathers	SDQ	Fathers' report: 17.7% target siblings in clinical range for emotional difficulties; 6.2% target siblings in clinical range for pro-social behaviours. Mothers' report: 17.2% target siblings in clinical range for total difficulties; 24.2% target siblings in clinical range for emotional difficulties; 27.9% target siblings in clinical range for conduct difficulties; 7.1% target siblings in clinical difficulties for pro-social behaviour. Percentage of target siblings in clinical range significant when compared to normative sample.

(continued)

Authors	Participating siblings' details	Informants	Measures	Findings
Petalas, Hastings, Nash, Dowey, & Reilly (2009)	<i>N</i> = 49 <i>M</i> = 10.75 years. Range = 5-19 years. ASD+ID vs. ID	Mothers	SDQ	ASD+ID more emotional problems vs. ID. 28% ASD+ID vs. 12.5% ID vs. 11.4% normative sample clinical range for emotional problems; 12% ASD+ID vs. 0% ID vs. 2.3% normative sample in clinical range for pro-social behaviour.
Orsmond & Seltzer (2009)	<i>N</i> = 57 <i>M</i> = 16 years Range = 12 -18 years	Target siblings	CES-D, RCMAS	36% of target siblings in clinical range for depression; 8.5% of target siblings in clinical range for anxiety. Females more depressive and anxiety symptoms than brothers. 52% females vs. 6% males in clinical range.
Rodrigue, Geffken, & Morgan (1993)	<i>N</i> = 19 <i>M</i> = 10 years Target siblings vs. Down syndrome vs. community	Mothers	CBCL	Internalising and externalising not within clinical range.
Verte, Roeyers, & Buysse (2003)	<i>N</i> = 29 Range = 9-16 years. Target siblings vs. community group.	Mothers	CBCL	Target siblings more internalising, externalising, and total problems than community group. Target siblings' difficulties not in clinical or subclinical range.
Giallo, Gavidia-Payne, Minett, & Kapoor (2012)	<i>N</i> = 52 Range = 10-18 years. Target siblings vs. normative sample.	Siblings	SDQ	Target siblings more emotional problems, conduct problems, hyperactivity, and total difficulties than normative sample. Target siblings' scores within non-clinical range. Target siblings at-risk range: 4% emotional difficulties, 19% total difficulties. Target siblings clinical range: 10% emotional difficulties, 12% total difficulties.

(continued)

Authors	Participating siblings' details	Informants	Measures	Findings
Macks & Reeve (2007)	Range = 7-17 years. Target siblings vs. community group.	Parents and siblings	BASC-PRS, CDI-S, Piers-Harris Children's Self-Concept Scale	Target siblings no different on internalising or externalising problems, depression, popularity, or happiness and satisfaction than community group. Target siblings scored lower anxiety levels than community group. Target siblings scored higher on intellectual and school status, and overall self-concept than community group.
Hastings (2007)	<i>N</i> = 24 <i>M</i> = 9.75 years Range = 3-19 years. Target siblings vs. Down syndrome vs. mixed aetiology ID vs. normative sample.		SDQ	Target siblings no different on emotional problems, peer problems, or total problems to Down syndrome or mixed aetiology ID. Target siblings fewer hyperactivity symptoms than normative sample.
Shivers, Diesenroth, & Taylor (2013)	<i>N</i> = 1755 Range: 3-18 years.	Mothers and fathers	CBCL	Target siblings borderline range: 8%, clinical range: 4%.
Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel (2012)	<i>N</i> = 486 Range = 6-18 years. Target siblings vs. normative sample	Teachers and parents	TRF, CBCL	Target siblings less internalising and externalising symptoms than normative sample.

(continued)

Authors	Participating siblings' details	Informants	Measures	Findings
Kaminsky & Dewey (2002)	<i>N</i> = 30 <i>M</i> = 11.67 years. Range = 8-18 years. Target siblings vs. Down syndrome vs. community group.	Parents	CBCL	No group differences.
Walton & Igersoll (2015)	<i>N</i> = 69 <i>M</i> = 9.35 years Target siblings vs. community group.	Mothers	SDQ	No group differences.
Tomeny, Barry, & Bader (2012)	<i>N</i> = 42 <i>M</i> = 12.33 years Range = 6-18 years Target siblings vs. community group	Parents (85% mothers)	CBCL	No group differences on internalising, externalising or social problems.
Hastings & Petalas (2014)	<i>N</i> = 94 <i>M</i> = 12.59 years Range = 7-17 Target siblings vs. British normative sample	Mothers and siblings	SDQ	No group differences.

Note: CDI = Children's Depression Inventory; CBCL = Child Behaviour Checklist; SDQ = Strengths and Difficulties Questionnaire; BASC-PRS = Behavior Assessment System for Children – Parent Rating Scales; CDI-S = Children's Depression Inventory – Short Version; CES-D = Center for Epidemiological Studies Depression Scale; RCMAS = Revised Children's Manifest Anxiety Scale; TRF = Teacher Report Form

A small number of researchers have reported that despite target siblings being at risk of greater psychological distress when compared to community or normative samples, the distress falls within the normal range (Giallo et al., 2012; Rodrigue et al., 1993; Verte et al., 2003). That is, mothers reported higher levels of internalising, externalising, and total difficulties, as measured by the Child Behavior Checklist (CBCL; T. M. Achenbach, McConaughy, & Howell, 1987) but the scores did not reach the clinical or subclinical range. While Giallo et al. (2012) reported similar results, their study utilised the reports of the target siblings themselves, rather than their parents' reports as is common in this area of research, thus making the study of particular interest. Although target siblings consisted of individuals whose brothers or sisters had been diagnosed with a range of disabilities almost 60% of the participants had brothers or sisters who had been diagnosed with ASD. Target siblings indicated experiencing more difficulties in a number of areas, such as emotional problems, conduct problems, hyperactivity, and total difficulties compared to the normative sample. However, the target siblings' scores fell within the non-clinical range. Consequently, while there is evidence to suggest that target siblings can experience greater psychological distress than children and adolescents with typically developing siblings, only a portion experience sufficient distress to warrant intervention.

In contrast, there are numerous studies that have reported that target siblings may not be at clinical risk nor experience greater psychological distress than siblings whose brothers or sisters have other developmental disorders, or who are typically developing. For example, numerous researchers have reported that target siblings experience similar psychological adjustment to siblings whose brothers or sisters do not have ASD (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012; Shivers, Deisenroth, & Taylor, 2013). Some researchers have asserted that, based on the reports

of parents, there are no differences in the psychological adjustment of target siblings when compared to other sibling groups, including those whose brothers or sisters have other developmental disorders, and those whose brothers and sisters are typically developing (Kaminsky & Dewey, 2002; Tomeny et al., 2012; Walton & Ingersoll, 2015). Other researchers have reported that target siblings can experience less externalising and internalising symptoms than community or normative samples of siblings (Hastings, 2007; Macks & Reeve, 2007). That is, the psychological adjustment of target siblings in some studies is better than the psychological adjustment of siblings whose brothers or sisters do not have ASD. As it can be seen, the available results regarding the psychological adjustment of target siblings vary considerably. However, the methodological designs of these studies also vary and thus, methodological issues should be considered when reviewing the findings from published data.

Despite studies often employing similar measures of psychological distress (i.e. SDQ, CBCL), a common methodological feature of the research studies investigating the experiences of target siblings is the various sibling cohorts that are used as comparison groups, which can make it difficult to draw conclusive interpretations of the data available. The psychological adjustment of target siblings have been compared to a number of other sibling cohorts with various developmental disorders; yet most studies include a sample of typically developing siblings (e.g., Hastings, 2003a; Mandlco, Olsen, Dyches, & Marshall, 2003; Yirmiya et al., 2001). It has been proposed that each developmental disorder presents the typically developing siblings with unique challenges and opportunities, and thus some of the variance in the literature can be accounted for by the cohort that is used to compare the outcomes of target siblings (Seltzer et al., 2005). Hastings (2007) sought to investigate this hypothesis by comparing the psychological adjustment of target siblings against three other cohorts of

siblings: a normative sample of British children involved in a large scale study of mental health, siblings of children with Down syndrome, and siblings of children with mixed aetiology ID. Target siblings scored no differently than the siblings of the other developmental disorders on the emotional, peer problems, or total problems scales of the SDQ. Moreover, the mothers of the target siblings reported significantly fewer symptoms of hyperactivity in their typically developing offspring than the mothers of the children in the normative sample. However, only 24 target siblings participated in the study.

A common limitation in the research regarding the psychological adjustment of target siblings relates to small sample sizes. Two studies have addressed this methodological issue by conducting studies with large sample sizes. Shivers et al. (2013) examined the anxiety levels of 1755 target siblings and reported that only a small percentage of target siblings scored in the borderline or clinical range (8% and 4% respectively) on the CBCL. The authors indicated that most target siblings scored in the average range for the anxiety subscale and thus did not display anxiety that would warrant concern. In the second study, Dempsey et al. (2012) investigated the psychological adjustment of 486 target siblings using the reports of a parent and a teacher for each target sibling using the CBCL and Teacher Report Form (TRF; T. M. Achenbach et al., 1987), respectively. Results indicated that target siblings not only scored in the average range as perceived by both parents and teachers, but target siblings scored significantly less internalising and externalising symptoms than children in the normative sample. In other words, target siblings had fewer emotional and behavioural problems than children in the comparison sample.

A very small number of researchers in this area have compared data from multiple informants as studies generally include mothers as primary or sole informants.

Studies in which the reports of multiple informants have been included, the results suggest low agreement between the different types of informants (e.g., mothers vs. fathers; parents vs. teachers; Dempsey et al., 2012; Griffith et al., 2014). Low agreement between different informants has also been documented by other researchers (e.g., T. M. Achenbach et al., 1987; Hart, Lahey, Loeber, & Hanson, 1994; Rothbaum & Weisz, 1994). It has been proposed that the low level of agreement between informants can be due to either the different perceptions of each informant (e.g., mothers and fathers; parents and teachers) or due to variances in behaviours across settings (e.g., school setting vs. at home; Hart et al., 1994; Rothbaum & Weisz, 1994). Thus, the type of informant used could be a factor that may be influencing some of the mixed results evident in the literature.

In addition, the role the target siblings' developmental stage plays in their experiences has not been thoroughly investigated. Most researchers include a wide age range of target siblings in a single study with no analysis of the impact of age on the outcomes. The ages of target siblings within a single study can range from 3 years to 19 years (e.g., Hastings, 2007; Petalas, Hastings, Nash, Lloyd, et al., 2009; Shivers et al., 2013). Researchers who have analysed differences in the psychological adjustment of target siblings based on their developmental stage (e.g., pre-adolescence vs. adolescence) have reported higher scores of distress in older siblings when compared to younger siblings (N. Gold, 1993; Rodrigue et al., 1993). The developmental framework indicates that childhood and adolescence are two distinct phases in the life course; each phase presents individuals with unique developmental risks and opportunities, and influences how they interact with their environment (Diamond, 2002; Holder & Blaustein, 2014; Piaget, 1972). Including vastly different developmental phases in a single study prevents the identification of unique developmental factors that influence

the psychological adjustment of the individuals. Consequently, it cannot be said whether the experiences of adolescent target siblings are the same as that of pre-adolescents unless developmental factors are considered when designing research studies. In sum, there are a number of methodological issues that can explain some of the discrepancy observed in the data. However, researchers have proposed that other factors must either moderate or mediate the experiences of target siblings (Meadan, Stoner, & Angell, 2010; Tomeny et al., 2012).

Factors Associated with Target Siblings' Psychological Adjustment

As proposed by the risk and protective factor framework, the psychological adjustment of target siblings is influenced by the number and combination risk and protective factors (Bogenschneider, 1996; Frankford, 2007). Both risk and protective factors can be present in the individuals, their families, and their environments (Coleman & Hagell, 2007). Theorists propose that the presence and interaction of risk and protective factors increase or decrease the degree of psychological adjustment in adolescents and youths (Costello et al., 2008; Rutter, 1985). In other words, while having brothers and sisters with ASD may increase the risk of psychological distress in target siblings, the risk and protective factor framework suggests that the psychological adjustment of target siblings is influenced by the presence of additional risk and/or protective factors. The additional risk and protective factors interact with the risk created by being a target sibling to precipitate the degree of psychological adjustment evident in target siblings. Consequently, understanding the risk and protective factors that target siblings are exposed to can assist in understanding their psychological adjustment.

To date, various factors have been investigated to determine their role in the psychological adjustment of target siblings. The most commonly investigated factors have been demographic factors such as gender (Di Biasi et al., 2016; Hastings, 2003b; Kaminsky & Dewey, 2002; Macks & Reeve, 2007), age (Giallo et al., 2012; N. Gold, 1993; Rodrigue et al., 1993), and birth order effects (Di Biasi et al., 2016; Macks & Reeve, 2007; Rodrigue et al., 1993). Some data are also available regarding the influence on the target siblings' psychological adjustment of factors external to the target siblings, including the severity of ASD (Benson & Karlof, 2008; Hastings, 2003b, 2007; Meyer, Ingersoll, & Hambrick, 2011), and parenting competence (Hesse, Danko, & Budd, 2013). Researchers have found that the relationship between the target siblings' psychological adjustment and risk factors is often complex, and the result of the interplay of numerous risk factors (Meyer et al., 2011; Walton & Ingersoll, 2015). Thus, the complex relationship between risk factors and the psychological adjustment of target siblings supports the argument put forward in the risk and protective factor framework. Amongst the factors that can impact on the target siblings' psychological adjustment some researchers have proposed that issues pertaining to the family unit are influential (Meyer et al., 2011; Tomeny, Baker, Barry, Eldred, & Rankin, 2016).

Family Functioning and Target Siblings' Psychological Adjustment

As highlighted in chapter 2, researchers have identified a link between family functioning and individual outcomes in children and adolescents (Anthony, 2009; Khanna et al., 2011; Sharkey, You, & Schnoebelen, 2008). Family functioning is a multifaceted construct that includes relational processes, such as communication, cohesion, and problem solving (Cano et al., 2016; Epstein, Baldwin, & Bishop, 1983; Ferro & Boyle, 2015). Researchers have reported that family functioning can influence psychological outcomes, such as

depression and anxiety, in clinical and community groups of children and adolescents (Ferro & Boyle, 2015; Morrison Gutman, McLoyd, & Tokoyawa, 2005; Nomura, Wickramaratne, Warner, Mufson, & Weissman, 2002; Schleider et al., 2015). The relationship between family functioning and psychological outcomes has also been identified in longitudinal studies (Cano et al., 2016; Sheeber, Hops, Alpert, Davis, & Andrews, 1997). In a study involving over 12,000 high school students in the United States, family functioning accounted for 15% of the variance in the emotional distress reported by the participants (Resnick et al., 1997). The researchers stated that family cohesion was a key variable in the variance evident in the adolescents' emotional distress.

Family functioning has also been reported to be a mediating factor when other risk factors are present. Family cohesion and communication, as indicators of family functioning, have been found to mediate adolescents' externalising behaviour when their parents' alcohol consumption is problematic (Finan, Schulz, Gordon, & Ohannessian, 2015; Soloski, Kale Monk, & Durtschi, 2016).

Similarly, family functioning has been reported to mediate the relationship between stress and adolescents and youths' depression and anxiety symptomatology (Sheidow, Henry, Tolan, & Strachan, 2014). Likewise, family cohesion, problem solving, and family responsibilities have been identified as mediating the relationship between maternal depression and adolescents' positive affect (Yeh, Huang, & Liu, 2016). Hence, more positive family functioning can protect adolescents and youths' psychological wellbeing when they are exposed to a range of risk factors. Despite the available research regarding the moderating and/or mediating role of family functioning on the psychological adjustment of adolescents and youths less research is available regarding family functioning and

the psychological adjustment of target siblings.

Research results regarding the impact of family functioning on the target siblings' psychological outcomes are very limited and contradictory. Benson and Karlof (2008) reported that family functioning factors, such as family connectedness and parental agreement, were not predictors of the target siblings' psychological adjustment as measured by the SDQ. On the other hand, Mohammadi and Zarafshan (2014) reported that aspects of family functioning, as measured by the Family Assessment Device (Epstein et al., 1983) were found to be related to the psychological adjustment of target siblings. Specifically, the affective response of the family members was positively correlated to total difficulties and negatively correlated to prosocial behaviour as measured by the SDQ. The inverse relationship was evident between roles and problem solving and total difficulties and prosocial behaviour. That is, total difficulties decreased and prosocial behaviour increased with higher scores in roles and problem solving. Finally, behaviour control was positively correlated with increases in prosocial behaviours. These studies indicate that the link between family functioning factors and psychological adjustment of target siblings is unclear as family functioning remains insufficiently researched in this population (J. B. Kelly, 2000; Pettit & Bates, 1989; Stormshak, Bierman, McMahon, & Lengua, 2000). Moreover, as family functioning has been primarily assessed based on the parents' reports no data are available regarding the target siblings' perspective of family functioning (e.g., Mohammadi & Zarafshan, 2014).

As it can be seen, family functioning can act as a protective factor for adolescents and youths, moderating or mediating the risk to their psychological adjustment posed by a range of adverse circumstances. While the impact of family functioning on the psychological adjustment of target siblings has been researched very

limitedly other protective factors are yet to be measured. Most specifically, there are no data available on the role psychological resilience plays in the experiences of target siblings.

Psychological Resilience and Target Siblings' Psychological Adjustment

Research regarding the experiences of target siblings is generally driven by the assumption that having brothers or sisters with ASD is a risk factor that must lead to some degree of psychological distress (M. Gold & McCabe, 2012). That is, research regarding the experiences of target siblings has generally been driven by deficits models where the focus is on the deficiencies evident (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Tomeny et al., 2012). As such, limited attention has been focused on the protective factors that can positively affect the psychological adjustment of target siblings. However, psychological resilience researchers have generally objected the premise that experiencing risk must lead to distress (Luthar, Cicchetti, & Becker, 2000; Masten, 2001).

Psychological resiliency or psychological resilience can be defined as a significant resistance to the negative effects associated with being exposed to adverse experiences (Prince-Embury, Saklofske, & Vesely, 2014; Rutter, 2000). There is no consensus regarding the use of the term psychological resiliency or psychological resilience in the literature, with psychological resilience often being more commonly utilised; however, researchers such as Luthar et al. (2000) proposed that psychological resilience should refer to the processes that lead to resilient outcomes for individuals while psychological resiliency should refer to the personal qualities that allow individuals to experience resilient outcomes. The debate regarding the use of terminology reflects the history of the construct of psychological resilience. In the past,

psychological resilience was conceptualised as a trait individuals possess; however, currently researchers disagree with this perspective given that individuals do not tend to demonstrate equal levels of psychological resilience to all forms of stress or adversity, rather individuals tend to demonstrate psychological resilience in some contexts but not in others (Richardson, 2002). While the debate regarding the use of the terminology of psychological resilience or psychological resiliency can assist in the furthering of this area of research, the current study will use the term psychological resilience to refer to the protective processes and mechanisms that contribute to good outcomes in individuals despite the presence of significant risks (Hjemdal, Friborg, Stiles, Martinussen, & Rosenvinge, 2006). This will include individuals' abilities to use available resources, both internal and external, as they encounter different challenges (Pooley & Cohen, 2010).

Psychological resilience involves two separate processes as described by Rutter (2000). The first process describes how individuals react to the initial stressful experience. The second aspect describes the individuals' process and course of recovery. The first aspect of psychological resilience must be considered in light of not only the individuals' genetic predispositions but also in terms of their prior experiences. There is some evidence that suggests that having previously navigated adverse conditions can help children cope more successfully with life's difficulties later on (e.g., Elder Jr, 1974). The second aspect of psychological resilience that must be taken into consideration is the additional risks that individuals are exposed to during, or after the initial stressful event. However, in most cases psychological resilience is a natural feature of human development; a basic aspect of human adaptation that is influenced by varying developmental tasks throughout the lifespan (Masten, 2001; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003).

The concept of psychological resilience can be closely linked to the risk and protective factor framework in a number of ways. First, psychological resilience is evident when there are significant threats or risks to the wellbeing of the individuals (Masten & O'Dougherty Wright, 2010). Therefore, both the risk and protective factor framework and the concept of psychological resilience assume risk to the individual is present. Second, the processes or factors that allow individuals to adapt to the risks to which they are exposed can be conceptualised as protective factors (Rutter, 2000). Even though there is no universal definition of psychological resilience the construct has been presumed by researchers to be an important protective factor (Bellin & Kovacs, 2006). Psychological resilience is generally measured by assessing the protective factors and resources, both personal characteristics and coping styles, evident in the individuals (B. W. Smith et al., 2008). These factors and resources include social competence, family cohesion, and social support (Connor & Davidson, 2003; Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003; Oshio, Nakaya, Kaneko, & Nagamine, 2002). Third, researchers investigating psychological resilience have been challenging the assumption that traumatic experiences, especially those that occur during childhood, are inevitably damaging (Walsh, 2003). Likewise, the risk and protective factor framework does not assume individuals exposed to risk will undoubtedly develop poor outcomes (Frankford, 2007; Vakalahi, 2001). Researchers and theorists propose that both the risk and protective factor framework and the psychological resilience research indicate that adaptation in the face of risks is possible; target siblings do not have to succumb to psychological distress. Researchers stipulate that adversity and successful adaptation must co-occur for resilient outcomes to be evident (Luthar et al., 2000; Ungar, 2009).

When discussing adversity or risk it is important to note there is a difference between risk factors and risk processes (Rutter, 2000). Risk processes are not risk

factors in and of themselves but rather they are processes that can lead to risk factors (Rutter & Sroufe, 2000). For example, parental separation has long been considered an important risk factor for the psychological wellbeing of children, however, it is not parental separation per se that causes negative psychological outcomes in children, rather it is the parental conflict, poor parenting, economic hardship, and the breakdown of relationships associated with parental separation that are directly linked to children's poor adjustment (Amato & Keith, 1991; J. B. Kelly, 2000). If parental separation does not lead to high parental conflict, poor parenting, economic hardship, and a breakdown of relationships between children and parents then the negative impact on children will be reduced. On the other hand, if there is high parental conflict, poor parenting, economic hardship, and a breakdown of relationships even in the absence of parental separation, children will experience increased risk of negative psychological adjustment.

The difference between risk factors and risk processes is important when considering the experiences of target siblings as it could assist in understanding the discrepancy evident in the psychological adjustment of target siblings. When individuals are diagnosed with ASD it often causes a number of changes in the family unit, including increased stress, reduced resources, and changes in roles (Gass, Jenkins, & Dunn, 2007; Stoner & Angell, 2006). Moreover, the spectrum nature of ASD means that the disruption to the family unit will vary depending on the severity of the disorder and the level of impairment experienced by the children (American Psychiatric Association, 2013; Hastings & Johnson, 2001; Lecavlier et al., 2006). These factors, precipitated by the disorder but not exclusive to families of individuals diagnosed with ASD, could be in part responsible for the target siblings' outcomes.

There is research evidence linking psychological resilience with the psychological wellbeing of adolescents and youths, but not that of target siblings. At-risk groups of children and adolescents do not generally report significantly different levels of psychological resilience when compared to community samples (Askeland, Hysing, Aarø, Tell, & Sivertsen, 2015; Malindi & Theron, 2010; Moreira, Soares, Teixeira, e Silva, & Kummer, 2015). However, researchers have reported that psychological resilience can buffer the effects of stressors as evident by lower levels of psychological distress in individuals who report higher levels of psychological resilience (Anyan & Hjemdal, 2016; Askeland et al., 2015; Hjemdal, Vogel, Solem, Hagen, & Stiles, 2010; Moreira et al., 2015; Piquart, 2009). Hjemdal, Aune, Reinfjell, Stiles, and Friborg (2007) stated that adolescents who reported higher levels of psychological resilience, as measured by the Resilience Scale for Adolescents (READ; Hjemdal & Friborg; cited in Hjemdal et al., 2006) reported significantly lower levels of depressive symptoms. The finding applied to the individual factors measured by the scale as well as to the total resilience score, thus suggesting that the protective value lies in all individual, familial, and environmental factors of psychological resilience measured by the READ. There is also some evidence that suggests that psychological resilience can offer long term protection. In a sample of 4000 adults the authors reported that the relationship between adulthood depression and adverse childhood experiences was moderated by the individuals' psychological resilience (Poole, Dobson, & Pusch, 2017).

In summary, the lack of clarity regarding the factors that influence the psychological adjustment of target siblings is a reflection of the complex interplay of numerous risk and protective factors in determining psychological outcomes (Bogenschneider, 1996). The ability for researchers to capture the complexity of the

experiences of target siblings can be limited by quantitative studies, as researchers can only measure a predetermined number of variables within a single study. On the other hand, qualitative research studies allow for a richer understanding of the experiences under investigation and the complexities surrounding a person's psychological resilience in light of living with a stressor (Castro, Kellison, Boyd, & Kopak, 2010; Morse, 1991). Consequently, the following section will review the qualitative data available regarding the experiences of target siblings in order to identify factors and processes that can help integrate what is currently known about the experiences of target siblings.

The Lived Experience of Target Siblings

The vast majority of research regarding the experiences of target siblings is quantitative in nature and has focused on the level of psychological distress of target siblings, particularly when compared to other sibling groups. While some qualitative research has been conducted to explore the experiences of this cohort of siblings, only a small number of studies have utilised target siblings as participants (Moyson & Roeyers, 2012). Despite the limited number of qualitative studies available with target siblings as participants, these studies shed some light on some of the complexities associated with the experiences of target siblings. Moreover, these studies provide insights into how target siblings adapt to the unique demands they encounter.

A summary of the qualitative studies examining the experiences of target siblings, including the themes reported by the authors is provided in Table 3.2. As it can be seen in Table 3.2 target siblings have tended to express both positive and negative aspects to their experiences of living with brothers or sisters diagnosed with ASD. Four broad themes are evident based on the studies available: the impact of ASD on the

target siblings; the target siblings' experiences with non-family members; the target siblings' attitudes towards their brothers or sisters with ASD; and the level of support received by the target siblings.

The first general theme evident in these studies relates to the impact the children with ASD have on the target siblings, whether directly or indirectly. Target siblings have consistently reported across studies being concerned for their own safety as well as for the safety of their parents and pets due to the violent behaviour of their brothers or sisters (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, & Reilly, 2009). In addition, the reactions from the target siblings to the physical violence tends to vary: some siblings experience fear and feel unsafe in their homes, while others experience anger, as they do not feel it is fair to retaliate (Benderix & Sivberg, 2007). The target siblings have also discussed the impact their brothers or sisters had on their social relationships. That is, a number of target siblings have expressed they were unable to invite friends to their homes as they were concerned about their brothers or sisters' behaviours, including aggression or atypical behaviours (Benderix & Sivberg, 2007). Moreover, the target siblings also perceived that their parents did not have the time to cater for the requirements of the visitors. Finally, target siblings' sense of responsibility towards their brothers or sisters with ASD tended to increase as the target siblings aged. These feelings of responsibility included protecting the brothers and sisters, giving parents respite, and feeling they would be responsible for their brothers and sisters once their parents were unable to care for the children with ASD (Benderix & Sivberg, 2007). The increased sense of responsibility as target siblings age is consistent with the developmental perspective which posits that developmental maturation is associated with changes in the challenges that individuals need to negotiate (Diamond, 2002; Holder & Blaustein, 2014; Steinberg & Morris, 2001).

The second general theme apparent in the qualitative data encompasses the experiences of target siblings as a result of, or related to, individuals outside the family.

Target siblings have reported two general sentiments regarding those outside their immediate families (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). The first sentiment has been positive in that non-family members were a source of support, help, and empathy during difficult or stressful times. The second sentiment has been negative. Across studies target siblings have consistently reported feeling embarrassed in public due to the behaviour of their brothers and sisters with ASD. Most specifically, target siblings have expressed that one of the most difficult aspects of having brothers or sisters with ASD is their ASD-related symptoms, such as acting out and stereotyped behaviours; when these behaviours occur in public they tend to be particularly distressing for the target siblings (Mascha & Boucher, 2006). Target siblings have often reported feeling embarrassed or unable to explain to others the reason for their brothers or sisters' behaviours (Petalas, Hastings, Nash, Dowey, et al., 2009). In addition, siblings have also reported having to endure the lack of awareness or lack of understanding of ASD from those outside of their immediate family. Last, siblings have also shared they felt the need to defend their brothers and sisters from unsympathetic friends and adults.

The third broad theme relates to the target siblings' attitude towards the brothers or sisters with ASD. Most often target siblings have expressed both negative and positive attitudes towards their brothers or sisters. Participants have described their brothers or sisters as being fun, and have stated that being able to play together and share enjoyment were among the best parts of having a brother or sister with ASD (Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). The behavioural problems, aggressive behaviours, and feeling embarrassed have been deemed as the most difficult parts of having brothers or sisters diagnosed with ASD (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). Shared enjoyment and playing together are not qualities exclusive to sibling relationships where one sibling has been diagnosed with ASD, if anything, these qualities

might be more common in relationships between typically developing siblings (Harrist et al., 2014; Howe, Abuhatum, & Chang-Kredl, 2014; Huskens, Palmen, Van der Werff, Lourens, & Barakova, 2015). However, these positive qualities do highlight the fact that target siblings are still able to identify and maintain what could be deemed typical characteristics in their sibling relationships despite the challenges they encounter as a result of the behavioural and emotional difficulties associated with ASD. Interestingly, almost all target siblings involved in qualitative research studies are able to identify positive characteristics in their brothers or sisters as well as positive experiences involving their siblings (Diener, Anderson, Wright, & Dunn, 2015; Petalas, Hastings, Nash, Dowey, et al., 2009). This would indicate that despite the challenges and stresses associated with ASD, target siblings can also benefit from and enjoy the sibling relationship, and the target siblings themselves do not interpret their experiences as solely negative.

The last broad theme evident in the qualitative literature relates to the support target siblings received or wished they could receive. Children and adolescents alike have expressed the need for, or benefit of having emotional support from parents, other siblings, relatives, friends, teachers, or even other target siblings (Moysen & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). The need for social support as expressed by the target siblings themselves suggests that they recognised that their experiences can be challenging at times. The ability of target siblings to access the support they require in order to cope with the challenges of their experiences can be interpreted as a sign of psychological resilience (Luthar et al., 2000; Masten & O'Dougherty Wright, 2010).

Table 3.2

Summary of Qualitative Studies with Target Siblings as Participants

Authors	Participant details	Analysis	Results/themes
Mascha & Boucher (2006)	$N = 14$ Age range: 11-18 years. $M = 14.73$ years	Content analysis	<ol style="list-style-type: none"> 1. Most difficult part of having brothers or sisters with ASD 2. Best part of having brothers or sisters with ASD 3. Time spent together as siblings 4. Pleasant and unpleasant events involving brothers or sisters 5. Communicating with parents and concerns about the future
Benderix & Sivberg (2007)	$N = 14$ Age range: 5-29 years. $M = n/a$	Phenomenology/ content analysis	<ol style="list-style-type: none"> 1. Target siblings' responsibilities for brothers or sisters with ASD 2. Sympathising with brothers or sisters with ASD 3. Experience of ASD behaviours 4. Empathising with brothers or sisters with ASD 5. Expectations of brothers or sisters living in group home 6. Target siblings feeling unsafe due to violence 7. Negative impact on peer relationships
Petalas, Hastings, Nash, Dowey, & Reilly (2009)	$N = 8$ Age range: 9-12 years. $M = 11.19$ years.	Interpretative phenomenological analysis (IPA)	<ol style="list-style-type: none"> 1. Impact of brothers' condition on target siblings' lives 2. Others people's reaction to sibling with ASD 3. Target siblings' acceptance of brothers' condition 4. Positive experiences of target siblings 5. Support
Moyson & Royers (2011)	$N = 17$ Age range: 5-16 years. $M = 10.41$ years.	Phenomenology/ grounded theory	<ol style="list-style-type: none"> 1 Invisibility of ASD 2. Coping with ASD behaviours 3 Ability to communicate with brothers or sisters with ASD 4 Siblings engaging in joint activities 5 Target siblings need for private time 6 Concerns about sibling 7. Acceptance of ASD and its implications 7 Exchanging experiences with other target siblings 8. Social support 9. Interactions with individuals outside the family unit

Note. N = sample size; M = mean age of the participants.

The results of the qualitative research studies provide contextual details that enhance the understanding of the target siblings' lived experiences. The available research suggests that the experiences of target siblings are multifaceted; that is, they report that being siblings of children with ASD has a number of characteristics, some positive and some negative. In particular, the qualitative data describe in detail how clinical features of ASD can impact negatively on the target siblings' day-to-day experiences. An important dimension that the qualitative results capture is the complex nature of the experiences of target siblings, as well as the number of factors that shape their experiences, such as social factors, psychological resilience, and family dynamics. However, more research is necessary in order to understand the role these factors play in the experiences of target siblings. Moreover, the age range of target participants in qualitative studies vary broadly across studies although the mean age tends to be late childhood (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). Consequently, there are no qualitative data that apply exclusively to adolescents and youths.

The integration of the qualitative data on the lived experiences of target siblings with the quantitative data on the psychological adjustment of target siblings provides a greater understanding of the topic under investigation. The combination of the findings from the quantitative and qualitative research designs indicates that target siblings are exposed to considerably difficult, stressful, and straining situations. However, there are also opportunities for positive experiences, and target siblings do not need to succumb to the stressors they face, particularly when they are able to access support. Despite the added layers of depth that combining quantitative and qualitative data bring to the understanding of what it means to be target siblings, no previous study has examined

the experiences of target siblings in adolescence and early adulthood using a mixed methodology.

Current Study: Aim, Research Questions, and Hypotheses

Overall, the results of previous research regarding the experiences of adolescents and youths whose brothers or sisters have been diagnosed with ASD are often complex due to the diverse nature of their experiences. Consequently, the overall purpose of the current study was to investigate the role of risk and protective factors in the experiences of target siblings in the developmental phases of adolescence and early adulthood. The current study aimed to build on the literature currently available regarding the psychological wellbeing of target siblings in order to address some of the methodological and theoretical issues evident. To do this, the current study drew on informants commonly used in past research studies – target siblings and their mothers (N. Gold, 1993; Griffith et al., 2014; Walton & Ingersoll, 2015). However, the present study adopted a mixed methodology, namely quantitative and qualitative methodologies, utilising multiple informants. Mixed methods, the use of multiple methodologies within a single study, draws on the strengths of both quantitative and qualitative research, and thus it allowed a more comprehensive exploration of the experiences of target siblings (Creswell & Plano Clark, 2011; R. B. Johnson, Onwuegbuzie, & Turner, 2007; Liamputtong & Ezzy, 2005). Mixed methods allowed for a greater number of research questions to be investigated within a single study. In addition, it allowed for the experiences of one sample of target siblings to not only be quantified and compared to a community sample of siblings, but it also permitted the experiences of these same target participants to be contextualised within their own narratives. In addition, it allowed the researcher to capture the dynamics of the

experience of living with brothers or sisters with ASD and the processes that impact the target siblings' experiences.

The current study sought to explore the perspectives of multiple informants, namely the participating siblings and their mothers. Researchers investigating the experiences of target siblings often rely on the reports of mothers rather than siblings despite evidence of low agreement between different types of informants (T. M. Achenbach et al., 1987; Griffith et al., 2014; Hastings, 2003b; Macks & Reeve, 2007; Rodrigue et al., 1993). The use of maternal reports can offer valuable information about the family, its functioning, and its members, while the use of target siblings provides direct data regarding their experiences. In the current study the use of multiple informants in both stages of the study allowed the experiences of target siblings to be viewed from different perspectives and to identify discrepancies between these perspectives. In particular, the use of mixed methods allowed for the examination of what drives mothers' perspectives regarding the experiences of target siblings.

The current study sought to explore the impact of psychological resilience and family functioning on the experiences of the target siblings. The role these two protective factors play in the experiences of the target siblings has not been researched as studies in this area have generally been driven by the assumption that living with children with ASD will lead to maladjustment in target siblings without considering the impact of other factors (M. Gold & McCabe, 2012). Data regarding family functioning and psychological resilience were explored for two purposes. First, to examine group differences between target siblings and the community samples on the abovementioned constructs to determine if target siblings were more likely to experience lower levels of psychological resilience and family functioning. Second, the study also sought to examine psychological resilience and family functioning as potential protective factors

associated with the psychological adjustment of the target siblings. The identification of psychological resilience and family functioning as protective factors would help determine the degree to which these factors could assist in understanding the discrepancies in the levels of psychological adjustment of target siblings evident in the available literature. While having brothers or sisters with ASD can be considered to be a factor that increases the risk that contributes to poor psychological adjustment, the risk and protective factor framework indicates that it is the combination of risk and protective factors that produce a given outcome. That is, other factors related to the target siblings themselves, their families, or their environments can increase or decrease the risk of target siblings experiencing psychological distress (Bogenschneider, 1996; Coleman & Hagell, 2007). There is mixed evidence that the target siblings' age and gender can affect the degree of psychological distress (Giallo et al., 2012; N. Gold, 1993; Orsmond & Seltzer, 2009; Walton & Ingersoll, 2015). Therefore, measuring other factors that can impact on the wellbeing of adolescents and youths helped provide a more accurate understanding of the psychological adjustment of target siblings.

Researchers have not reached a consensus regarding what makes an optimal comparison group for target siblings (Hastings, 2007; Macks & Reeve, 2007). However, comparing the psychological adjustment of target siblings to a community sample of adolescents and youths with typically developing brothers or sisters provided a clearer understanding of the unique differences between "typical" siblings and "atypical" siblings. Moreover, the collection of data from typically developing adolescents and youths allowed for an appreciation of the mental health concerns of the community sample.

Each stage of the current study investigated a number of research questions and associated hypotheses. Stage one of the study sought to compare the experiences of

target siblings, as measured by their psychological distress, psychological resilience, and family functioning, to the experiences of a community sample. It also sought to determine how family functioning and psychological resilience impacted the target siblings' psychological adjustment. Consequently, stage one sought to answer the following three research questions:

Research question 1: How do the reports of target siblings differ from the reports of community siblings on the measures of psychological resilience, psychological distress, and family dysfunction? As no data are available exploring psychological resilience in target siblings no hypothesis was made regarding differences between the target siblings' and the community siblings' psychological resilience.

Hypothesis 1a: Researchers have reported mixed findings regarding the psychological distress of target siblings when compared to other sibling groups. However, being a target sibling is considered a risk factor by researchers (N. Gold, 1993; Hastings, 2007; Rodrigue et al., 1993). Therefore, it was expected that target siblings would report greater psychological distress than community siblings.

Hypothesis 1b: Researchers have reported that parents of children with ASD report greater family dysfunction when compared to other families (Gua et al., 2012; Sullivan et al., 2012). Despite the lack of data regarding the target siblings' perception of family functioning it was expected that target participants would report greater levels of family dysfunction than community participants.

Research question 2: How do the reports of target mothers differ from the reports of community mothers regarding the psychological resilience and psychological distress of participating siblings, and the degree of family dysfunction? As with the

target siblings, no data are available exploring psychological resilience in target siblings therefore no hypothesis was made regarding differences between the target siblings and the community siblings' psychological resilience.

Hypothesis 2a: Researchers have reported mixed findings regarding the psychological distress of target siblings when compared to other sibling groups, however, being a target sibling is considered a risk factor by researchers (N. Gold, 1993; Hastings, 2007; Rodrigue et al., 1993). Therefore, it was expected that mothers would report greater psychological distress in the target siblings than in the community siblings.

Hypothesis 2b: In published research studies target mothers have reported greater family dysfunction when compared to families whose children do not have ASD (Higgins et al., 2005; Sikora et al., 2013). Therefore, it was predicted that target mothers would report greater levels of family dysfunction than community mothers.

Research question 3: To what extent are family dysfunction and psychological resilience as reported by the target siblings and the target mothers associated with psychological distress in target siblings after controlling for informant type (target siblings vs. target mothers) and the target siblings' age and gender?

Hypothesis 3a: It was predicted that the target siblings' psychological resilience and family dysfunction would account for a significant portion of the variance of the target siblings' psychological distress as there is evidence that indicates that psychological distress can be influenced by psychological resilience and family dysfunction (Anyan & Hjemdal, 2016; Ferro & Boyle, 2015).

Hypothesis 3b: It was expected that psychological resilience would have a negative relationship to the target siblings' psychological distress as psychological resilience has been negatively associated to psychological distress (Hjemdal et al., 2007).

Hypothesis 3c: It was expected that family dysfunction would have a positive relationship to the target siblings' psychological distress as previous research has indicated that family dysfunction is positively associated with psychological distress (Mohammadi & Zarafshan, 2014).

Stage two sought to explore the lived experience of adolescents and youths who had participated in stage one, as siblings of individuals diagnosed with ASD, and to explore the factors that shaped these experiences. This stage of the study aimed to answer two research questions:

Research question 4: How do adolescents and youths perceive their experiences as siblings of individuals diagnosed with ASD?

Research question 5: How do mothers perceive the experiences of the adolescents and youths as siblings of individuals diagnosed with ASD?

In the following chapter the methodology adopted for the present research study is outlined.

Chapter 4:

Research Design

Chapter Overview

In this chapter the research framework utilised in the present study is described. An outline of the mixed methods approach, describing the philosophical underpinnings of each methodology utilised in the present study is also provided. The chapter also contains a description of the methods used in each stage, as well as a discussion of issues pertaining to rigour.

Chapter 4:

Research Design

Introduction

In order to investigate the experiences of the adolescents and youths as siblings of individuals diagnosed with ASD the present research study utilised a mixed methods approach. That is, both qualitative and quantitative methodological approaches were integrated into the study design. For stage one (quantitative) postpositivism was used, while for stage two (qualitative), social constructivism was utilised. In stage one, questionnaires were utilised to identify group differences between target participants (adolescents/youths and their mothers) and community participants (adolescents/youths and their mothers) on measures of family functioning, and the psychological resilience and psychological distress of the participating siblings. In stage one the aim was also to identify factors that impacted on the target siblings' psychological distress. In stage two the researcher sought to explore the experiences of the target siblings from a phenomenological perspective with the use of individual in-depth semi-structured interviews (Becker, 1992; Moustakas, 1994).

The research design associated with the two stages of the present research study is outlined in this chapter. A description of the postpositivism and social constructivism frameworks, a discussion of the mixed methods, quantitative, and qualitative methodologies utilised in the study, and the use of surveys and in-depths interviews to collect data are also included in the chapter. An explanation of how rigour was ensured is presented at the conclusion of the chapter.

Philosophical Frameworks

The research study adopted a mixed methods design, thus two philosophical frameworks guided each of the two stages of the study. The philosophical framework is an important aspect of a study as it informs all aspects of the research process (Burns Cunningham, 2014). The philosophical framework contains the epistemological (the relationship between the researcher and the object being researched), ontological (the nature of reality), and methodological (the process of conducting research) premises that guide the actions of the researcher (Anfara, 2008; Noonan, 2008; Schensul, 2008; Stone, 2008). The philosophical framework also impacts on the selection of the sample and the analysis of the data; it reveals and conceals meaning as phenomena are viewed through a particular lens; it positions the research study within the broader scholarly knowledge; and it reveals the study's strengths and weaknesses (Anfara, 2008). Figure 4.1 depicts the frameworks, methodologies, and methods utilised in this study. Stage one, the quantitative phase, was informed by the postpositivism framework to examine data collected through questionnaires using a cross-sectional methodology. Stage two, the qualitative phase, adopted a social constructivism framework, and employed a phenomenological methodology to examine data collected through in-depth interviews. The frameworks, methodologies, and methods used in the research study are discussed below.

Postpositivism (Quantitative Stage)

Postpositivism was developed as scholars attempted to overcome the inherent flaws associated with positivism, namely the narrow and simplistic ideas on what constituted reality and how to discover the true nature of reality (Corbetta, 2003).

Postpositivism maintains that phenomena can be researched and understood; however, it

has considerably different ontological and epistemological ideas to positivism (L. Cohen, Manion, & Morrison, 2011). The ontological position of postpositivists indicates that while reality is ‘real’, it can only be known in an imperfect form (Corbetta, 2003). Postpositivists believe in multiple yet coexisting realities because they view phenomena as multilayered, thus making multiple interpretations, depending on the view point, possible (L. Cohen et al., 2011). Critical differences are also evident in the epistemology of postpositivism compared to positivism.

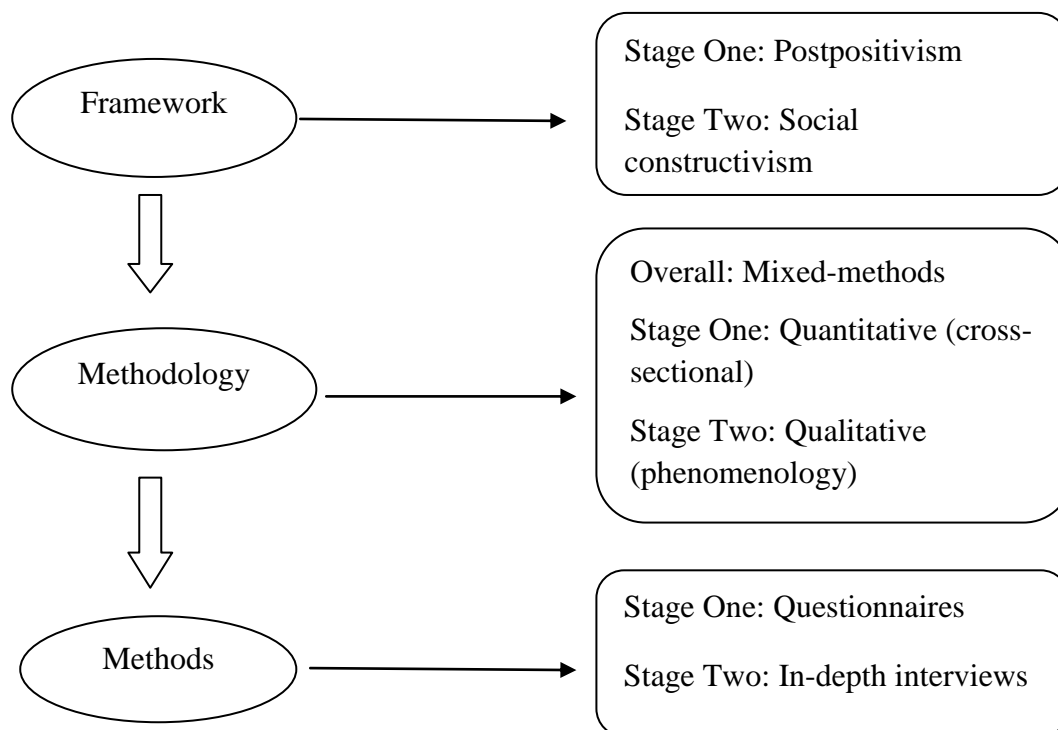


Figure 4.1. Visual representation of the framework, methodology and methods utilised in the current study.

The epistemological position of postpositivists assumes that the results of research studies are probably true based on the information available at the time (Corbetta, 2003). Postpositivists accept the concept of fallibility as an inherent aspect of life; consequently, according to postpositivists, knowledge is made up of conjectures that are supported by the warrants available at that point in time (Phillips & Burbules,

2000). As a result of this, generalisations can be made, however, these are always provisional and open to revision as further knowledge on the phenomena is gained (Corbetta, 2003). Postpositivists, unlike their positivist counterparts, are not interested in seeking absolute truth, rather they are interested in forming beliefs that are true (Phillips & Burbules, 2000). Postpositivism provides a satisfactory framework for the study of social phenomena, such as the experiences of target siblings, allowing the development of true statements that are relevant for the context of interest (Phillips & Burbules, 2000).

Social Constructivism (Qualitative Stage)

The qualitative stage of the research study was guided by the philosophical framework of social constructivism. Social constructivism as a paradigm rejects the positivism and postpositivism ideas regarding ontology, epistemology, axiology (the role of values), and methodology (Creswell & Plano Clark, 2011). Social constructivists posit that knowing is an active process where knowledge is constructed by the individuals rather than found (Schwandt, 2000). It adheres to the belief that there are multiple realities, and that these realities are constrained by social, political, and cultural parameters (Creswell & Plano Clark, 2011; Schwandt, 2000). In the present study social constructivism was defined as a paradigm that considers reality to be socially constructed and subjective (Grbich, 2007; Talja, Tuominen, & Savolainen, 2005). Moreover, the construction of knowledge was considered to be embedded within a historical and cultural context, so that the participants' reality was influenced by meanings, symbols, and language that are shared with members of their culture, including the researcher (Schwandt, 2000).

Social constructivism denies the naïve realist view that there is a singular reality that can be appreciated through the individuals' senses (Creswell & Plano Clark, 2011). This paradigm adheres to the belief that there are multiple realities, and that these realities are value-laden (Schwandt, 2000). Much of the research into the experiences of target siblings has relied on parental reports alone (e.g., Petalas, Hastings, Nash, Lloyd, et al., 2009). This indicates a positivist understanding of the nature of reality, in that it suggests that target siblings experience a singular reality, and that this reality can be understood without the direct input of the siblings themselves. In utilising a social constructivism perspective, the target participants themselves must share their own stories. This necessity reflects two fundamental aspects of social constructivism. First, the premise that reality is dependent on how each participant understands and constructs his or her own experience as a target sibling; and second, the principle denoting the importance of language in the construction of this reality. The need to understand the phenomena under investigation from the perspective of the individuals experiencing them ties in with the epistemology of social constructivism. Studies adopting social constructivism tend to utilise inductive methodologies, such as phenomenology in order to explore and understand the experiences of individuals, and how the social environment affects the construction of these experiences (Creswell & Plano Clark, 2011; Denzin & Lincoln, 2000). The present study utilised phenomenology in order to collect data during stage two of the study. Mixed methods, cross-sectional survey, and phenomenology, the methodologies employed, will be explained in greater detail below.

Methodology

A mixed methods research design was utilised in the present study, and thus both quantitative and qualitative methods were used to collect the data. While the data were collected and analysed independently, as depicted by Figure 4.2, the two sets of

data were utilised to deepen the interpretation and understanding of the target siblings' experiences. The following section discusses the mixed methods design along with a summary of the quantitative and qualitative methodologies.

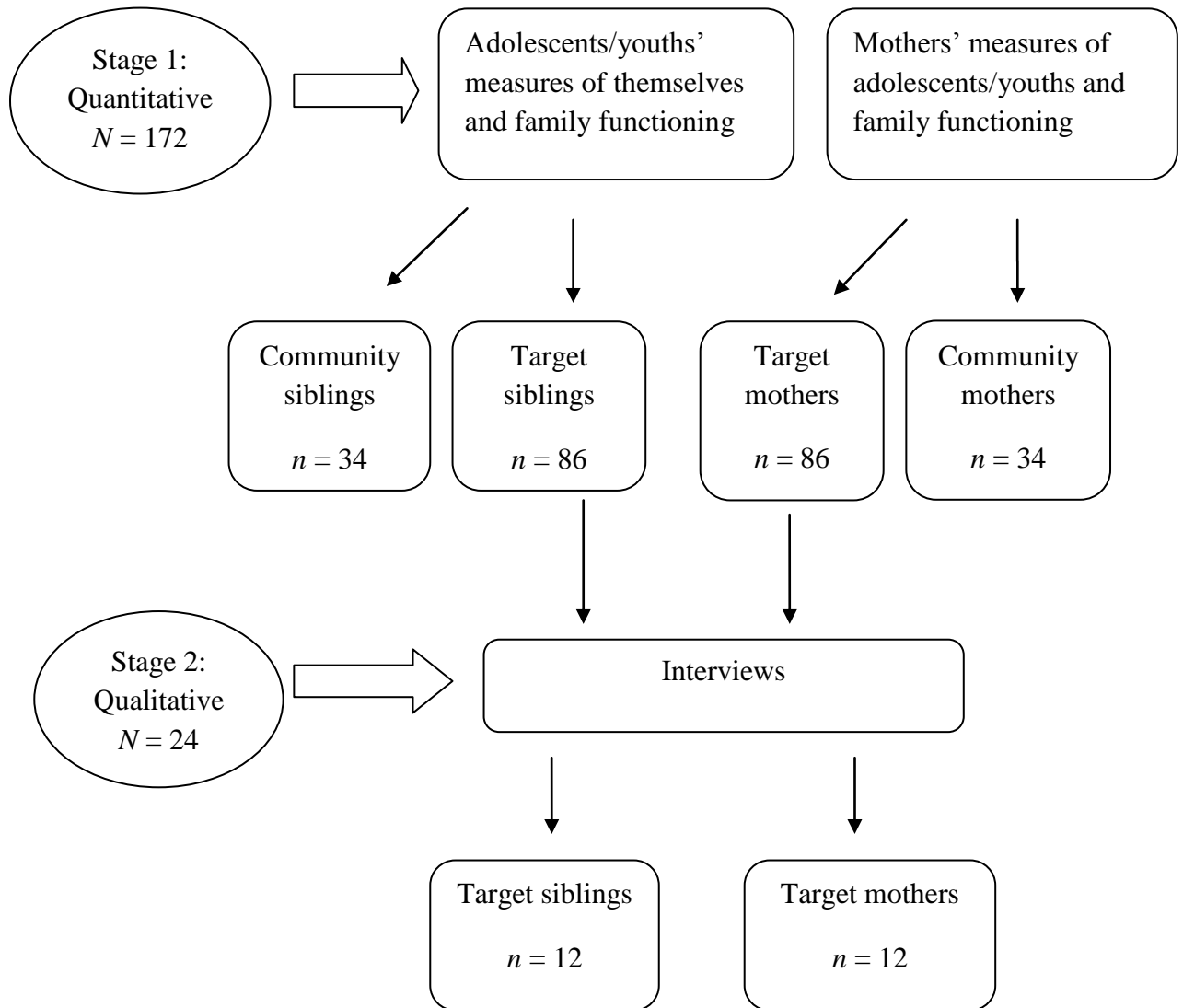


Figure 4.2. Research design of stage one and stage two of the study.

Mixed Methods

Mixed methods research consists of using multiple research methodologies within a single study (Liamputtong & Ezzy, 2005), and it is the third major research paradigm following the quantitative and qualitative research approaches (R. B. Johnson

et al., 2007). The definition of mixed methods has evolved over the years since Campbell and Fiske (1959) first introduced the use of multiple quantitative methods within a single study. Creswell and Plano Clark (2011) proposed that mixed methods is a type of research design with its own philosophical assumptions, and its own specific methods of data collection and analysis. The mixed methods paradigm attempts to find a balance between the qualitative and quantitative approaches by collecting, analysing, and mixing qualitative and quantitative data within a single study or within a series of studies (R. B. Johnson et al., 2007). Mixed methods designs are said to be able to draw on the individual strengths of quantitative and qualitative approaches while simultaneously minimising their inherent limitations.

Quantitative research utilises the scientific method of investigation with the aim of measuring behaviours or phenomena (Salkind, 2008). Quantitative research endeavours to identify relationships between variables by analysing numerical data utilising a range of statistical methods that allow the researchers to describe or draw inferences about the phenomena being researched (Howell, 2014). Quantitative research is deductive by its nature, seeking to test hypotheses in a number of ways (Martin, 2008; Muijs, 2004; Searle, 2000). The present study utilised a cross-sectional survey design as the study focused on the attitudes and behaviours of the participating siblings and their mothers as measured by a number of questionnaires. The cross-sectional design allowed for the collection of data from a number of groups of participants (i.e., siblings and mothers, and target participants and community participants) as well as for comparisons to be conducted amongst the different groups of participants (Salkind, 2010). The survey design allowed for the collection of data from a large number of participants on numerous variables, and thus it permitted to test several hypotheses utilising a single

survey (McNeill & Chapman, 2005). Moreover, it also allowed for the identification of variables that impacted on the psychological adjustment of the target siblings.

Among the strengths of quantitative methods are the ability to test hypotheses, do group comparisons, examine correlations between variables, and to extrapolate the results to the population from which the sample is drawn (Babbie, 2002; Castro et al., 2010). A major deficit of this type of research method is the loss of contextual information; that is, the results in quantitative studies are isolated from their original context and consequently a significant loss of information transpires (Salkind, 2008). On the other hand, qualitative research studies can often address the limitations inherent to quantitative methodologies.

Qualitative research is a methodology that provides findings that are not derived from statistical calculations (Strauss & Corbin, 1990). It is based on the philosophical assumption that there are multiple socially constructed realities rather than a single truth (McGettigan, 2008; Sale, Lohfeld, & Brazil, 2002). Qualitative research can be used for exploring many phenomena, and it is commonly used when the topic of interest relates to stories, behaviours, and lives (Strauss & Corbin, 1990). This approach is most appropriate when phenomena want to be understood from their emic perspective or when there is limited prior knowledge about the phenomena (Morse, 1995). Qualitative research is also useful when the context in which the phenomena occurs is considered to be an important aspect of the phenomena themselves (Morse, 2008). The present study utilised phenomenology as the methodology of stage two.

Historically phenomenology was understood as seeing phenomena without holding preconceptions in order to discover new or enhanced meanings of the phenomena (Crotty, 1998). According to Becker (1992), modern phenomenology

consists of studying situations from the individuals' points of view. Thus, the aim of phenomenology is to determine how individuals construct their world and to establish the meaning individuals attribute to the events they have experienced (Moustakas, 1994). Phenomenologists emphasise the importance of understanding the meaning people attribute to their own actions (Liamputtong & Ezzy, 2005). Consequently, phenomenology is defined as the study of the 'lived experiences', aimed at understanding the meaning or nature of everyday experiences (van Manen, 1990). This study explored the experiences of target siblings via semi-structured, in-depth interviews. The study sought to attain a comprehensive description of these experiences from the perspective of the target siblings themselves. Moreover, it sought to investigate how mothers perceived and interpreted the experiences of the target siblings. The phenomenological approach allowed for both the target siblings and their mothers to express the meaning they attributed to the experience of being a sibling of a person with ASD within each individual's social context and own perspective.

Qualitative research has numerous strengths that include the capacity to collect richer and more detailed data, analyse data within their original context, as well as being able to capture complex experiences in a way that questionnaires alone cannot do (Morse, 1991; Rapley, 2004). However, qualitative research methodologies also have significant limitations. These can include small, unrepresentative samples that decrease the applicability of the results to other samples, difficulties in integrating data reliably across cases, and difficulties assessing associations between cases (Castro et al., 2010).

As previously stated, mixed methods research draws on the individual strengths of quantitative and qualitative research methodologies while overcoming some of the most significant limitations inherent to each approach (Creswell & Plano Clark, 2011). Mixed methods research achieves this by combining both methodologies in a single

study; consequently it is able to expand on the breadth and depth of understanding of the phenomena of interest or to corroborate the results obtained (Castro et al., 2010). Mixed methods research also provides researchers with more tools to investigate phenomena, and it encourages the researchers to consider the phenomena from a number of different paradigms (Creswell & Plano Clark, 2011). Mixed methods research is not without its own challenges; namely additional time required to collect and analyse two complete sets of data, and researcher expertise in utilising both methodologies (Creswell & Plano Clark, 2011). Despite this, a mixed methods methodology is able to add to a research study in many ways.

A mixed methods methodology was chosen for the present study as it enhanced the investigation in several ways. First, it allowed a number of research questions to be answered. Quantitative and qualitative research methodologies are usually not able to answer the same type of questions (Bryman, 2006) therefore, by utilising a mixed methods design a broader spectrum of questions were able to be addressed. Questions regarding differences between the experiences of the target siblings and the community siblings were able to be explored from a quantitative perspective. The quantitative methodology also allowed for factors that impact on the psychological adjustment of target siblings to be identified. On the other hand, questions regarding the meaning of the experiences of the target siblings as well as how this meaning was constructed were explored utilising a qualitative methodology. Second, by utilising a mixed methods design, a fuller understanding of the experiences of the target siblings could be obtained (Neuman, 2006). That is, by combining the quantitative and qualitative data, a more comprehensive understanding of what it means to be a target sibling was achieved. Third, the research design provided a context for the findings of the study (Bryman, 2006). Researchers investigating the experiences of target siblings have often relied on

quantitative methodologies, and thus results have frequently been isolated from their contexts. However, by utilising a mixed methods design, the present study was able to analyse the data while retaining contextual information. Last, the present research methodology was used as a form of triangulation (Bryman, 2006). Triangulation is a technique which can be used to overcome the inherent biases associated with utilising a single method of research (Denzin, 1989).

In this chapter the philosophical paradigms that guided the research project have been described. The present study adopted a mixed methods design; consequently, the quantitative and qualitative methodologies, and the methods used to collect the data have been discussed. In this chapter the benefits of the mixed methods approach and its ability to enhance the research design of the current study have also been discussed. The following sections will discuss how rigour was ensured.

Rigour

The quality of quantitative research is measured by its validity and reliability (Neuman, 2006). Validity, which can take on a number of forms, such as internal and external validity, or measurement validity, refers to the accuracy of a study in measuring the phenomena of interest (Noble & Smith, 2015). That is, a study that is valid would provide results that accurately reflect the reality that has been researched. Reliability indicates the extent to which the results are dependable or consistent (Twycross & Shields, 2004). Therefore, a research study that is reliable would be able to be replicated and it would yield almost identical results if the phenomena were investigated under the same circumstances as in the original study (Neuman, 2006). In qualitative research, the rigour of a project is assessed quite differently (Liamputtong & Ezzy, 2005).

The issue of rigour in qualitative research is dependent on the theoretical approach of the study, as one must define the relationship between the observed reality and the observer in order to determine how rigour will be assessed (Liamputtong & Ezzy, 2005). Despite these theoretical variations there are specific techniques that can be applied to qualitative research in order to ensure it is rigorous (Kitto, Chesters, & Grbich, 2008; Liamputtong & Ezzy, 2005). Theoretical rigour can be achieved by adopting research strategies that are consistent with the aims of the study. In the current research study, theoretical rigour was achieved by adopting a mixed methods approach as the aim of the study was to explore differences between groups as well as the meaning attributed by the participants to their experiences. Methodological rigour consists of documenting the process involved in order to reach the reported findings (Liamputtong & Ezzy, 2005). Methodological rigour was ensured through the use of an audit trail, a record of the steps taken from the beginning of the research process until the reporting of the data (Fassinger, 2005). Interpretative rigour relates to the validity of the interpretations and was ensured via the use of the audit trail as well as the use of direct quotes in the final project, and the conservation of the complete interviews (Liamputtong & Ezzy, 2005).

In mixed methods research, rigour takes on yet another form. In this type of research validation shifts depending on which paradigm is dominant within the study (Andrew & Halcomb, 2009). In a research project such as the current study, in which the qualitative and quantitative phases were complementary to each other, the issue of validation took on both a quantitative and qualitative approach. Rigour in the present study was ensured as described above. As previously noted, rigour must also occur within the context of the theoretical framework of the study. Within a social constructivism framework two key issues regarding validity must be noted. First, social

constructivists do not adhere to an absolute definition of reality with strict criteria applied to evaluate the truthfulness of a study, rather they assess validity through a community consensus of what is considered real, useful, and meaningful as applicable to that specific context (Lincoln & Guba, 2000). Second, in a social constructivist framework where the researcher is an interpreter of the participants' stories, self-reflexivity is a key technique needed to ensure the validity of the study (Andrew & Halcomb, 2009). Self-reflexivity involves the researcher being explicitly aware of how his or her prior assumptions and experiences can influence the data collection and analysis (Lincoln & Guba, 2000). The audit trail, with a record of the researcher's thoughts and impressions, is one form utilised to record self-reflexivity (Fassinger, 2005).

Summary

In this chapter the key aspects of the methodology of the study have been addressed. First, the philosophical framework adopted by the study has been reviewed. Second, the research design and how it related to the aims of the study and the data collection methods has been discussed. Third, the steps adopted in order to ensure the study was reliable and valid were discussed. Last, issues pertaining to rigour were outlined. In the following chapter the method, results and discussion of stage one are addressed.

Chapter 5

Stage One:

Psychological Adjustment, Family Functioning, and Psychological Resilience in Adolescents and Youths

Chapter Overview

In this chapter, the research methods and quantitative findings of the questionnaires administered to the participants are discussed. The participants, materials, and procedure of recruitment are also described. In addition, the chapter contains an explanation of the statistical analyses and results, and it concludes with a discussion of the findings.

Chapter 5

Stage One:

Psychological Adjustment, Family Functioning, and Psychological Resilience in Adolescents and Youths

The literature reviewed has provided contradictory data regarding the psychological adjustment of target siblings (Macks & Reeve, 2007; Pilowsky et al., 2004; Rodrigue et al., 1993; Yirmiya et al., 2001). On the one hand, some researchers have reported that target siblings tend to experience more internalising and externalising problems, such as depression and anxiety, when compared to community samples (N. Gold, 1993; Griffith et al., 2014; Hastings, 2003b; Rodrigue et al., 1993). In contrast, other researchers have reported that target siblings have a similar or better psychological adjustment when compared to community samples or to siblings of individuals who have other developmental disorders, such as ID (Hastings, 2007; Macks & Reeve, 2007). Therefore, despite researchers proposing that children with ASD can be a risk factor for poor wellbeing in target siblings, given the literature currently available, it cannot be clearly argued that target siblings are more likely to experience increased levels of psychological distress.

The risk and protective factor framework suggests that it is the interplay between risk and protective factors that precipitates positive or negative outcomes (Bogenschneider, 1996). There are some data that indicate that the psychological adjustment of target siblings can be influenced by factors regarding the target siblings (e.g., gender or age) and factors regarding their families (e.g., parenting practices; Di Biasi et al., 2016; N. Gold, 1993; Hesse et al., 2013). Despite the evidence described in chapter 3 that factors regarding the target siblings and their families can impact the

target siblings' psychological adjustment no data are available regarding the role family functioning and psychological resilience play. Consequently, stage one of the study had two aims: to compare the psychological adjustment, psychological resilience, and family functioning of target siblings to that of community siblings based on the reports of the siblings themselves and their mothers; and to explore how family functioning and psychological resilience influenced the psychological adjustment of target siblings after controlling for the age and gender of the target siblings, and the type of informant (i.e., siblings vs. mothers).

Method

Participants

A total of 97 siblings and 96 mothers (193 participants) completed the measures of stage one of the study. The siblings were aged between 12 and 24 years ($M = 16.90$ years, $SD = 3.26$). Of the siblings 31% were male. Siblings and mothers were grouped into one of two groups: the 'target group' or the 'community group'. A visual representation of stage one can be seen in Figure 5.1.

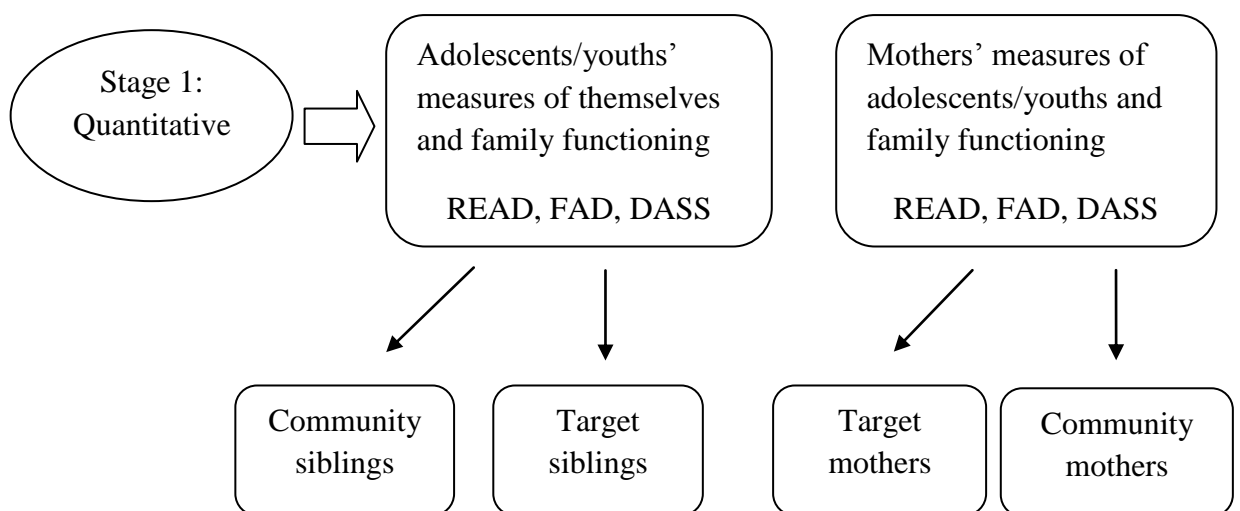


Figure 5.1. Visual representation of stage one.

Table 5.1

Demographic Characteristics of the Participants and their Families

	Target (N = 104)	Community (N = 68)	Statistic	<i>p</i>
'Participating sibling'				
<i>N</i>	52	34		
Age in years <i>M (SD)</i>	16.58 (3.10)	16.59 (3.32)	$t(84) = -.02$.99
Range	12- 23	12-24		
Sex			$\chi^2(1, N= 86) = 0.001$.97
Females	35 (67.31%)	23 (67.64%)		
Males	17 (32.70%)	11 (32.35%)		
'Other sibling'				
<i>N</i>	95	64		
Age in years <i>M (SD)</i>	13.41 (5.70)	18.26 (6.99)	$t(152) = -4.72$	<.001**
Range	2-29	5-40		
Sex			$\chi^2(1, N= 157) = 8.67$.003**
Females	29 (31%)	35 (55%)		
Males	64 (69%)	29 (45%)		

(continued)

LIVING WITH AUTISM

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	Target (N = 104)	Community (N = 68)	Statistic	<i>p</i>
'Family'			$\chi^2 (2, 86) = 1.28$.53
Single-parent	11 (21.15%)	4 (11.76%)		
Nuclear	35 (67.31%)	26 (76.47%)		
Blended	6 (11.54%)	4 (11.76%)		
Number of siblings	2.75 (0.79)	2.94 (1.13)	$t(84) = -0.93$.36
Number of siblings with ASD	1.19 (0.49)	n/a		
Additional diagnosis				
None	38 (73.08%)	29 (85.29%)		
ASD sibling	11 (21.15%)	n/a		
Other sibling	1 (1.92%)	2 (5.88%)		
Participant	1 (1.92%)	3 (8.82%)		
Two or more family members	1 (1.92%)	0 (0%)		

Note: * $p < .05$; ** $p < .01$.

Target group. In order to be included in this group, potential participants had to meet the following criteria: (1) be aged between 12 and 24 years; (2) not have been diagnosed with ASD or ID; (3) had at least one sibling, of any age, who had been formally diagnosed with ASD with or without ID, as ID is common amongst individuals with ASD (Mefford, Batshaw, & Hoffman, 2012); (4) had mothers or legal female guardians willing to participate in the study; and (5) reside in Australia. The mothers reported that the children with ASD had been officially diagnosed by a paediatrician, a clinical psychologist, or a multi-disciplinary team with autism, Asperger's syndrome, or PDD-NOS according to DSM-IV-TR (American Psychiatric Association, 2000) criteria. Initially, a total of 54 siblings and 57 mothers formed part of the ASD group. However, 2 siblings and 5 mothers (7 cases) were excluded from all analyses as their mothers and children, respectively, had not completed the questionnaires. Consequently, 52 siblings and their mothers (104 cases) formed part of the final target group. The mean age of these siblings was 16.58 years ($SD = 3.10$). Thirty-two percent were males. Thirty-one percent of target siblings had brothers or sisters with a dual diagnosis of ASD plus ID based on maternal reports. Sixty-seven percent of families were described by mothers as nuclear (i.e., consisting of biological mother and biological father), 21% were single-parent homes, and 11% were blended families.

Community group. In order to be included in this group, potential participants had to meet the following criteria: (1) be aged between 12 and 24 years; (2) not have been diagnosed with ASD or ID; (3) had at least one sibling of any age. None of the siblings in the family must have been formally diagnosed with ASD or ID; (4) had mothers or legal female guardians willing to participate in the study; and (5) reside in Australia. A total of 41 siblings and 40 mothers formed part of the community group. All analyses excluded seven siblings and six mothers (13 cases) as their mothers and

children, respectively, had not completed the questionnaires. Therefore, 34 siblings and their mothers (68 cases) formed the final community group. The mean age of these siblings was 16.59 years ($SD = 3.32$). Thirty-two percent were males. Seventy-six percent of families were described by the mothers as nuclear families (while 12% were single-parent homes, and 12% were blended families).

Participant characteristics. Of the 193 participants, 172 (86 siblings, and their mothers) were included in the preliminary and final analyses. Sixty percent of the participants formed part of the target group, while 40% of the participants formed part of the community group. The demographic characteristics of each group can be found in Table 5.1. The distribution of males to females was almost identical in the target and community groups. In the target group more ‘other siblings’, that is, the target siblings’ brothers or sisters, were males whereas in the community group the gender of the ‘other sibling’ was closer to a 50-50 split ($\phi = .24$, small effect ; J. Cohen, 1992). The greater number of male ‘other siblings’ in the ASD group is consistent with the higher prevalence of ASD in males (American Psychiatric Association, 2013). ‘Other siblings’ in the community group were also significantly older than in the target group ($d = .76$, large effect).

Materials

Three questionnaires - the READ, the DASS-21, and the FAD, and a demographic sheet - were utilised in stage one of the study. The demographic sheet (Appendix A) was completed by the mothers and focused on information about the participating sibling (target and community), including their age, gender, any diagnosed conditions, and significant life events. The demographic sheet also recorded information regarding the participating siblings’ brothers or sisters’ age, gender, diagnosed conditions, and in the case of the target group who diagnosed the children with the

disorder. Lastly, information regarding the family structure, and postcode were recorded in the demographic sheet. The three scales are described below.

Resilience Scale for Adolescents (READ). The READ is a scale that was developed to measure psychological resilience in adolescents (Hjemdal et al., 2006). The measure consists of 28 items on a 5-point Likert scale ranging from ‘totally agree’ (5) to ‘totally disagree’ (1). Items on the scale include: ‘I am good at organising my time’; ‘I easily find new friends’; and ‘I always have someone that can help me when I need it’ (see Appendices B and E for the full READ scale). The READ measures the following five factors: personal competence, social competence, structured style, social resources, and family cohesion (Hjemdal et al., 2006). The total READ score, a composite of the five factors, was used in the analyses. The ratings on each of the items were summed and divided by the number of relevant items to produce the total psychological resilience score (O. Hjemdal, personal communication with L. Cohen, March 21, 2006). Mean psychological resilience total scores have been reported as 4.02 for girls and 4.04 for boys with a potential range of 1 to 5, and higher scores indicative of higher levels of psychological resilience (Hjemdal et al., 2006). In the present study the scores of the siblings reflected their self-report on the construct of psychological resilience, while the scores of the mothers reflected their perception of their sons or daughters’ response on the psychological resilience scale.

Hjemdal et al. (2006) and von Soest, Mossige, Stefansen, and Hjemdal (2010) reported similar Cronbach’s alphas for the subscales and total score ranging from .69 to .94. In the current study the Cronbach’s alpha coefficient was .92. Convergent validity has been reported in a number of studies utilising community samples between the READ and a number of factors associated with psychological wellbeing, such as depressive symptoms, symptoms of anxiety, suicidal ideations, self-harm, as well as

measures of negative life events (Hjemdal et al., 2007; Hjemdal et al., 2006; von Soest et al., 2010). Validity and reliability studies have been conducted with adolescents from a number of countries suggesting the validity of the READ across numerous cultures (Y. Kelly, Fitzgerald, & Dooley, 2016). The READ has also been used to measure parents' understanding of their children's psychological resilience (Hjemdal et al., 2007).

Depression Anxiety Stress Scales-21 (DASS-21). The DASS is a self-report scale used to gauge psychological distress (Lovibond & Lovibond, 1995). The DASS-21 is the briefer version of the DASS, consisting of 21 statements similar or identical to the 42 items included in the full DASS. While the instrument was originally developed to measure three aspects of psychological distress in adults, namely depression, anxiety, and stress, researchers have also used the instrument with children and adolescents (Duffy, Cunningham, & Moore, 2005; Mellor et al., 2015; Szabó & Lovibond, 2006; Tearne et al., 2016; Willemsen, Markey, Declercq, & Vanheule, 2011). Debate exists regarding the applicability of adult models of psychological functioning on children and adolescents (Bottesi et al., 2015; Tully, Zajac, & Venning, 2009). However, there is evidence that the use of the DASS in children and adolescents is appropriate particularly when the total DASS score, a measure of psychological distress, is used rather than the subscale scores (Patrick, Dyck, & Bramston, 2010; Szabó, 2010).

In the current study siblings rated how much each statement applied to them on a 4-point Likert scale (0 = 'did not apply to me at all'; 3 = 'applied to me to me very much, or most of the time'). Mothers were asked to rate how much they thought each statement applied to their participating children. Statements in the DASS-21 included: 'I tended to over-react to situations'; 'I felt I was close to panic'; and 'I felt down-hearted and blue' (see Appendices C and F for full DASS-21 scale). The ratings on each item

were summed and multiplied by two to produce a total DASS score. The total DASS score, which was used in the analyses, could range from 0 to 126 with higher scores indicating more severe psychological distress (Lovibond & Lovibond, 1995). The internal consistency of the DASS-21 total DASS score has been reported as .93 (Henry & Crawford, 2005). In the current study the Cronbach's alpha coefficient was .94. The DASS-21 has been utilised in both community, and clinical samples diagnosed with depressive or anxiety disorders (Antony, Bieling, Cox, Enns, & Swinson, 1998; Clara, Cox, & Enns, 2001).

Family Assessment Device (FAD). The FAD is a self-report questionnaire intended to evaluate family functioning according to the McMaster Model of Family Functioning (Epstein et al., 1983). The FAD consists of 60 items that are rated on a 4-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The FAD includes statements such as 'in times of crisis we can turn to each other for support'; 'we make sure members meet their family responsibilities'; and 'we often don't say what we mean' (see Appendix D for the full FAD). The FAD consists of seven scales measuring the following areas of family functioning: problem solving; communication; roles; affective responsiveness; affective involvement; behavioural control; and general functioning (GFS), which assesses the overall health or pathology of the family unit (Epstein et al., 1983). All seven scales were utilised in the present research study. High scores indicate greater dysfunction in the family as perceived by the rater. Epstein et al. (1983) reported the clinical cut-off for each sub-scale as follows: problem solving, communication, and affective response 2.20; roles 2.30; affective involvement 2.10; behavioural control 1.90; general functioning 2.00. The FAD has acceptable levels of validity and reliability with internal consistency ranging from .72 to .92, and test-retest reliability ranging between .66 and .76 (Epstein et al., 1983). In the current study the

Cronbach's alpha coefficients ranged from .76 to .82. The Cronbach's alpha coefficient for the FAD – GFS was .91.

The FAD has been used in both clinical and community samples, including families of children with ASD (Barney & Max, 2005; Herring et al., 2006; Khanna et al., 2011; Miller, Bishop, Epstein, & Keitner, 1900; Mitchell et al., 2016; Staccini, Tomba, Grandi, & Keitner, 2015). Although the device comprises seven scales that measures various aspects of family functioning, the GFS has been used by researchers as a measure of overall family functioning as it has been found to have a high positive correlation with other measures of family functioning, such as the Family Environment Scale (Barney & Max, 2005; Berge, Wall, Larson, Loth, & Neumark-Sztainer, 2013). Family functioning has been assessed from children's perspective (aged 12 years and older) or from parents' perspective (Akister & Stevenson-Hinde, 1991; Berge et al., 2013; Staccini et al., 2015) with the use of the FAD.

Procedure

Before the commencement of the data collection approval to conduct the study was granted by the Human Ethics Committee of Edith Cowan University in Western Australia. Participants were firstly assessed against the study's inclusion criteria. In families with multiple siblings, siblings were selected for the study based on their expressed consent to participate. Participants were then given the option of completing hard or electronic copies of the questionnaires. Participants who wanted electronic copies were emailed the Qualtrics link; those who wanted hard copies were posted the questionnaires, consent form (Appendix G), and a copy of the information letters (Appendices H, I, J & K), with self-addressed, replied paid envelopes so they could return the completed questionnaires. Participants who had expressed an interest in participating but had not completed the online questionnaires or returned the hard copies

within two to four weeks were sent periodical reminder emails unless they stated they wished to withdraw from the study or requested further reminders. Questionnaires were scored on a weekly basis, and scores and demographic information were collated on Excel spreadsheets, and then entered into IBM SPSS v. 22.

To ensure confidentiality of the participants and their families, all identifiable electronic data were stored under double password protection in the researcher's computer. In addition, identifiable documents were de-identified shortly after receiving them. Identifiable documents, such as consent forms, were kept in a secure location in the researcher's office. A portion of families were recruited through service providers therefore it was important that both the mothers and the target siblings were made aware that their participation, or lack thereof, would not affect their current or future service provision. This was explained in the information letters and participants were informed again when they contacted the researcher. Research involving children and adolescents must be careful to ensure participants are able to provide informed consent while also acknowledging the parental legal care. This was addressed in two manners. First, information letters were tailored to the level of comprehension of adolescents. Second, only the data of adolescents whose mothers had consented to the study were included in the analysis. In addition, participants were informed that they were able to withdraw from the study at any point in time. Participants who scored with extreme scores were provided with the contact details of a number of support services (Appendix L).

Target group. Target participants were recruited from a number of associations and groups that provide support to families of children diagnosed with ASD across Australia. The associations and groups were contacted and requested to advertise the research study amongst their members. The associations and groups that advertised the study were located in Western Australia, Victoria, and Queensland. In addition, a

number of schools with special education units in Western Australia were also contacted (Appendix M), with three of these schools providing the families of their students with the study's advertising materials. The procedure for advertising the study differed from organisation to organisation but generally a call for participants was placed on the organisation's official website or the members of participant databases were emailed the call for participants (Appendices N & O). Potential participants then contacted the primary researcher via email or telephone expressing their interest in participating in the study; they were assessed against the study's inclusion and exclusion criteria and then provided with the questionnaires. Fourteen out of 52 target participant-mother dyads completed hard copies of the questionnaires.

In addition, a number of participants were recruited from the Western Australian Autism Biological Registry. The primary researcher contacted the individual in charge of the registry who then identified potential participants based on the study's selection criteria. These potential participants were contacted by the individual in charge of the registry, and if they expressed interest in the study their contact details were provided to the primary researcher. These participants were offered to complete the questionnaires as described above.

Community group. Several recruitment procedures were utilised to recruit the community group. First, a number of high schools in Western Australia were contacted to request their assistance in the recruitment process, with three of these accepting to advertise the study amongst their students (Appendix M). Second, a call for participants was placed in the student portal of Edith Cowan University and in the university's online newsletter (Appendix P). Third, flyers were placed at various locations in the Edith Cowan University, Joondalup campus (Appendix Q). Last, snowballing was also utilised to recruit participants. The researcher distributed a flyer (Appendix Q) amongst

her personal contacts across Australia who then forwarded it to their contacts, and participants were asked to forward the study's details to their contacts. Identically to the target group, potential participants contacted the primary researcher via email or telephone and she then assessed their suitability for the study against the inclusion and exclusion criteria. Those who met the study's inclusion criteria were then provided with the questionnaires. All participants in the community group, with the exception of two participant-mother dyads, completed the questionnaires online.

Analyses

There is some evidence to suggest that the degree of impairment in the children diagnosed with ASD can impact on the adjustment of their family members, including the target siblings (Benson, 2006; Benson & Karlof, 2008; Dunn et al., 2001; Hastings, 2007). Therefore, preliminary analyses aimed to identify if differences were evident between target siblings whose brothers or sisters had a dual diagnosis of ASD plus ID and target siblings whose brothers or sisters had a single diagnosis of ASD. In addition, there is evidence that reports of child and adolescent psychological wellbeing vary based on the type of informant (e.g., mothers vs. fathers; parents vs. teachers; Dempsey et al., 2012; Griffith et al., 2014). Consequently, preliminary analyses sought to determine if differences were evident between the reports of mothers and siblings. The preliminary analyses also involved a series of t-tests and chi-squares to examine differences in the demographic variables of the participants and their families. Correlations between the responses of the target siblings and the target mothers, as well as the response of the community siblings and the community mothers on the READ total, DASS total, and FAD - GFS were also examined.

Two main data analyses were utilised to analyse the data in stage one. First, a series of Multivariate Analysis of Variance (MANOVA) were utilised to answer research questions 1 and 2. A one-way MANOVA was utilised to identify group differences between target siblings and community siblings on the scores of total psychological resilience (READ total), family functioning (FAD – GFS), and total psychological distress (DASS total; research question 1). As the FAD assesses numerous aspects of family functioning, a second one-way MANOVA was utilised to identify group differences between target siblings and community siblings on the scales of the FAD, except for the FAD –GFS (research question 1). A one-way MANOVA was also utilised to identify group differences between target mothers and community mothers on the scores of total psychological resilience, total psychological distress, and family functioning (FAD - GFS; research question 2). A second one-way MANOVA was utilised to identify group differences between target siblings and community siblings on the scales of the FAD, except for the FAD –GFS (research question 2). To control for false positives due to the multiple analyses conducted (Type I error) the alpha level for the MANOVAs was set at .01. Effect sizes were described based on the criteria stipulated by J. Cohen (1992). The identification of cut-offs for the FAD followed the guidelines described by Epstein et al. (1983), which are described in the materials section above, and identified the threshold of unhealthy functioning for each scale (Akister & Stevenson-Hinde, 1991; Mansfield, Keitner, & Dealy, 2015).

Second, hierarchical multiple regression was utilised to assess the unique effect of psychological resilience (READ total) and family functioning (FAD - GFS) in predicting the psychological distress (DASS total) of the target siblings (research question 3). The demographic variables of age and gender of the target siblings were entered as control variables in step one of the analysis. Researchers have identified

gender as a factor that can impact on the psychological adjustment of target siblings; however, the results are inconsistent (Hastings, 2003b; Orsmond & Seltzer, 2009; Rodrigue et al., 1993). On the one hand, some researchers have reported that males are at greater risk of poor psychological adjustment than females (Macks & Reeve, 2007; Walton & Ingersoll, 2015). However, other researchers have reported that females are at greater risk of poor psychological adjustment than males (Di Biasi et al., 2016; Orsmond & Seltzer, 2009). Still other researchers, have reported no differences in the psychological adjustment between male and female target siblings (Kaminsky & Dewey, 2002; Rodrigue et al., 1993). Similarly, inconsistent results are available regarding whether older target siblings are at greater risk of psychological distress than younger target siblings (Giallo et al., 2012; N. Gold, 1993; Rodrigue et al., 1993).

In step two of the analysis, the type of informants (target siblings vs. target mothers) was entered as a third control variable as researchers have indicated that there can be a low level of agreement between the reports of multiple informants (T. M. Achenbach et al., 1987; Coldwell, Pike, & Dunn, 2008; Lawrence et al., 2015). Step three of the analysis included the psychological resilience of the target siblings (READ total) and the measure of family functioning (FAD –GFS). The alpha level was set at .05 for the regression analysis.

Results

Preliminary Analyses

No missing data were identified on the three measures as participants who completed questionnaires online were prompted to fill in all items before progressing to the next section of the survey, and those participants who completed hard copies of the questionnaires did not leave any items blank. Some demographic data were missing for

two target and three community participants. Two participants (one target sibling and one target mother) were identified as univariate outliers because they obtained z scores greater than 3.29 on at least one measure (Tabachnick & Fidell, 2014). The target sibling was identified as an outlier on the DASS total scale and the FAD - GFS, while the mother was identified as an outlier on the DASS total scale. However, as the pattern of significant results did not vary when the analyses were conducted with and without the outliers, the participants initially identified as outliers were retained for subsequent analyses (Renjan, McEvoy, Handley, & Fursland, 2016).

No significant differences were evident between the target siblings whose brothers or sisters had a dual diagnosis of ASD plus ID and target siblings whose brothers or sisters had a single diagnosis of ASD on the READ total, DASS total, FAD – GFS $F(3, 100) = .11, p = .95$; Pillai's Trace = .003; partial $\eta^2 = .003$ or the FAD remaining scales $F(8, 95) = .32, p = .32$; Pillai's Trace = .03; partial $\eta^2 = .03$. As a result, subsequent analyses did not differentiate between the two subgroups of target participants. The means and standard deviations of the scores included in the final analyses can be seen in Table 5.2.

No significant differences were detected between siblings (target and community) and their mothers, independent of the diagnosis of their siblings/children, on the total scores of psychological resilience, psychological distress, and family functioning (FAD - GFS) $F(3, 166) = 2.55, p = .06$; Pillai's Trace = .044; partial $\eta^2 = .044$. Results of t-test analyses for psychological resilience, psychological distress, and family functioning (FAD – GFS) between siblings and their mothers can be found in Appendix W. Pearson's r correlations on the READ total, DASS total, and READ GFS of target siblings and their mothers ranged from medium to large while for community siblings and their mothers ranged from small to large as can be seen in Table 5.3.

Research Question 1: Group Differences Between Target Siblings' and Community Siblings' Reports

Analysis of the READ total, DASS total, and FAD – GFS identified a statistically significant difference between target siblings and community siblings on the combined dependent variables, $F(3, 82) = 4.23, p = .008$; Pillai's Trace = .13; partial $\eta^2 = .13$. When the results for the three dependent variables were considered separately, only differences between target siblings and community siblings for psychological resilience reached statistical significance $F(1, 84) = 12.65, p = .001$, partial $\eta^2 = .13, d = .80$ (large effect). Differences between target siblings and community siblings did not reach statistical significance for psychological distress $F(1, 84) = 1.52, p = .22$, partial $\eta^2 = .02, d = .28$ (small effect); and family functioning $F(1, 84) = 1.72, p = .19$ partial $\eta^2 = .02, d = .30$ (small effect). As it can be seen in Table 5.2, target siblings reported lower levels of psychological resilience, higher levels of psychological distress, and greater levels of family dysfunction than community siblings. Family dysfunction, as measured by the FAD –GFS, reached the clinical cut-off based on the reports of the target siblings but not those of community siblings.

Analysis of the remaining scales of the FAD (excluding FAD – GFS) indicated no statically significant differences between target siblings and community siblings on the combined dependent variables, $F(6, 79) = 1.98, p = .08$, Pillai's Trace = .13 partial $\eta^2 = .13$. The descriptive statistics of the remaining scales of the FAD can be seen in Table 5.2. Target siblings' reports of family functioning reached clinical significance on all scales except behavioural control. The reports of family functioning of the community siblings did not reach clinical significance on any of the scales.

Research Question 2: Group Differences Between Target Mothers' and Community Mothers' Reports

Analysis of the READ total, DASS total, and FAD – GFS identified a statistically significant difference between the reports of target mothers and community mothers on the combined dependent variables, $F(3, 82) = 3.91, p = .01$; Pillai's Trace = .13; partial $\eta^2 = .13$. When the results for the three dependent variables were considered separately only differences between the reports of the target mothers and the community mothers for psychological resilience $F(1, 84) = 8.17, p = .005$, partial $\eta^2 = .09, d = .62$ (medium effect); and psychological distress reached statistical significance $F(1, 84) = 6.68, p = .01$, partial $\eta^2 = .07, d = .58$ (medium effect). While differences between the reports of the target mothers and the community mothers for family functioning did not reach statistical significance $F(1, 84) = 3.48, p = .07$ partial $\eta^2 = .04, d = .4$ (small effect). As it can be seen in Table 5.2, target mothers reported lower levels of psychological resilience in the target siblings than the levels of psychological resilience reported by community mothers in the community siblings. However, target mothers reported greater psychological distress in the target participants than the psychological distress reported by community mothers in the community siblings. The target mothers reported a greater level of family dysfunction than community mothers.

Analysis of the remaining scales of the FAD (excluding FAD – GFS) did not indicate a statistically significant difference between the reports of target mothers and community mothers on the combined dependent variables $F(6, 79) = 2.65, p > .01$ Pillai's Trace = .17 partial $\eta^2 = .17$. The descriptive statistics of the remaining scales of the FAD can be seen in Table 5.2. Target mothers' reports of family functioning reached clinical significance on two scales, namely roles and affective involvement. The reports of family functioning of community mothers failed to reach clinical significance on any scale.

Research Question 3: Predictors of Target Siblings' Psychological Distress

No multivariate outliers were identified using the cut-off point of 15 suggested by Barnett and Lewis (1978) for Mahalanobis' distance. Correlations between the predictor variables (age, gender, informant, and READ total) and the outcome variable (DASS total) were negative, and using the criteria detailed by J. Cohen (1992) they ranged from very small (age) to moderate (READ total) with the exemption of FAD - GFS which had a positive moderate correlation to the DASS total. See Table 5.4 for a summary the correlations. The assumption of collinearity was met indicating that multicollinearity was not a concern (age, tolerance = .86, VIF = 1.12; gender, tolerance = .89, VIF = 1.1; informant, tolerance = .97, VIF = 1.03; READ total, tolerance = .79, VIF = 1.27; FAD - GFS, tolerance = .79, VIF = 1.26).

The results of the hierarchical regression analysis appear in Table 5.5. At step 1 of the analysis, the demographic variables explained 1% of the variance in psychological distress of target siblings $\Delta F(2, 101) = .45, p = .64, f^2 = .01$ (no effect). The relationship of both age ($p = .85$) and gender ($p = .35$) to the target siblings' psychological distress was not significant. The addition of type of informant (i.e., target siblings or target mothers) into the model at step 2 led to the model accounting for 0.2% of the variance in the psychological distress of the target siblings $\Delta R^2 = .00, \Delta F(1, 100) = 0.20, p = .66, f^2 = .01$ (no effect). The addition of psychological resilience (READ total) and family functioning (FAD - GFS) led to the model accounting for 36% of the variance in the target siblings' psychological distress $F(5, 98) = 11.03, p < .001$. In the final step of the model psychological resilience and family functioning explained 35% of the variance in the psychological distress of the target siblings, $\Delta R^2 = .35, \Delta F(2, 98) = 26.74, p < .001, f^2 = .35$ (large effect).

Table 5.2

Mean and Standard Deviations for READ Total, DASS Total and FAD Scales

Scale	<i>M (SD)</i>			
	Siblings		Mothers	
	Target (<i>n</i> = 52)	Community (<i>n</i> = 34)	Target (<i>n</i> = 52)	Community (<i>n</i> = 34)
READ total	3.63 (.50)	3.98 (.35)	3.68 (.56)	4.00 (.44)
DASS total	30.81 (25.73)	24.24 (21.51)	29.27 (21.01)	18.53 (14.86)
FAD – GFS	2.09 (.52)	1.95 (.38)	1.92 (.50)	1.74 (.33)
FAD – problem solving	2.23 (.40)	2.07 (.37)	2.05 (.41)	1.92 (.40)
FAD – communication	2.39 (.38)	2.17 (.41)	2.18 (.46)	2.03 (.39)
FAD – roles	2.33 (.35)	2.18 (.34)	2.30 (.34)	2.04 (.38)
FAD – affective response	2.36 (.55)	2.11 (.52)	2.01 (.54)	1.80 (.39)
FAD – affective involvement	2.23 (.50)	2.26 (.32)	2.14 (.48)	1.96 (.43)
FAD – behaviour control	1.89 (.39)	1.88 (.36)	1.78 (.38)	1.82 (.33)

Table 5.3

Correlation (r) of Informants' Reports (Siblings vs. Mothers) by Group for READ Total, DASS Total and FAD - GFS

	Target						Community					
	1	2	3	4	5	6	1	2	3	4	5	6
1 Siblings READ total	1						1					
2 Siblings DASS total	-.55**	1					-.10	.1				
3 Siblings FAD – GFS	-.59**	.70**	1				-.28	.45**	1			
4. Mothers READ total	.58**	-.19	-.25	1			.37*	-.19	-.54**	1		
5 Mothers DASS total	-.41**	.51**	.31*	-.40**	1		.06	.53**	.31	.01	1	
6 Mothers FAD – GFS	-.11	.26	.37**	-.29*	.41**	1	-.19	.18	.37*	-.14	.06	1

Note: * $p < .05$; ** $p < .01$.

Table 5.4

Summary of Correlations (r) of Variables of Regression Analysis (N = 104)

	1	2	3	4	5	6
1 DASS total	1					
2 Age	-.01	1				
3 Gender ^a	-.10	.33**	1			
4 Informant ^b	-.05	.00	.00	1		
5 READ total	-.53**	.21**	.09	.04	1	
6 FAD – GFS	.46**	-.11	-.02	-.16*	-.43**	1
<i>M</i>	31.46	16.58	.67	.5	3.66	2.03
<i>SD</i>	23.43	3.09	.47	.5	0.53	0.51

Note: * $p < .05$; ** $p < .01$.

^a 0 = male, 1 = female; ^b 0 = sibling, 1 = mother.

In the final step of the model, age, gender, and type of informant did not reach statistical significance while psychological resilience and family functioning were statistically significant. Psychological resilience was the largest predictor of psychological distress ($p < .001$), followed by family functioning ($p = .002$). These findings indicate that, while controlling for the effects of age, gender, and type of informant, greater levels of psychological resilience were associated with lower levels of psychological distress in the target siblings; and greater levels of family dysfunction were associated with greater levels of psychological distress in the target siblings.

Table 5.5

Summary of Hierarchical Regression Analysis for Variables Predicting Psychological Distress in Target Siblings (N = 104)

Variable	Step 1				Step 2				Step 3			
	<i>B</i>	<i>SE</i>	β	95% CI for <i>B</i>	<i>B</i>	<i>SE</i>	β	95% CI for <i>B</i>	<i>B</i>	<i>SE</i>	β	95% CI for <i>B</i>
Age	0.16	0.79	.02	-1.43, 1.74	0.16	0.80	.02	-1.43, 1.73	1.02	.66	.14	-.30, 2.34
Gender	-4.90	5.22	-.10	-15.24, 5.46	-5.00	5.24	-.10	-15.23, 5.50	-4.56	4.26	-.09	-13.01, 3.90
Informant					-2.10	4.64	-.05	-11.28, 7.13	.97	3.82	.02	-6.62, 8.55
READ total									-18.66	4.06	-.42**	-26.72, -10.60
FAD – GFS									13.30	4.13	.29**	5.10, 21.50
R^2				.01				.01				.36
ΔF in R^2				.45				.20				26.74**
ΔR^2								.002				.35

Note: * $p < .05$; ** $p < .01$

Discussion

Stage one of the study had two main aims. First, stage one sought to examine if target siblings reported greater psychological distress and greater family dysfunction than community participants, while exploring differences in the levels of psychological resilience between target participants and community participants. Second, stage one also sought to identify whether lower psychological resilience and greater family dysfunction would be associated with lower levels of psychological distress in the target siblings.

Target siblings reported lower levels of psychological resilience than community siblings (research question 1). Psychological resilience has not been measured in target siblings and therefore the results cannot be compared to prior studies. A small number of studies comparing psychological resilience in at-risk groups of children and adolescents to psychological resilience in community samples have not indicated differences between the two groups (Askeland et al., 2015; Moreira et al., 2015). However, the pattern of results is consistent with the psychological resilience literature in that a negative relationship has been consistently identified between psychological resilience and psychological distress (Cole et al., 2015; Flett & Hewitt, 2014; Hjemdal et al., 2007; Hjemdal et al., 2010; Masten, 2014; Sagone & De Caroli, 2014; Tol, Song, & Jordans, 2013). Psychological resilience has been identified as a protective factor against a range of stressors (Ungar, 2009, 2005). The target siblings' lower levels of psychological resilience suggest that they may be at greater risk of succumbing to the stressors they face.

A significant difference was detected when the mothers' reports regarding their perception of the siblings' psychological resilience were examined (research question

2). Target mothers reported lower levels of psychological resilience in the target siblings than community mothers. As previously stated, psychological resilience in target siblings has not been measured and thus the current results cannot be compared to published data. As seen in the target siblings' results, there was a negative relationship between psychological resilience and psychological distress. The direction of the relationship is consistent with prior research regarding psychological resilience and psychological distress (Flett & Hewitt, 2014; Hjemdal et al., 2007; Hjemdal et al., 2010). As previously stated, the lower levels of psychological resilience in target siblings, as perceived by their mothers, indicate that it is possible the target siblings may be at greater risk of experiencing psychological distress than community siblings.

Contrary to what was expected (hypothesis 1a) no difference regarding the level of psychological distress was observed between target siblings and community sibling as reported by the siblings themselves. These results are consistent with some of the available literature while contrary to another portion of the research literature. A portion of the literature indicates that target siblings experience better or comparable psychological functioning when contrasted to siblings of typically developing individuals (Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Yirmiya et al., 2001). Consequently, the results of the current study support the notion that having brothers or sisters with ASD does not always translate into increased psychological distress for the target siblings. Researchers have suggested that other factors relating to the target siblings (e.g., their gender or age) and to their families (e.g., the severity of their brothers or sisters' impairment) can influence the level of distress experienced by the target siblings (Benson & Karlof, 2008; N. Gold, 1993; Walton & Ingersoll, 2015). Therefore, target siblings that are not exposed to other risk factors can be expected to experience similar psychological distress to community siblings as proposed by the risk

and protective factor framework (Frankford, 2007; Vakalahi, 2001). It is possible that target siblings in the current study were exposed to fewer risk factors or more protective factors than target siblings included in other published investigations, and as a consequence of this they did not express greater psychological distress compared to the community siblings.

As predicted (hypothesis 2a) mothers perceived the target siblings were experiencing greater levels of psychological distress than community siblings. This finding is consistent with a number of studies where mothers have reported that target siblings tend to experience poorer psychological adjustment than children in community samples (Griffith et al., 2014; Petalas, Hastings, Nash, Lloyd, et al., 2009; Verte et al., 2003). A small number of studies have reported that target siblings' themselves indicate they experience greater psychological distress than community samples (Giallo et al., 2012; N. Gold, 1993). The results of the current study support the notion that having brothers or sisters with ASD can cause psychological distress to target siblings, based on their mothers' perspective (N. Gold, 1993; Hastings, 2003b; Ross & Cuskelly, 2006). Researchers have proposed that the unique demands associated with living with children diagnosed with ASD increases the likelihood of target siblings experiencing psychological distress when compared to other sibling groups (Shivers et al., 2013). Some researchers have also proposed that target siblings can be at risk of increased psychological distress due to genetic vulnerability or BAP (Dempsey et al., 2012; Orsmond & Seltzer, 2009). However, the current results contradict a portion of the literature that indicates target siblings do not experience greater psychological distress than other sibling groups (Dempsey et al., 2012; Kaminsky & Dewey, 2002). As stated above, the risk and protective factor theory suggests that the psychological distress of

target siblings is the result of the interplay of multiple risk and protective factors (Bogenschneider, 1996)

Together the contradictory results of the target siblings and the mothers regarding the target siblings' psychological distress are reflective of the literature currently available. Researchers investigating the psychological outcomes of target siblings frequently report contradictory results across studies (Hastings, 2003b; Kaminsky & Dewey, 2002; Ross & Cuskelly, 2006; Walton & Ingersoll, 2015). Therefore, based on the published data it cannot be said with certainty whether target siblings are at increased risk of poorer psychological adjustment. The risk and protective factor framework proposes that having brothers or sisters with ASD can lead to psychological distress in target siblings when other risk factors are present or when protective factors are absent (Frankford, 2007; Vakalahi, 2001). However, the discrepancy in the results between the reports of the siblings and their mothers suggest that perception bias influences the data (Hastings, 2007). Researchers have argued that the inherent biases of informants influence their perception (T M Achenbach, 2006; T. M. Achenbach et al., 1987). This suggests that the perspective of each informant is likely to influence the results gathered and strengthens the argument to use multiple informants whenever possible.

Contrary to what was predicted, target siblings did not report greater family dysfunction than community siblings (hypothesis 1b). Target siblings did not report differences in family functioning when compared to community siblings on the FAD – GFS. Analysis of the remaining scales of the FAD, as rated by the target siblings and community siblings, indicated no significant differences; however, target siblings reported family dysfunction that reached the clinical cut-off in all but one scale of the FAD. In past studies family functioning has been examined from the parents'

perspective and therefore no data are available regarding the target siblings' perception of family functioning. However, when compared to other families, parents of children with ASD tend to report more family dysfunction (Benson & Karlof, 2008; Gray & Holden, 1992; Kaminsky & Dewey, 2002; Lutz et al., 2012; Meirsschaut et al., 2010). The discrepancy between the current results and the published data suggests the significance of perception bias (Hastings, 2007; Ohannessian, Lerner, Lerner, & von Eye, 2000). That is, assessing family functioning is likely to be influenced by the perspective and role of each informant (Hastings & Brown, 2002; McStay et al., 2014; Niemi, 1974; Warfield, 2001). The current results do indicate that the dysfunction reported by target siblings is of clinical significance, even if no group differences are apparent. Target siblings reported clinically significant dysfunction on the FAD scales of problem solving, communication, roles, affective response, and affective involvement. On the other hand, the reports of community siblings did not reach the clinical cut-off point. However, given the lack of statistical differences between the groups it is likely that the families of the community siblings were functioning at a level that is close to the clinical cut-off threshold rather than the families of the target siblings displaying low levels of dysfunction.

Contrary to what was predicted, target mothers did not report greater family dysfunction than community mothers as measured by the FAD – GFS and the remaining scales of the FAD (hypothesis 2b). As previously stated, parents of children diagnosed with ASD have generally reported greater family dysfunction when compared to other families (Benson & Karlof, 2008; Gray & Holden, 1992; Kaminsky & Dewey, 2002; Lutz et al., 2012; Meirsschaut et al., 2010). The results of the present study indicate that the functioning of families with children diagnosed with ASD can be comparable to that of community families, despite the unique stressors the former families often face.

Target mothers reported clinically significant levels of family dysfunction on the scales of roles and affective involvement. The reports of community mothers, on the other hand, did not reach clinical significance, thus indicating that clinically relevant discrepancies between the two groups of families are evident even in the absence of statistically significant differences.

As predicted, family functioning and psychological resilience, as reported by target participants, accounted for a significant portion of the variance of the target siblings' psychological distress after controlling for type of informant (target siblings vs. mothers), and the target siblings' age and gender (hypothesis 3a). As predicted, the greater the psychological resilience levels the lower the psychological distress (hypothesis 3b). The results of the current study are consistent with prior researcher in that psychological resilience is considered an important protective factor that can mitigate the negative impact on psychological adjustment associated with exposure to a wide range of risks (Masten, 2001, 2014; Ungar, 2004, 2005). Moreover, there is evidence that individuals who report greater levels of psychological resilience also report lower levels of psychological distress (Hjemdal et al., 2007; Hjemdal et al., 2010; Moreira et al., 2015).

As predicted, family functioning also accounted for a significant portion of the variance in the psychological distress of target siblings (hypothesis 3c). Higher levels of family dysfunction were associated with increased levels of psychological distress in the target siblings. As previously discussed, a positive relationship between family functioning and the psychological adjustment of family members has been identified (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Cowen, 2000). The present findings indicate that in the experiences of the target siblings, family dysfunction can have an important negative impact on their psychological adjustment. As indicated by the risk

and protective factor framework, psychological distress is the result of a combination of factors (Bogenschneider, 1996; Coleman & Hagell, 2007). Therefore, having brothers or sisters with ASD can be a risk to the target siblings' psychological adjustment; however, the current findings indicate family dysfunction can also impact on their psychological distress. It is possible that having brothers or sisters with ASD is a risk process that may precipitate a number of risk factors that impact on the psychological adjustment of the target siblings. In other words, the risk to the target siblings is not in having brothers or sisters with ASD per se but rather the risk is associated with other risk factors this can trigger, such as family dysfunction (Rutter, 2000; Rutter & Sroufe, 2000).

Models of adaptation and coping indicate that the relationship between risk and outcome is complex. The Double ABCX model proposes that psychological distress is the result of numerous factors, including the presence of additional stressors or risks, the resources available to meet the crisis, and the coping strategies employed (McCubbin & Patterson, 1983). Consequently, according to the Double ABCX having brothers or sisters with ASD in and of itself does not translate into psychological distress for the target siblings. Rather, the target siblings' psychological distress is dependent on additional factors.

The present study has provided evidence that psychological resilience and family functioning can impact on the psychological distress of the target siblings, while the demographic variables of age, gender and informant type do not. Mixed findings are evident regarding the role of age and gender on the psychological adjustment of target siblings (M. Gold & McCabe, 2012; N. Gold, 1993; Rodrigue et al., 1993; Walton & Ingersoll, 2015). However, the present findings indicate that neither factor impacted on the target siblings' psychological adjustment. Consequently, further research is

necessary to identify the role demographic factors play in the experiences of target siblings. It is acknowledged that other demographic variables (e.g., birth order, socio-economic status) were not analysed and could have provided further insight regarding the target siblings' experiences.

The current findings are difficult to compare to the published literature since no data are available regarding the role of psychological resilience and family functioning on the psychological adjustment of target siblings. While there is evidence supporting the link between psychological resilience and psychological distress in adolescents and youths, no data exist specifically relating to target siblings (Hjemdal et al., 2007; Hjemdal et al., 2006; Hjemdal et al., 2010; Rutter, 2000). Few researchers have reported contradictory data describing the link between family functioning and the target siblings' psychological adjustment. On the one hand, Benson and Karlof (2008) reported no link between family functioning and the target siblings' psychological adjustment while Mohammadi and Zarafshan (2014) reported a link between these two factors. Therefore, it is not possible to draw conclusions from such limited data and more research should be conducted in order to investigate whether family functioning and psychological resilience are consistently identified as significant predictors of the target siblings' wellbeing.

The current findings indicate that the psychological adjustment of target siblings is dependent on a number of factors. From a theoretical perspective, the risk and protective factor framework proposes that having a brother or sister diagnosed with ASD is a risk that does not necessarily lead to psychological distress in and of itself (Bogenschneider, 1996). That is, it is possible that the combination and interplay of risk and protective factors and processes, personal, familial and/or environmental, could lead to negative or positive outcomes in the typically developing siblings (Coleman &

Hagell, 2007; Rutter & Sroufe, 2000). In other words, target siblings may experience poor psychological adjustment when there are other risk factors or risk processes present because the cumulative effect of all the risk factors increases their vulnerability to poor outcomes. On the other, target siblings may experience better or no different outcomes when there are a lesser number of risk factors or when there are protective factors at play that enhance the target siblings' ability to resist the negative outcomes. Many studies published in this area do not analyse potential protective and/or risk factors such as psychological resilience or family functioning in either the target group or the comparison groups. Therefore, the risk and protective factor framework can provide a theoretical framework that can help contextualise and guide further research.

Summary

The aims of stage one of the study were to: determine if differences could be detected between the target and community groups on measures of psychological resilience and psychological wellbeing in the siblings, and family functioning as perceived by multiple informants (i.e., siblings and mothers); and to explore the role of psychological resilience and family functioning as predictors of psychological distress in the target siblings. No differences were detected between the reports of target siblings and community siblings on the measures of psychological distress, and family functioning. Target siblings reported lower levels of psychological resilience than community participants. Mothers reported greater levels of psychological distress and lower levels of psychological resilience in target siblings than in community siblings. No differences were detected in family functioning as perceived by target mothers and community mothers. Psychological resilience and family functioning were identified as significant predictors of the target siblings' psychological distress. Despite some limitations, which will be discussed in the general discussion, the results provide further

evidence regarding the complex experiences of adolescents and youths whose siblings have been diagnosed with ASD, and the role that risk and protective factors can play their experiences. In the following chapter the method of stage two of the research study is discussed.

Chapter 6

Stage Two:

Exploring the Lived Experiences of Adolescents and Youths - Method

Chapter Overview

In this chapter, the method employed in stage two of the research project is described. The aims and research questions for the qualitative stage are stated.

Following these, the participants, materials, procedure, and analysis are described.

Chapter 6

Stage Two:

Exploring the Lived Experiences of Adolescents and Youths - Method

Stage two of the present research study sought to address a number of issues evident in the current literature. Quantitative research studies investigating the experiences of target siblings outnumber qualitative studies despite the richness of the data that can be gathered utilising the latter methodology (Moyson & Roeyers, 2012). In particular, qualitative data allow researchers to explore the perspective of the actors as well as to report the results within their original context (Yilmaz, 2013). Consequently, in the present study the qualitative research design allowed for the target siblings' psychological adjustment to be interpreted within the narratives of the informants. These factors, namely, the lack of qualitative research, and the inherent strengths of qualitative research in exploring the lived experiences of the participants influenced stage two of the research study.

As evident by the quantitative literature reviewed in chapter 3 target siblings are reported as either experiencing poorer, similar, or better psychological outcomes than siblings with typically developing brothers or sisters (Dempsey et al., 2012; Giallo et al., 2012; N. Gold, 1993; Griffith et al., 2014; Hastings, 2003b; Macks & Reeve, 2007; Rodrigue et al., 1993; Ross & Cuskelly, 2006). The results of stage one of the current study, as reported in chapter 5, indicated that target siblings can be at risk of greater psychological distress as perceived by their mothers. Moreover, the results of stage one also suggested that target siblings can be at risk of lower levels of psychological resilience as perceived by the target siblings and their mothers. The qualitative literature available allows researchers to gain further insights into the data available as the

qualitative results highlight the complex nature of the target siblings' experiences and the factors that can impact their experiences (Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). In these findings, some target siblings have reported social difficulties and feelings of anxiety and stress (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Dowey, et al., 2009). On the other hand, target siblings have also reported increased empathy, compassion, maturity, and shared enjoyment with their brothers and sisters who have been diagnosed with ASD (Mascha & Boucher, 2006; Taunt & Hastings, 2002).

The nature of qualitative research lends itself to highlight the complex and multi-faceted experiences of the target siblings in a manner that is not always as clearly captured in quantitative research (Morse, 1995). Moreover, when utilised within a mixed methods design qualitative data have the ability to offer an even more detailed understanding of the target siblings and the factors that impact on their experiences, thus providing a context for the quantitative results (Creswell & Plano Clark, 2011). In addition, exploring the experiences of the target siblings from multiple perspectives, namely the target siblings themselves as well as their mothers, increases the depth and breadth of the narratives (Kendall, Marrs-Garcia, Nath, & Sheldrick, 1999). Despite the benefits of qualitative research in capturing complex experiences, the literature reviewed indicated that there are a limited number of qualitative research studies regarding the experiences of target siblings, particularly during adolescence and early adulthood. Moreover, there are no mixed methods data (quantitative and qualitative) on the same sample of target siblings. Consequently, stage two sought to investigate the experiences of target siblings who had participated in stage one via in-depth interviews.

Aims and Research Questions

The aim of stage two of the study was to examine the experiences of the target siblings from a phenomenological perspective using multiple informants. Previous qualitative research on the experiences of target siblings has generally only been based on a single informant (e.g., Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, et al., 2009). The present study sought to explore the experiences of target siblings and the factors that shaped these experiences from their own perspective, as well as to explore how their mothers interpreted what it meant to be a target sibling. Consequently, two research questions were addressed in the stage two of the current study.

Research question 4: How do adolescents and youths perceive their experiences as siblings of individuals diagnosed with ASD?

Research question 5: How do mothers perceive the experiences of the adolescents and youths as siblings of individuals diagnosed with ASD?

Method

Participants

Twelve target siblings and their mothers took part in stage two of the study. The target siblings were aged between 12 and 20 years ($M = 15.67$ years, $SD = 2.71$). Six of the target participants were females. Four of the twelve mothers had three biological children, while the rest had two biological children. Half the mothers indicated being employed at the time of the study. No other demographic information was obtained about the mothers. Sixty-six percent of participants lived in nuclear families, and 44%

lived in separated/divorced families. Further demographic details can be seen in Table 6.1.

In order to be eligible to participate in the interview phase of the study target siblings and their mothers had to have participated in stage one, as seen in Figure 6.1. Moreover, they also needed to live in the Perth metropolitan area because all interviews were conducted face-to-face. Twenty-two target siblings and their mothers were invited to participate and 12 accepted the invitation, the remainder declined or did not respond to the invitation to be interviewed.

Materials

Two semi-structure interview schedules - one for the target siblings and the other for the mothers - were utilised for stage two of the study (Appendices Q & R). The interview schedules contained eight questions each, and consisted of a combination of open-ended and closed-ended questions, plus a number of prompts for each question. Target siblings were asked questions regarding their experience as adolescents/youths whose siblings had been diagnosed with ASD. For example, "Tell me what it is like to be (sibling's name) brother/sister?" Mothers were asked questions regarding their perception of the family, especially the target sibling and the child with ASD. Mothers were also asked to discuss their perception of the target siblings' experience. For example, "What do you think it is like for (target sibling) to be (child with ASD)'s sibling?" A digital audio recorder was used to record the interviews.

Table 6.1

Demographic Data of the Participants of Stage Two

ID	Pseudonym of target participants	Age	Gender	Pseudonym of mother	Number of siblings /Number of siblings with ASD	Pseudonym of sibling	Diagnosis of sibling	Age/ Gender of sibling with ASD	Age/ Gender of other siblings	Family type
1	Bianca	18	F	Diana	1	Cameron	Autism	15/M		Single parent
2	Natalie	20	F	Lisa	1	Michael	Autism	18/M		Nuclear
3	Ursula	12	F	Lauren	2/1	Fletcher	PDD-NOS+GDD	4/M	2/M	Nuclear
4	Talea	18	F	Tamara	1	Scott	Autism+ID	21/M		Single parent
5	Brandon	16	M	Maya	1	Toby	Autism	13/M		Nuclear
6	Hugo	12	M	Monica	2/1	Demi	Autism+ID	5/F	6/F	Nuclear
7	Belle	16	F	Barbara	1	Dan	LFA	13/M		Nuclear
8	Finn	14	M	Lorna	1	Isaac	Autism	11/M		Nuclear
9	Patrick	14	M	Fiona	2/1	Felix	Asperger's	19/M	16/M (Down syndrome)	Nuclear
10	Daniel	13	M	Eva	1	Mary-Kate	HFA	17/F		Single parent
11	Kyle	16	M	Caitlin	1	Thomas	Asperger's	14/M		Nuclear
12	Kirra	19	F	Stephanie	2/2	Kallen Faith	HFA; Asperger's	22/M; 19/F		Single parent

Note. PDD-NOS = pervasive developmental disorder – not otherwise specified; GDD = global developmental delay; ID = intellectual disability; LFA = low functioning autism; HFA = high functioning autism.

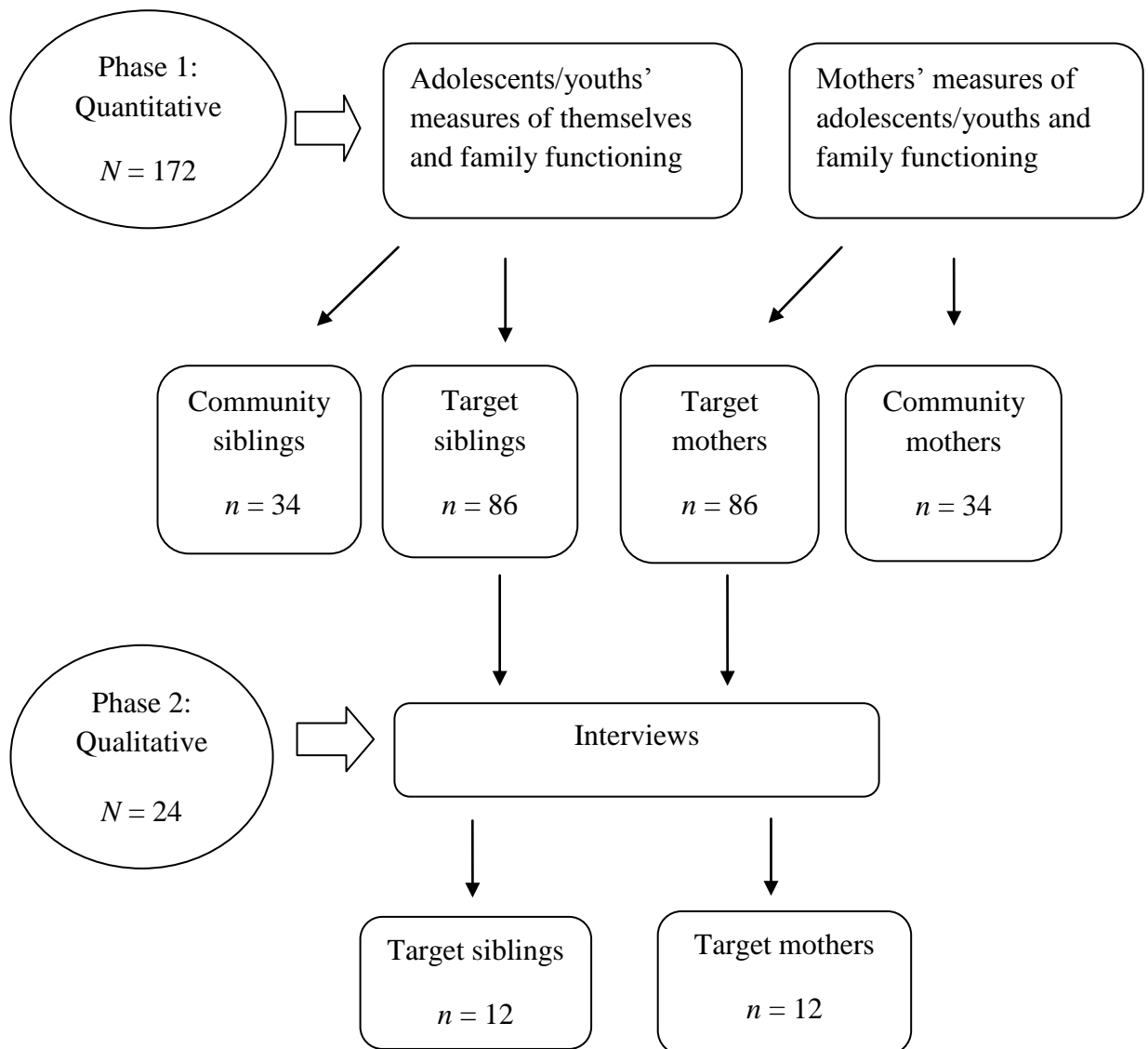


Figure 6.1. Visual representation of the research design.

Procedure

Once both the mother and the target sibling had completed the questionnaires of stage one they were sent an email inviting them to participate in stage two of the study. The email included the information letters and instructed the participants that they should contact the primary researcher if they were interested in being interviewed. Only families where both the mother and target sibling responded positively to the invitation were interviewed. Participants were given the option of being interviewed at their

homes or at either Edith Cowan University metropolitan campus. Mothers and target siblings were interviewed on the same day.

Upon meeting the participants, the purpose and structure of the interviews were briefly explained to the mothers and target siblings, and they were asked to choose who would be interviewed first. Before the interview began the participants were given an information letter (Appendices S & T), a consent form to sign (Appendix U), and questions or concerns were answered. Participants were reminded that they were free to refuse to answer any questions and they could stop the interview or request a break at any time. Brief notes were usually taken during the interview to serve as prompts or as part of the field notes. At the end of the interview time was taken to debrief with each participant and ensure that they were not distressed following the interviews.

Participants who had become teary or upset during the interview, or who wished to discuss additional issues arising from the questionnaire phase of the study were given the contact details of a number of support services (Appendix L).

Immediately following both interviews, the primary researcher made brief notes about the interviews including any significant themes that had been discussed, and the general demeanour of the participants. Half of the interviews were transcribed by the primary researcher, whilst the other half were transcribed by a professional transcription service. Once each interview had been transcribed, the primary researcher read the transcript while listening to the original recording to correct any errors in the transcription process, and to remove identifying information and replace names with pseudonyms. During this time, notes were also made regarding gaps in the data collected, that is, issues that needed to be addressed in future interviews. The primary researcher conducted all of the interviews. The interviews were conducted over a period of two years with the majority of the interviews being conducted within the first six

months of the data collection phase. Most participants were interviewed within a few weeks of having completed the stage one questionnaires. The analysis of the interviews began as soon as the first set of interviews had been conducted.

Analysis

NVivo v.10 was utilised in the analysis process. The mothers' data were analysed separately from the target siblings' data yet all the data were analysed with the use of interpretative phenomenological analysis (IPA; J. A. Smith, 1996). The data were analysed following the steps outlined by Willig (2008). The first step consisted of open coding; each transcript was read line by line a number of times while annotations were made on the margin of the document regarding descriptive labels, associations, questions, comments, absences, and the language used. The second step began once the transcripts had been read and coded. This step consisted of conceptually grouping the reflections identified during the first step and assigning them a label. For example, all the codes describing social skills deficits, friendships, or situations involving social interactions were grouped together and assigned the label 'social issues'. This was done for each transcript individually. The relevant quotes were stored with each conceptual group using NVivo. The last stage consisted of structuring the themes identified in step two and naming them. All the themes that had been identified during step two were listed and relationships between the themes were identified. Some themes represented hierarchical relationships, others clustered together, and some were deemed extraneous. Themes were named either using descriptive terms, such as 'being a sibling' or utilising participants' words, such as 'life is limited.' At the end of this process two collective sets of themes and subthemes had emerged, one for the target siblings and one for the mothers.

Confirmability and transferability were ensured through a method of member checking as described by Miles and Huberman (1994). This consisted of confirming the researcher's interpretations by contacting a random sub-sample of participants once the data had been coded and the themes had been developed. Member checking ensured the researcher had correctly interpreted the data (Braun & Clarke, 2006). Moreover, the themes and sub-themes were checked against the original transcripts by a researcher independent to the study. The feedback from this researcher helped refine the final themes and sub-themes. In addition, in order to aid with the analysis and the conclusion drawing process a reflective journal was utilised (Fassinger, 2005). An audit trail was kept to allow for transparency in the research progress, as described by Fassinger (2005). The audit trail consisted of a record of the steps taken from the beginning of the research process until the reporting of the data, as well as the researcher's thoughts and impressions during the data analysis (Richards, 2005). The audit trail also included the preservation of the raw data, that is, the original transcripts of the interviews.

In conclusion, in this chapter the method employed during stage two of the study during which qualitative data in the form of semi-structured interviews were collected, was described. Given that the target siblings and their mothers were interviewed separately, the results are also presented separately. The subsequent two chapters will be utilised to depict the results obtained. In chapter 7 the target siblings' data are described and interpreted, while in chapter 8 the mothers' data are described and interpreted.

Chapter 7

Stage Two:

Exploring the Lived Experiences of Adolescents and Youths - Part One, Target Siblings' Findings and Interpretations

Chapter Overview

In this chapter the findings of the first part of stage two are discussed. The themes obtained following the analysis of the interviews conducted with the target siblings are reported. The results are then discussed in relation to the aims and research questions. In addition, the findings are interpreted in light of the literature.

Chapter 7 Stage Two:

Exploring the Lived Experiences of Adolescents and Youths - Part One, Target Siblings' Findings and Interpretations

The nature of qualitative methodology assists researchers to explore aspects of the experiences of target siblings not evident in quantitative methodologies (Morse, 2008; Salkind, 2008). The qualitative data available indicate that target siblings can experience positive and negative aspects simultaneously (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, et al., 2009), thus highlighting the complex, and multi-faceted nature of their experiences. While researchers have used qualitative methodologies to investigate the experiences of target siblings, no studies have employed mixed methods (quantitative and qualitative methodologies) with the same sample of target participants. Moreover, qualitative studies have not generally sampled adolescents and youths exclusively but have also included children.

The experiences of the target siblings in the current study clustered around three superordinated themes, with most themes consisting of a number of sub-themes, as seen in Table 7.1. Most of the target siblings generally spoke of their experiences with a sense of acceptance or compliance to the needs of their brothers or sisters, even while describing challenging aspects of adjusting to these needs. However, a small number of target siblings expressed feeling more negative emotions regarding their experiences as target siblings. The first theme - evolving experiences - represented how target siblings had changed and matured over the course of time as well as the impact these changes had had on their experiences living with brothers or sisters with ASD. The second theme - "it's difficult sometimes" - highlighted the challenges the adolescents and youths encountered as part of their experiences as target siblings. The third theme -

target siblings as carers - explored the role of the target siblings as carers of their brothers or sisters with ASD both at the present time as well as in the future.

Table 7.1

Themes and Sub-Themes Relating to the Experiences of the Participants' as Siblings of Individuals Diagnosed with ASD

Themes	Sub-themes
Evolving experiences	Awareness of ASD
	Character development
"It's difficult sometimes"	Aggressive and violent behaviour from the sibling with ASD
	Social challenges
	Time spent worrying
Target siblings as carers	Present-day caring
	Caring in the future

Evolving Experiences

The narratives of all the target siblings indicated that their experiences were imbedded within the overarching theme of evolution of the target siblings and their experiences. The target siblings, their brothers or sisters, and their families changed over time and consequently, the experiences of the target siblings also evolved. Therefore, in order to understand the experiences of the target siblings one needs to continually consider that their experiences were not static and would, at no point in the future, remain static. From a developmental perspective changes occur throughout the lifespan with significant changes evident in all areas of development in adolescence and early adulthood (Paus, 2005; Steinberg, 2005). The theme of evolving experiences portrayed some of the changes the target siblings had experienced in themselves, and

how these changes had shaped their perceptions as target siblings. The theme was divided into two sub-themes; ‘awareness of ASD’ and ‘character development’.

‘Awareness of ASD’ described the target siblings’ understanding of their brothers or sisters’ disorder and its implications, and how this understanding had changed over the years. In this sub-theme target siblings also described the relationship they had with their brothers or sisters. The second sub-theme - character development - explored the development of positive character traits in the target siblings over time.

Awareness of ASD

Central to the experiences of the target siblings was their awareness of ASD and what this meant for their brothers and sisters. In particular, ten of the target siblings spoke of gradually gaining an understanding of the disorder. “I don’t think I actually knew much about autism or what it was before [he was diagnosed] but over the past few years I’ve learnt a little bit about it.” (Ursula); “I guess [understanding ASD] kind of came progressively as I learnt more about disabilities and all that through school and home, and all that sort of stuff. It’s hard to totally understand stuff like all at once.” (Brandon);

Obviously when I was in primary school I didn’t understand about disabilities and I thought... people his age would act like him but obviously that’s not correct.... So then I had to adapt and realise that he isn’t entirely, you know, normal. (Patrick).

The target siblings’ awareness of ASD was evident in their understanding of ASD symptoms and the impact the disorder had on their brothers or sisters. Target siblings were aware of how the most common characteristics of ASD were displayed in their brothers or sisters’ behaviours. “Language is probably the biggest [difficulty he

experiences].” (Natalie); and “He mostly gets very distracted and he goes into his own sort of world.” (Brandon). Other target siblings described their brothers or sisters’ difficulties socialising. “I think it is a bit like socialising with people in a way is pretty hard... he is getting a lot better, but he still has a lot of trouble with it.” (Finn); “She is pretty good at just about anything besides... social skills.” (Daniel).

I think socially, and understanding, like, the way other peoples’ minds work, I guess. ‘Cause you know, he’s obviously different in the way that he thinks about things, so he just doesn’t understand why people do things or why they do things the way they do it sometimes. (Patrick).

Along with the understanding of the limitations their brothers or sisters encountered target siblings also felt sympathy for them. Feelings of pity by target siblings for their brothers or sisters have been reported in the literature, and these feelings are often linked to the consequences of the limitations target siblings perceive in their brothers or sisters (Benderix & Sivberg, 2007). In the present study, these feelings of sympathy were expressed as wishes or hopes for their brothers or sisters. The younger target siblings’ wishes tended to be more generic. “[I would] probably just [wish for] no autism because it might be easier for him.” (Ursula). However, the older target siblings tended to demonstrate more sophisticated reflective capacities in their ability to consider specific difficulties they wished they could alleviate in their brothers or sisters. “Maybe just for him, like having friends and stuff, which he doesn’t have, like so I think that’s something that’s a bit upsetting.” (Natalie); “I wish she did have friends, yeah. It makes me sad to think about it.” (Kirra); and “I wish he could kind of go back to high school because I feel like, just with school in general, just because he was like learning stuff.” (Talea). The narratives of the target participants in the present study thus indicate that an aspect of their experiences consists of the target siblings

coming to terms with the challenges their brothers or sisters face. In other words, target siblings can feel negative emotions in response to aspects of their brothers or sisters' experiences even though these experiences do not directly impact on the target siblings.

Awareness of ASD and its impact on their brothers or sisters did not translate into solely negative appraisals by the target siblings of their brothers or sisters. Positive aspects regarding the experiences of target siblings are well documented in qualitative research, highlighting the important contributions of this methodology to this field of knowledge. There is evidence that target siblings consistently report that their brothers or sisters have some positive characteristics, such as describing their brothers or sisters' personalities positively, and reporting shared enjoyment (Benderix & Sivberg, 2007; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Petalas, Hastings, Nash, Dowey, et al., 2009). Positive aspects of their brothers or sisters were an integral part of the narrative of all target siblings in the present study. These positive characteristics most often related to the personality of the brothers or sisters with ASD.

Target siblings described a range of characteristics that they admired in their brothers or sisters. "I think he is just funny, like, just some of the things he says." (Talea); "[He is] very caring." (Brandon); "He is very, very protective of the women in his life." (Kirra); and "Well, Demi is smart, strong and pretty" (Hugo).

Target siblings were also able to identify strengths in the skills of their brothers or sisters despite acknowledging their limitations.

I mean, maybe not like intellectually, he doesn't have many strengths, but, like, he is really sort of carefree.... I mean, I think it is good. Like, he is not worried about, you know, he is not, like, stressed by certain things, whereas, you know,

the average person may be. So, in some ways, you know, he has his own kind of strength. (Talea).

Some target siblings identified cognitive strengths in their brothers or sisters. “Science is very strong with him, he’s very good at it.” (Belle); “He is a pretty smart kid. And so, all like maths and everything in school he is doing really well with, so that is another pretty good strength.” (Finn); and “Even though he struggles because of his disability, he is a very quick learner in that way.” (Brandon). Other target siblings were able to identify specific skills their brothers or sisters possessed. “He’s good organising things, like he has a large collection of transformers and gundams [Japanese robots].” (Patrick); and “He is very good at reading, finding stuff on the Internet.” (Ursula). As it can be seen, the target siblings in the present study were able to identify strengths in their brothers or sisters with ASD.

The ability of target siblings to identify strengths and limitations in their brothers and sisters has been recorded in other studies (Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). Despite the observation that most target siblings tended to discuss more challenges in the experiences of their brothers and sisters than strengths, a common characteristic of qualitative research is that target siblings tend to be able to identify at least one positive attribute in their brothers or sisters (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, et al., 2009). The ability of target siblings to identify both positive and negative attributes consequently suggest the importance of exploring all facets of their experiences when investigating what it means to be target siblings. In addition, the ability of target siblings to identify positive attributes can be a sign of positive adaptation (Taunt & Hastings, 2002). That is, target siblings do not have to succumb to the challenges they experience, and thus they can experience positive outcomes despite increased stressors.

In addition to identifying positive characteristics and areas of weaknesses in their brothers or sisters' personalities, target siblings also described the sibling relationship as mostly positive. In the present study shared enjoyment was the most common characteristic in the sibling relationship identified by nine of the target siblings. "Yeah, he's a pretty fun kid, so I enjoy being around him." (Finn); "I'd say we get along better than the average brother and sister since we never fight about anything... He's fun to be around; we end up like singing and stuff." (Bianca); and "He is my brother and I need a brother just to hang out with, apart from my parents.... I guess we help each other in a way sometimes at home." (Brandon).

A positive sibling relationship is consistent with some of the research available (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009). Previous researchers have reported that target siblings can experience positives such as less conflict, less competition and more admiration between the siblings (Kaminsky & Dewey, 2001; Walton & Ingersoll, 2015). Therefore, there is evidence that target siblings can experience benefits in their sibling relationships despite the social and behavioural difficulties displayed by the children with ASD.

In the present study some target siblings highlighted the developmental differences between themselves and their brothers or sisters. "It's been quite fun because it keeps us all a bit young." (Natalie); and "I just enjoy his company. He is very light-hearted, kind of thing. He is like having a little five-year-old as a brother, kind of thing, you know, so he is pretty fun to be around." (Talea). Even though target siblings did not frame the developmental discrepancies as negative it does highlight that target siblings can experience less support and reciprocity particularly as the target siblings mature and the developmental gap between the target siblings and their brothers or

sisters with ASD widens (Buist, Deković, & Prinzie, 2013; Weaver, Coleman, & Ganong, 2003).

The ability of the target siblings to identify positive features to their experiences despite the challenges suggests that their experiences are not dichotomous, and hence why results may at times be contradictory (N. Gold, 1993; Macks & Reeve, 2007). That is, it is likely that the complex nature of the experiences of the target siblings and the various factors that can impact on their experiences can explain some of the inconsistency evident in the literature currently available. Moreover, the complexity of their experiences is likely to change as the target siblings, their brothers and sisters, and their families continue on their developmental journeys.

Finally, despite shared aspects of their journeys as target siblings their experiences were also idiosyncratic, as their brothers and sisters, their diagnoses, families, and events they had encountered were unique to each target sibling. The distinctive nature of each experience was encapsulated by Hugo's reflection: "I think, you know, people [target siblings] learn eventually and there is really nothing you can say to them to make them feel any different until they learn what [having a brother or sister with ASD] is like."

Overall, the above excerpts indicated that target siblings were well aware of the challenges and limitations experienced by their brothers and sisters due to ASD. Despite the varied severity of the diagnosis, the target siblings' understanding of the challenges encountered by their brothers and sisters, and their strengths and limitations had grown over time. Sympathy towards their brothers and sisters was a common experience for the target siblings, and some explicitly wished that the lives of their brothers or sisters could improve. Target siblings also described their relationship with their brothers or

sisters as consisting of positive aspects. However, for some target siblings developing a positive relationship had been an evolving process. In addition, the narratives of the target siblings indicated that having brothers or sisters diagnosed with ASD had an impact in the development of the target siblings' characters.

Character Development

The literature presents different perspectives on the social competence of target siblings. Some researchers have reported that mothers perceive target siblings as displaying lower rates of pro-social behaviour when compared to normative samples (Hastings, 2003b) while others have reported equal or greater rates of social competence when compared to normative samples (Kaminsky & Dewey, 2002). There is evidence that target siblings can learn to view people as individuals possessing both strengths and weaknesses at a younger age when compared to children whose siblings are typically developing (Benderix & Sivberg, 2007; Powell & Ogle, 1985).

In the present study, having brothers or sisters who were not typically developing offered some target siblings the opportunity to develop a range of positive attitudes and character traits. Most target siblings reported greater understanding of others as a consequence of having brothers or sisters with ASD. This increased understanding was expressed in different forms. Hugo and Patrick believed it was an advantage having brothers or sisters with ASD as it gave them a different perspective on how to relate to others. "A lot of people just don't understand and get really angry at people with autism, and we just wouldn't know that [if my sister did not have ASD] and we would just be the same as all those people, I guess." (Hugo); and "As an experience I think I'm better with, like understanding and being more patient with people than if he didn't have Asperger's." (Patrick). Patience was also a trait other target siblings had

developed over time. “Honestly I think the biggest thing is patience, not getting angry as easily, not being on edge all the time, just patience is the biggest thing.” (Kyle).

Others agreed: “I have become very, very patient.” (Bianca); “Patience is a big thing that you should really work on [as target siblings].” (Kirra).

The target siblings’ ability to reflect on their own personal growth as a result of their experiences was irrespective of their age or gender. Bianca and Daniel, the oldest female and the youngest male target siblings, stated that over time they had learnt to value diversity and tolerance. “People are different and they might think differently, act differently and you just have to try [to] understand what it’s like to be them” (Bianca); “I suppose tolerance of people who are classed as different” (Daniel). While for Brandon, his brother had taught him to be kind to all. “To respect everyone whatever the challenges are or whoever they are, and how much kindness Toby has to everyone else.” Natalie had a similar experience:

I think it’s made me a lot more understanding and just a bit more tolerant and caring, I guess. I think anyone who has experience with someone with autism, or any kind of disability, you do become a bit more accepting.

For Finn, in addition to becoming more caring as he had matured, he thought he had become more responsible over time. “I think it has helped me be a lot more responsible as a kid... it’s hard to describe but it kind of, like, makes me feel like a more caring person in a way because I’m always looking out for people now.” For Finn, having firsthand experience of the emotional pain caused by bullying fuelled his caring nature. “Well, Isaac gets a lot of bullying and so you see him come home and he’s absolutely, like, distraught and he’s like, so upset, and just because I know what it does to someone now.”

In sum, the development of a range of positive character traits was an integral part of the experiences the target siblings, and a phenomenon expected to carry on evolving in line with the target siblings' developmental trajectory (Paus, 2005; Steinberg, 2005). The target siblings perceived their experiences as siblings of individuals with ASD as critical in the development of these positive character traits. For some target siblings it was the challenges they had experienced that they believed had contributed towards the development of some of the character traits discussed above.

“It’s Difficult Sometimes”

Target siblings reflected that a significant part of their experiences consisted of the various difficulties that they encounter as siblings of individuals with special needs. It is well documented that target siblings can experience a variety of negative outcomes in social, emotional, behavioural, and/or familial domains (Benson & Karlof, 2008; Lutz et al., 2012; Meirsschaut et al., 2010). Despite the risks to the target siblings' wellbeing, poor outcomes are not the unavoidable result of their experiences. The presence of protective factors and processes, as well as the successful adaptation of the target siblings can lessen the impact of the risks posed by having brothers or sisters with ASD (Frankford, 2007; Luthar et al., 2000). However, protective factors and processes appeared not to eliminate all negative aspects of the risk factors, and target siblings, even those who had reported better than expected outcomes, still experienced challenging issues. Some of these challenging experiences were encompassed in the theme “it’s difficult sometimes.”

“It’s difficult sometimes” described the most common challenges and issues experienced by the sample of target siblings. The target siblings associated the

challenges they experienced to having brothers or sisters with ASD. These challenges ranged from issues directly to do with their brothers or sisters' behaviour, to difficulties associated with the reactions of others towards their brothers or sisters. The theme was subdivided into three sub-themes. The first sub-theme - aggressive and violent behaviour from the sibling with ASD - detailed the varying degrees of violence and aggression witnessed by the target siblings. The second sub-theme - social challenges - described the challenges the target siblings experienced from individuals outside the immediate family unit. The third sub-theme - time spent worrying - encompassed the range of concerns the target siblings expressed regarding their brothers or sisters.

Aggressive and Violent Behaviour from the Sibling with ASD

Aggressive and violent behaviour from the children with ASD has been described in the literature as a significant concern for a portion of target siblings (Mascha & Boucher, 2006; Ross & Cuskelly, 2006). Aggression by individuals with ASD has been attributed to the cognitive deficits, particularly theory of mind, high sensory sensitivity, and behavioural reactivity associated with ASD (Sabuncuoglu et al., 2015). Aggression and violence can be targeted at the brothers or sisters with ASD (self-harm), the target siblings, parents, pets, or individuals outside the family (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009).

Target siblings in the present study reported their brothers or sisters with ASD displayed varying degrees of aggression and violence. The behaviour was targeted at various sources including the target siblings, their parents, or strangers. The reaction from the target siblings ranged from annoyance, to sadness, to nervousness and worry. "So sometimes it is a bit of a trial with him 'cause the littlest thing can get him cranky, and when he is cranky it's the slamming doors, it's the yelling." (Belle); "Sometimes

[violent behaviour] is not always, like, triggered by something as such and he will just like go really angry so, like, I'm always kind of like nervous." (Talea); and "I feel pretty sad [when she bites me].... [O]ne [incident] happened recently and she was, you know, starting to get upset so I tried to give her a hug and she chomped on my shoulder." (Hugo).

The exposure of children and adolescents to the aggressive and violent behaviour within the family context has been associated with a wide range of difficulties including internalising and externalising problems, as well as social and academic problem, thus making it a risk factor to their development (Espelage, Low, & De La Rue, 2012; Evans, Davies, & DiLillo, 2008; Kitzmann, Gaylord, Holt, & Kenny, 2003). In addition to impacting their development, aggressive and violent behaviour can cause varying degrees of distress to the target siblings as reflected in the present study (Briggs-Gowan, Carter, & Ford, 2012; Holt, Buckley, & Whelan, 2008; McDonald, Jouriles, Briggs-Gowan, Rosenfield, & Carter, 2007; Moyson & Roeyers, 2011). For Talea the anxiety she experienced was associated with the unpredictability of the behaviour of her brother with ASD.

But now it is more like, 'Oh, what is he going to do next?' like, because it used to be that he would just, like, hit my parents and stuff.... But now he has started, like, when we go out in public he has, like, sort of, not hard, but he has hit a couple of people... who he doesn't know at all, so it is, like, is that going to escalate? It is more kind of, like, worried, like, 'What is he going to do next?' because he would never have done that before.

While Patrick conveyed significant distress due to his brother's self-harm and suicidal tendencies.

There've been various incidents ... where something's happened and he thinks that it is his fault, or that he's done something wrong, or that people are really angry at him, or that he's worthless or something. And [he] gets really angry at himself and almost suicidal. I've actually been really worried, like, when he's in those moods, I actually worry about him taking it to that level. At one point he was banging himself on his head on the wall like, really hard like, almost damaging the wall.

Although displays of aggression could be distressing for the target siblings, a number of them were able to rationalise the behaviour. "Sometimes he does hit me and pinch me and all this.... Sometimes I just think it's just because of the way he is, like the autism so I don't really think much of it." (Ursula); and "He has never, even in his utmost anger, he has never wanted to hurt us. Like, he would rather hurt himself than hurt us..." (Kirra).

In sum, a number of target siblings disclosed that their brothers or sisters could be aggressive and violent. The degree of violence ranged from verbal aggression to aggressive acts. Likewise, the reactions of the target siblings to the violence also varied with some target siblings becoming anxious while others were less distressed by the behaviour. While some target siblings discussed serious episodes of violence that were distressing to them, others reported less serious incidents and demonstrated the ability to rationalise the challenging behaviour. Given the evidence that target siblings can be exposed to aggressive and violent behaviour, the distress they can feel, and the detrimental impact this exposure can have on their developmental outcomes when investigating the outcomes of target siblings this phenomenon should be a key issue of interest for the researchers. Moreover, the level of violence and aggression target siblings are exposed to could be considered as one of the mediating variable that can

affect their wellbeing, and therefore further research is required to draw more conclusive findings. Another challenging aspect of the experiences of the target siblings that can impact on their wellbeing relates to the social challenges they encountered.

Social Challenges

Researchers have proposed that having brothers or sisters with ASD can present challenges to the target siblings' social development (Macks & Reeve, 2007; Pilowsky et al., 2004). In the present study target siblings identified some of the social challenges they experienced as they grew up as being precipitated by the responses of others to their brothers or sisters with ASD, with these responses leading some target siblings to feel negative emotions such as embarrassment or anger. The target siblings reported they perceived a lack of understanding about ASD from members outside the family unit. "People always have their sort of preconceptions about autism." (Natalie); and "Some people [do] not understand [ASD]" (Bianca).

Target siblings described this lack of understanding regarding their brothers or sisters with ASD as having impacted them differently; however, most target siblings said they had been most affected as children. "It wasn't direct bullying [when we were at school] but it was just like reminding, sort of thing, and acting like it is something to be ashamed of [having a sibling with ASD], like, expecting us to be ashamed of it by projecting that shame or something." (Kirra). Natalie went on to reflect that while she did not find her brother's behaviour unusual her difficulties as a child were caused by her inability to explain the behaviour to others.

When I was younger, [his behaviour] was always kind of normal to me but it used to bother me a bit that other people didn't understand what he was

doing.... [And] not being able to explain it when I was little as well, just like, 'it's just Michael, it's just what he does' but other kids didn't really understand. (Natalie).

On the other hand, Finn stated that it upset him when he needed to intervene when Isaac's behaviour caused Isaac social difficulties.

I used to have people come to me like, 'Oh, your brother is so weird, nah-nah-nah-nah-nah, Why is your brother so weird?' ...I used to get really mad if I [had been] hanging out with my mates and I had had to stop Isaac doing stuff and then everybody was like, 'Oh, he is so weird' and stuff. I would come home and I would be like so mad and I would throw stuff around, and Isaac never really knew why I was doing it. (Finn).

While most target siblings had learnt to cope with the lack of understanding they encountered outside their immediate families one target sibling expressed feeling considerably uncomfortable when her brother's behaviour was not typical of most other individuals his age.

So when he is really happy, I mean it is a good thing but it is sometimes embarrassing just because he is really loud and talkative, he claps a lot and he'll, like, dance around. I mean, it is like funny but sometimes it is kind of embarrassing when you are out in public, you know. People don't, like, understand. They are just like, 'Who is this?' So sometimes it is embarrassing and sometimes I am just like nervous because I don't know what he is going to do next basically. (Talea).

Some target siblings stated that the lack of understanding from those outside of the family unit impacted more on their brothers or sisters than on themselves.

Consequently, the target siblings thought that greater understanding in the community would benefit their brothers or sisters with ASD more so than the target siblings. “So that people don’t see him as being weird, I would make it more so that [others] kind of like understand what’s going on.” (Finn); and “I think people just need to understand [individuals with ASD] more, like in society.” (Patrick).

Target siblings expressed that they had encountered a number of social challenges by being siblings of individuals with ASD, particularly social challenges that related to lack of understanding from individuals outside the family unit. There is some evidence to suggest that target siblings can experience social difficulties (Petalas, Hastings, Nash, Dowey, et al., 2009). Researchers have reported that one of most difficult aspects of having brothers or sisters with ASD is when they act out stereotyped behaviours or ASD-related symptoms in public (Mascha & Boucher, 2006) and this is consistent with the narratives of the target participants in the present study. Likewise, feelings of embarrassment or being unable to explain their brothers or sisters behaviour has also been reported in the literature thus providing empirical support for the narratives of the target siblings (Petalas, Hastings, Nash, Dowey, et al., 2009). The current results indicate that these social issues can vary based on the target siblings’ developmental stage. That is, the target siblings expressed experiencing more social difficulties when they were younger. In addition to experiencing some social issues, the accounts of many target siblings also conveyed a range of worries and concerns.

Time Spent Worrying

The cognitive changes associated with developmental maturation allow individuals to think more sophisticatedly about situations they encounter (Ferraioli & Harris, 2010). These cognitive changes can in turn contribute towards many target siblings, as they enter adolescence, to begin worrying about their brothers or sisters with ASD. These concerns about their brothers or sisters with ASD can become central issues in the lives of target siblings (Berger, 2011).

Worry about their brothers or sisters, was a key aspect of the experiences of the target siblings in the present study discussed by ten of the target siblings. Some target siblings expressed feeling concerned about their brothers and sisters' future. "So I do worry about things like that [the future]. So in that kind of area I do worry about what's going to happen in like 50 years." (Natalie); and "But that's what I'm worried about sometimes is that he won't become independent. He will lose that and will be reliant on other people, which I know he's not." (Brandon) While other target siblings expressed feeling concern about their brothers and sisters at the present time. "We're also a little worried that Fletcher might get picked on at school" (Ursula); and "Yeah, in a way it would be a lot easier because I don't have to worry about him as well. Yeah, I could just worry about me." (Finn).

While worry was a common phenomenon in the experiences of many target siblings, the areas that concerned them ranged greatly. Some target siblings were concerned about challenges their brothers or sisters would encounter in everyday life. "I think for the first couple of months [of high school] when he is just starting out I will [worry], because he is Year 8 and they get into a lot of trouble." (Finn). Other target siblings were aware of their parents' worries. "My mum is always like, kind of, like,

stressed and it seems like she sort of always, like, is busy and stuff, and it is, like, if he didn't have autism she wouldn't have to worry about as much." (Talea). While concerns about the future of the children with ASD were common amongst the target siblings, the concerns held by Patrick were particularly serious.

I think, yeah, I'm a bit worried about that [the future] 'cause as I've said, he has emotional, I guess for lack of a better word, fits or yeah, fits where he needs someone to help calm him down and if - - ... he can't reach mum or something, then I'm not sure, like that's probably going to be really bad. He might just spiral into something really bad. Worst case scenario he might commit suicide because he takes it too seriously. (Patrick).

In both theoretical and empirical literature, researchers have reported the increased frequency of worries in target siblings during adolescence and early adulthood as a reflection of their ability to consider the long term impact of ASD, their brothers and sisters' potential future as well as the present-day implications of the disorder (Berger, 2011; Mascha & Boucher, 2006). The presence of worries about the future as well as worries about their brothers or sisters when target siblings reach adolescence and early adulthood was consistent with the experiences of the target siblings in the present study. Researchers have argued that the worries target siblings have in adolescence and early adulthood are beyond the worries other adolescents and youths experience during these developmental phases (Cree, 2003; Hooper, DeCoster, White, & Voltz, 2011; Rutter, Izard, & Read, 1986).

Patrick also disclosed a particular reason that caused him concern, one that highlights the fact that target siblings can have specific worries that other adolescents or youths do not generally have. Patrick had two older siblings, both of them with

developmental disorders, and this had caused him to worry about his own developmental health.

I worried about [having a developmental disorder] for about 2 or 3 years and then kind of got over it, realised that I'm normal, and that wasn't going to happen... 'Cause I have two brothers like that, I remember starting to wonder about if I was a bit different that way too 'cause you know, if there's two out of three, might as well be three out of three. (Patrick).

Patrick was only one of two target siblings in the study with multiple brothers or sisters with developmental disorders, and consequently it is not possible to determine whether this issue is an integral part of the experiences of the target siblings; however, it is an area that warrants further research.

As it can be seen target siblings worrying about their brothers or sisters was a common part of their experiences. Target siblings were concerned about a range of issues, depicting the idiosyncratic nature of their experiences. The seriousness of the concerns of the target siblings varied, while the distress experienced by the target siblings tended to be associated to the seriousness of their worries. While experiencing a range of difficulties was a common theme in the narrative of all the target siblings, they also frequently discussed their roles within their family units.

Target Siblings as Carers

Changes in the roles of family members following the diagnosis of a child with ASD is a common phenomenon, and it can be a sign of adaptation (Benson et al., 2008; Lazarus & Folkman, 1984; Lutz et al., 2012). One of the most commonly recorded changes in the roles of target siblings is that they can take on greater care-giving

responsibilities when their brothers or sisters have been diagnosed with ASD (Dodd, 2004; Fletcher, Hair, & Wolfe, 2012). Sometimes the parents place the responsibility on the target siblings in order to cope with the new demands, while at other times the target siblings themselves think it is their duty to assist their parents by taking on added care-giving responsibilities (Benderix & Sivberg, 2007; Stoner & Angell, 2006). Care-giving responsibilities can also be influenced by developmental factors. That is, target siblings tend to take on more care-giving responsibilities as they age, which for some culminate in adulthood, once their aging parents lose the ability to care for the children with the disorder (Bigby, 1996, 1998; Heller & Arnold, 2010).

The theme of the target siblings as carers was evident in the present study. The target siblings described the various ways they cared for their brothers or sisters, which centred primarily on being helpers or teachers to their brothers or sisters with ASD. In addition to discussing their current role as carers, the target siblings also contemplated their role as carers in the future. The theme was consequently divided into two sub-themes; 'present-day caring' explored the target siblings' current duties as a carer, while 'caring in the future' summarised the target siblings' current beliefs about their potential caring responsibilities in the future.

Present-Day Caring

Nine of the target siblings spoke of providing present-day care for their brothers or sisters with ASD. Nevertheless, the frequency and extent of the care-giving varied considerably. Target siblings provided care for their brothers or sisters in a number of ways ranging from emotional support to physical care and supervision. Likewise, the frequency of care ranged; for some target siblings caring for their brothers or sisters was a more frequent phenomenon than for others. These variances reflect the idiosyncratic

nature of families. That is, the roles that family members assume within a system are dependent on a number of individual and collective factors as the family unit attempts to maintain homeostasis (Minuchin, 1974; Sanders, Szymanski, & Fiori, 2014; Scaturro, 2005). Target siblings in the present study spoke of both specific as well as general instances when they identified themselves as providing care for their brothers or sisters.

Some target siblings discussed certain events when they had provided emotional support for their brothers or sisters. “She was, you know, starting to get upset so I tried to give her a hug” (Hugo); “If it’s really heated then I just step back but if it’s in the process of escalating I try to calm it down like a peacekeeper.” (Patrick). Ursula specified that her responsibility to assist her brother occurred when their mother was otherwise unable to do so. “Sometimes when mum’s busy or something and Fletcher’s upset I have to go and calm him down.” Belle expressed a similar context for providing care to her brother. “He calls me up and if it’s late at night or something, and mum’s at painting or whatever and he goes, ‘Belle, I’m getting scared’, straight away I’ll come home, no hesitation, I’m home just to keep an eye on him.”

Siblings caring for other siblings is not a phenomenon exclusively present in families of children with disabilities, in fact, it can be a feature of the typical sibling relationship (Goetting, 1986; McHale, Updegraff, & Whiteman, 2012; Weaver et al., 2003). However, the amount of responsibility that rests on the target siblings can be greater when compared to families with typically developing children (Cree, 2003; Dellve et al., 2000; Opperman & Alant, 2003). Also, the roles the target siblings take on can be more rigid reflecting the limited flexibility associated with strained family resources; thus placing more pressure on the target siblings to adopt and maintain the role of carer (Barnable, Gaudine, Bennett, & Meadus, 2006; Dimitropoulos, Klopfer, Lazar, & Schacter, 2009; Reinhard & Horwitz, 1995).

Some target siblings in the present study described caring for their brothers or sisters with ASD in a broader context, rather than providing specific examples. These target siblings appeared to indicate that they had greater care-giving responsibilities as they discussed how they would provide care for their brothers or sisters in numerous domains. The target siblings often described taking on parental-like responsibility of their brothers or sisters in certain contexts or at certain times. The care provided by the target siblings, was often linked to the limitations or difficulties experienced by the individuals with ASD. Kyle spoke of providing "...all the food and that kind of stuff for him [brother with ASD]..." as well as completing all "...chores he [brother with ASD] can't do..." Brandon described that "I usually have to look after him a lot, so I'm babysitting him." Brandon also said that he "tried to teach him [brother with ASD]... sport...piano...and guitar." Caring for her siblings' daily needs was also highlighted by Kirra.

I make sure they have their medication, which for my brother also includes making sure he has breakfast... Now that I'm older it is more of a social looking after, social caring... sometimes they need reassurance [in social situations]. I am teaching him how to sort his clothes and to put them in the dryer and for how long and stuff, but he knows how to use the washing machine. (Kirra).

Finn highlighted the discrepancy between the amount of caring he did for his brother, and the amount of caring his friends did for their siblings. Thus, indicating that at times target siblings can recognise that their role as a carer is greater or at least different when compared to their peers (Reinhard & Horwitz, 1995). Finn, in particular, spoke of the increased need to manage his brother's social interactions at school, and consequently the negative impact this had on his own time.

Like, it is a bit harder really when you see, like, my friends don't really have to look out for their brothers as much as I do. Like, I'm kind of always having to, like, look out for him and see what's happening,... so it was pretty hard because it kind of stopped me doing what I wanted to do. (Finn).

In sum, a central aspect of the narratives of the target siblings interviewed was their role as carers for their brothers or sisters with ASD. Most target siblings discussed the care-giving they provided as a natural part of their sibling relationship but they also described that they had added responsibilities when compared to their peers. The literature indicates that target siblings tend to provide more care for their brothers or sisters than siblings in typically developing families, often in order to assist family functioning (Benderix & Sivberg, 2007; Lutz et al., 2012; Stoner & Angell, 2006). Another aspect associated with the experiences of the target siblings both in the literature and in the current study related to their beliefs regarding their ongoing role as carers in the future (Burke, Fish, & Lawton, 2015; Coyle, Kramer, & Mutchler, 2014).

Caring in the Future

A few studies have reported concerns about the future, including the future needs of their brothers or sisters and the target siblings' role, as a significant theme in the interviews with target siblings (Bågenholm & Gillberg, 1991; Benderix & Sivberg, 2007; McHale et al., 1986). In these studies, concerns for the future of the children with ASD tended to be more common amongst older target siblings. Adolescence and early adulthood are characterised as phases during which individuals consider major future developmental tasks such as family, education, and employment, all of which will influence their adult life (Nurmi, 1989). Future thinking is a particularly important phenomenon as there is a link between how adolescents and youths perceive the future

and their identity formation (Boyes & Chandler, 1992; Nurmi, 1991). The development of more sophisticated and abstract thinking which occurs during adolescence and early adulthood allows target siblings to think about not only their own futures but also about the futures of their brothers or sisters with ASD (Ferraioli & Harris, 2010).

It is therefore not surprising that given the age range of target siblings in the present study (adolescents and youths rather than children) the future was a common sub-theme in their narratives. Despite the fact that the target siblings were relatively young, in that they all resided with their family of origin, they conveyed that many of them had thought about their responsibilities towards their brothers or sisters once they were adults. Almost all the target siblings, when speaking about the future, made reference to the care their brothers or sisters would require. A portion of the target siblings assumed that they would take on a significant caring role in the future. In some cases, the target siblings' sense of duty towards their brothers or sisters was strong.

And like, obviously it's going to be such a long term thing, like when mum and dad eventually die, hopefully in a very very very very long time, you know, it's going to be me who has to look after him. And hopefully my kids aren't horrible, and then if I die first they can look after him. (Natalie).

Natalie, the eldest target sibling interviewed, revealed that her future decision to have children could be affected by her concern regarding who would take care of her brother if neither she nor her parents were able to. "I don't know if I want to have kids yet, [I] probably will 'cause I'd worry that if something happened to me I'd need my kids to look after Michael, 'cause there'd be no one else." Brandon and Finn also expressed a strong sense of responsibility to care for their brothers in the future. "I feel a responsibility that when I get older I might actually have to look after my brother."

(Brandon); and “But I think I would always, like, try to look after my brother in a way.” (Finn).

Other target siblings were not as certain of their future caring role or expressed that they did not envision becoming their brothers or sisters’ primary carers. “Well, I think Connor will need like a carer or someone. I don’t know if that’s gonna have to be me or a professional, so I don’t really know what’s going to happen.” (Bianca); and “I mean, in the future when my parents can’t look after him he will probably go to, like, a group home, I guess.” (Talea). These target siblings generally demonstrated a higher degree of ambivalence in their narratives towards their brothers or sisters, and their brothers or sisters often had more challenging or severe behavioural problems. When these target siblings discussed their future relationship with their brothers or sisters they also demonstrated less certainty about the quality of the sibling relationship. “I hope that by then [in a few years’ time] I will be brave enough... to take him out somewhere on my own, kind of thing. I think that is what I would like to do.” (Talea), and “Well I’d like to think that I’d still, if I’m not still living with him that I’d, you know, visit him.” (Bianca).

Researchers have suggested that there is a link between the sibling relationship and the adjustment process of the target siblings (Petalas, Hastings, Nash, Dowey, et al., 2009). Furthermore, N. Gold (1993) reported that target siblings who asserted there was nothing positive about having a brother with ASD scored higher on measures of depression. It has been proposed that ambivalence towards the brothers or sisters with ASD can serve as a coping strategy for the challenges the target siblings encounter, especially during adolescence (Opperman & Alant, 2003). Therefore, it is possible that high levels of ambivalence or even rejection may be a temporary coping mechanism in

response to specific developmental stages of the target siblings' journeys and their associated developmental tasks.

Most target siblings associated caring for the brothers or sisters in the future with becoming their carers but for one target sibling caring for her brother took on a different form. For Talea, her sense of responsibility was associated with ensuring her brother had a stimulating life.

Talking about Fletcher's future, I think I need to sort of focus more on [educational opportunities for him] because I think my parents are, like, busy and stuff and, like, I really want to see him sort of, like, grow and develop, because I mean, if things stay as they are, I don't see him growing.

There are a number of possible reasons as to why some target siblings demonstrated a greater sense of personal responsibility for their brothers or sisters' wellbeing. Primarily, it is possible that the target siblings' sense of responsibility is related to family expectations. That is, target siblings who expressed a greater sense of personal responsibility towards their brothers or sisters came from families who had stronger beliefs about the role the target siblings would play as carers in the future. The expectations of the parents regarding the level of care target siblings are expected to offer vary from family to family, consequently the target siblings' beliefs could be evidence of the internalisation of these expectations (Bigby, 1996; Burke, Taylor, Urbano, & Hodapp, 2012; Heller & Arnold, 2010). If target siblings did internalise their families' expectations regarding their role as their brothers or sisters' carers it would signify that understanding the context of the family unit, such as the parents' expectations, would help researchers better comprehend the experiences of the target siblings. Researchers have also proposed that gender differences are evident in the

target siblings' sense of responsibility towards their brothers or sisters, with females generally experiencing greater pressure to become carers than males (Burke et al., 2012; Friedemann & Buckwalter, 2014; Neal, Ingersoll-Dayton, & Starrels, 1997). Although gender differences were not clearly evident in the present study it is possible it is an influential factor in the experiences of other target siblings.

As it can be seen, the majority of target siblings had reflected on their future and that of their brothers or sisters. A portion of the target siblings stated they assumed they would become their brothers or sisters' carers, while another portion described their caring role as being less defined. The accounts of the target siblings illustrated that caring was a broad concept for them consisting of numerous aspects, imbedded within the family context, but nonetheless, caring for their brothers or sisters was an important part of their experiences.

Summary

The results of the semi-structured interviews with the target siblings, which were analysed with the use of IPA, revealed a number of key themes and related sub-themes regarding how the adolescents and youths construct their experiences as siblings of individuals with ASD and the factors that impact on these experiences. It was evident that the experiences of the target siblings had been evolving and changing, and consequently they could be anticipated to continue changing in the future. Therefore, the current findings must be considered a reflection of the target siblings' experiences and their interpretation of these experiences at a specific point in time. The target siblings gradually understood more about their brothers or sisters' disorder, learnt about the behavioural and emotional concerns and strengths of their brothers or sisters, considered the future implications of having a brother or sister with a disability, and

over time the target siblings' characters changed, which in turned impacted on their experiences. The evidence of the evolution in the experiences of target siblings supports the premise for contextualising the research about target siblings within a developmental framework in order to gain the most accurate understanding of the opportunities and challenges they encounter. That is, despite experiencing unique challenges and experiences target siblings continue to be influenced by developmental aspects common to any individual their age.

Consistent with previous research on families and parents regarding the impact of having children with ASD, target siblings in the present study faced a number of challenges. Even though target siblings spoke of idiosyncratic difficulties they experienced, there were three common sub-themes in their narratives that are rarely captured in quantitative research. First, aggressive or violent behaviour was a concern for some of the target siblings. The behaviour from the brothers or sisters varied considerably from verbal aggression to physical aggression, and likewise the target siblings' ability to comprehend and cope with the aggressive behaviour also varied. That is, while some target siblings were able to rationalise the behaviour they witnessed, others expressed distress when discussing these kinds of behaviours.

Second, target siblings also experienced social challenges, which they recounted were precipitated by their brothers or sisters with ASD. The social challenges focused primarily on the target siblings' struggle to negotiate their brothers or sisters' atypical behaviour outside the family unit, particularly in the presence of peers or strangers. As target siblings matured these challenges appeared to be less common or less of a concern, again highlighting the evolving nature of their experiences and their ability to adapt and cope with the challenges they encountered.

Third, target siblings also disclosed a range of concerns that worried them. Concerns tended to focus on the unknown aspects of the brothers or sisters' future lives, such as coping with changes in schooling, negotiating future social challenges, and eventually being able to live independently. Similarly, the worries of the target siblings revealed some degree of personal responsibility towards their brothers or sisters.

A significant aspect of the experiences of target siblings was the roles they adopted in their family units, most specifically their role as care-givers. The types of care-giving tasks ranged considerably; however, what was consistent was the target siblings' ability to identify situations when they provided care for their brothers or sisters. Care-giving was also a service that for some target siblings they anticipated they would continue to provide in the future, once both siblings were considerably older; thus suggesting that the roles target siblings adopt within their families of origin can become a defining aspect of the sibling relationship.

Therefore, target siblings generally conceptualised their experiences as consisting of some common aspects of being siblings, such as shared enjoyment; however, there was evidence that they encountered challenges that were not as typical. It is thus clear that the experiences of the target siblings cannot be conceptualised as solely negative or solely positive but rather as complex and multilayered. Moreover, the target siblings' ability to negotiate these challenges changed over time, with most target siblings being better able to adapt to their unique experiences as they matured, indicating that the experiences of target siblings are ever-evolving.

In the following chapter the results of the second part of stage two are reported. The aim of the second part of stage two was to explore how mothers perceived and

interpreted the experiences of the target siblings; consequently in the next chapter the results of the mothers' interviews are reported and interpreted.

Chapter 8**Stage Two:****Exploring the Lived Experiences of Target Siblings - Part Two, Mothers' Findings
and Interpretations****Chapter Overview**

In this chapter, the findings of the second part of stage two are discussed. The themes obtained following the analysis of the interviews conducted with the mothers are reported in this chapter. The results are discussed in relation to the aims of the study and the research questions. In addition, the findings are interpreted in light of the literature.

Chapter 8

Stage Two:

Exploring the Lived Experiences of Adolescents and Youths - Part Two, Mothers'

Findings and Interpretations

Mothers are frequently utilised as informants in studies researching the experiences of families whose children have been diagnosed with ASD (Higgins et al., 2005; Rao & Beidel, 2009; Ross & Cuskelly, 2006; Sullivan et al., 2012). Mothers are considered to be able to provide valid quantitative and qualitative information regarding the family unit as well as its members (Bayat, 2007; Hastings, 2007; Myers et al., 2009; Nealy, O'Hare, Powers, & Swick, 2012; Rodrigue et al., 1993). That is, mothers are able to comment on how ASD can impact on various family members, including target siblings, as well as how changes in the family unit impacts directly or indirectly on the experiences of the family members (Benson et al., 2008; N. Johnson et al., 2011; Lutz et al., 2012; Taunt & Hastings, 2002).

The mothers' interviews can be summarised in four superordinated themes, and a number of sub-themes. The themes and sub-themes can be seen in Table 8.1. The theme of 'family unit' encompassed the impact having children with ASD had on the family system as well as on the mothers themselves. This theme provided the backdrop against which the mothers interpreted the experiences of the target siblings. Mothers identified how they perceived the experiences of the target siblings in the themes 'being a target sibling' and 'target siblings' interpersonal relationships'. Both themes addressed a number of areas of the target siblings' development that mothers believed had been impacted by living with brothers or sisters with ASD. Lastly, 'developmental

maturation' encompassed the notion that the experiences of the target siblings, as well as that of their families had evolved over time as the target siblings had become older.

Table 8.1

Themes and Sub-themes Relating to the Experiences of Adolescents/Youths as Siblings of Individuals Diagnosed with ASD

Themes	Sub-themes
Family unit	Families managing ASD Mothers' own experiences
Being a target sibling	Reorganisation of resources Target siblings' revised roles Character development
Target siblings' interpersonal relationships	Sibling relationship Social relationships outside the family unit
Developmental maturation	

Family Unit

Although the focus of the interviews centred on the target siblings, the narratives of their mothers indicated that the experiences of the target siblings were contextualised within the experience of the family unit. During the interviews, the mothers of the target siblings (referred to from here as 'the mothers' or 'mothers') often referred to the impact having children with ASD had on the functioning of the family and how the family had had to adjust in order to accommodate the needs of the children with ASD. The narratives of the mothers reflected how ASD impacted on the entire family system; consequently, the experience of the family unit became the backdrop against which the experiences of the target siblings played out. That is, the experience of the family unit helps increase the understanding of the experiences of the target siblings. The first sub-

theme - families managing ASD - focused on the impact children with ASD had on the entire family unit. The second sub-theme - mothers' own experience - encompassed how the mothers' perceived the children with ASD to have impacted on themselves as individuals.

Families Managing ASD

It is widely accepted that raising children with special needs such as ASD can be considerably different and more taxing than raising typically developing offspring (Abbeduto et al., 2004; Estes et al., 2009; N. Johnson et al., 2011; Taunt & Hastings, 2002; Weiss, 2002). A common experience amongst nine of the mothers interviewed in the present study was the belief that having children diagnosed with ASD impacted on the family unit as well as on the target siblings. In turn, target siblings were affected by the changes the family unit experienced. Mothers described the need for the family to reorganise its priorities, with the needs of the children with ASD dictating a significant portion of the family life.

When Lisa was asked if anything would be different for the target sibling if the target sibling's brother had not been diagnosed with ASD Lisa replied by focusing on the entire family. "I think our lives would be completely different." Lisa continued: "So I guess in some ways she's [the target sibling] - - well, not just her, I guess we've all, you know, had, you know, our lifestyle is ruled by Michael really." Similarly, Diana described how the life of the family often revolved around the child with ASD and his needs. "And a lot of the time we had to stop doing things because it would upset him if we were all together as a family in a confined space, like a car, and that was a bit frustrating, you know." The idea of the family life revolving around the children with ASD has been reported by some parents who have said that it is a necessity that

unwittingly becomes a central aspect of family life (Hoogsteen & Woodgate, 2013).

This idea was also illustrated by Tamara:

It could be a lot of it that we are busy or I have been busy, so it is not like other families. They can, you know, do more at the weekend or, you know, we can't because we are busy because we have got Scott [child with ASD]... And just after a while that is how you become. You just live that way and it is hard to then undo that.

For some families the challenges experienced by the children with ASD became limitations for the entire family unit, especially in regards to their ability to engage in social activities as a collective unit. As the needs of the children with ASD are often prioritised ahead of those of other family members the family unit can suffer.

I think his [child with ASD] behaviour is his number one problem so that presents challenges in itself, especially for us in term of where we can take him and stuff like that... Because we are quite structured we don't tend to do things outside of the box, we always do things the same, we don't really try a lot of new things. (Lauren).

We had to try to do everything we could for Michael [child with ASD] so Natalie [target sibling] sort of was ... given a slight backward step. I don't mean like she was ignored or neglected or anything, it wasn't any of that but Michael was the primary focus to try to give him the therapy he needed and the time he needed. (Lisa).

Unsurprisingly, the mothers who reported the greatest impact to the family unit also reported that their children with ASD often had more severe forms of the diagnosis

or had an additional diagnosis of ID or global developmental delay (GDD). Researchers have identified the severity of the disorder as an important factor in the experiences of target siblings and their families, with more severe symptomatology associated with poorer outcomes for the family members (Benson, 2006; Benson & Karlof, 2008; Dunn et al., 2001; Hastings, 2007). It has been proposed that this could be due to the presence of more negative and less positive behavioural features, the persistence of the difficulties throughout the individuals' lives, as well as the social isolation families can experience (Abbeduto et al., 2004).

Diana, Lisa, and Barbara believed that the re-organisation of priorities of the family unit had had a direct impact on the target siblings. "Well, perhaps we would go out more, we would be more social, more sociable. She [target sibling] would probably not feel as inhibited," (Diana); "I do feel that she's [target sibling] probably missed out on some things... Oh, just some opportunities I guess but-- and you know, like I said, time and things we could've done as a family but we probably haven't or didn't." (Lisa); and "I think she [target sibling] would've been more outgoing, more social but I think because we didn't get out all that much in the early years that we became quite a tight family unit, so I think she probably would've been going out a lot more." (Barbara).

These experiences are consistent with the arguments of some researchers who posit that target siblings are at risk of poorer outcomes in all areas of development (Randall & Parker, 1999; Strohm, 2001). These narratives, however, indicate that the increased risk of poor outcomes could be partially accounted for by the experiences of the family unit and its members responding to the challenges associated with raising children with ASD. Mothers of children with ASD tend to report less family satisfaction, lower family adaptation, lower family cohesion, and poorer family

functioning than mothers whose children do not have ASD (Gua et al., 2012; Higgins et al., 2005; Sikora et al., 2013; Sullivan et al., 2012). Moreover, families of children with ASD often experience a change in the roles of its members (Benson et al., 2008) and a reallocation of the family's financial, physical, and emotional resources (Bellin & Kovacs, 2006; Benson et al., 2008; E. Johnson & Hastings, 2002). The pressure on the family unit created by the unique demands of raising children with ASD can affect the other children in the unit, as illustrated by the narratives of the mothers in the present study (Hoogsteen & Woodgate, 2013; Pilowsky et al., 2004). However, raising children with ASD can also trigger positive outcomes for the family system.

Mothers in the present study recounted that the children with ASD not only generated challenges for the family unit, they also precipitated growth by improving the family unit in various ways. For some mothers, they believed that having children with ASD had taught the family members a number of skills or helped them develop certain traits. Patience, compassion, and tolerance were the most common traits described by the mothers in the present study. "I think it makes us all a little bit more compassionate" (Lisa); "And I think that's built up a lot of patience in all of us" (Barbara); "I certainly think that we're more tolerant of each other and more tolerant of other people." (Lorna). These experiences add to the very limited data that indicates that children with ASD can lead family members to experience personal growth (Myers et al., 2009; Taunt & Hastings, 2002).

Monica identified a different benefit of having a child with ASD. The diagnosis of ASD interrupted her career plans leading her to remain a full time mother. She balanced the positive and negative impact of the diagnosis on the family concluding that the family unit were closer as a result of the child with ASD.

I think as a family we would have more money but probably less time... I've had a lot more time with all the kids than I probably would've if Diana hadn't been diagnosed, so that's a positive. And I think we are a closer family than we would've been. I think we would've been far more, doing our own things. I think Diana, yeah, has really brought us together. (Monica).

Greater family functioning and satisfaction were also by-products of having a child with ASD, according to Lorna. "I think we work quite well together as a family... I think he has brought a lot of entertainment and a lot of happiness as well, for sure."

Despite evidence that families of children with ASD can experience greater family dysfunction, in qualitative research mothers have reported that children with ASD can improve the family dynamics (Dąbrowska & Pisula, 2010; Myers et al., 2009; Taunt & Hastings, 2002). The differences between the quantitative and qualitative results could be due to the distinct qualities of each methodology therefore making it difficult to compare the results. Taunt and Hastings (2002) propose that researchers do not design studies in order to research the positive aspects of having children with special needs and as a consequence of this there exists copious amounts of literature describing only the negative experiences of families. Thus, it is plausible that if studies focused on the positive aspects of having children with special needs a more balanced view could emerge.

The presence of positive aspects of family functioning or the improvement of the family dynamics when children have developmental disorders such as ASD can also be a sign of adaptation (Taunt & Hastings, 2002). The narratives of some of the mothers in the present study depicted the two key aspects of coping and adaptation as described by Lazarus model of coping and adaptation (Lazarus & Folkman, 1984; Taunt & Hastings,

2002). The first aspect is a change in their behaviours and cognitions in order to deal with the needs of the children with ASD, and the second aspect is the report of positive outcomes and perceptions as a result of their experiences.

In sum, the mothers in the present study reported that the children with ASD became the focus of the family, and the other members, including target siblings, had to take in many respects a second place. This reflects a portion of the literature that indicates that raising children with ASD has a significant impact on the entire family unit (Abbeduto et al., 2004; Gua et al., 2012). Subsequently, the changes the family unit experiences can then impact on the experiences of the target siblings (Dodd, 2004; Opperman & Alant, 2003). Despite experiencing challenges, mothers also spoke of positive changes to the family unit, a much less researched aspect of the experiences of families with children with ASD (e. g., Myers et al., 2009; Taunt & Hastings, 2002). These positive aspects of the experiences of the families are consistent with the notion of successful adaptation (Lazarus & Folkman, 1984; Pakenham et al., 2005). Another aspect discussed by the mothers that they believed impacted on the target siblings yet did not relate directly to their experiences was that of the mothers' own experiences.

Mothers' Own Experiences

A common sub-theme in the narratives of the mothers in the present study was their own experience raising children with ASD. The fact that over half of the mothers reflected on their own experiences despite the focus of the study being on the mothers' perception of the experiences of their typically developing children is not surprising if viewed through a phenomenological lens. Phenomenology posits that individuals create meaning as they experience events (Liamputtong & Ezzy, 2005). Parents, and particularly mothers, have commonly commented on their perceptions of the

experiences of other family members, including target siblings (Chang & McConkey, 2008; Dyson, 1996; Myers et al., 2009) and consequently, mothers would interpret and understand the target siblings' experiences based on their own experiences. In other words, the experiences of the mothers as parents of children with ASD become a central premise through which researchers can understand the experiences of other family members. Therefore, the experiences of the mothers, is another critical aspect of the backdrop necessary to understand the experiences of the target siblings.

The research exploring the experience of mothers of children with ASD has mostly focused on the negative aspects of the parenting experience (e.g., Abbeduto et al., 2004; Benson, 2006; Dunn et al., 2001; Meirsschaut et al., 2010). However, the presence of both positive and negative aspects to parenting children with ASD was evident in the present study. Mothers in the present research study described how they had been affected as a result of having children with ASD, yet they focused on both negative and positive features of their experiences.

In terms of positive experiences, some mothers spoke of a change in the way they viewed the world as a result of parenting children with ASD. "Isaac has given me a really good way of seeing the world in a different way and seeing people in a different way." (Lorna); and "It's been an experience having Dan because he's opened my eyes a lot more. And the questions he asks sometimes just absolutely floor me, and I think, well you know, this is what society dictates and I've never questioned it." (Barbara). There is very limited research exploring the positive aspects of parenting children with ASD and consequently it is difficult to draw inferences from the findings (Hornby, 1992; Taunt & Hastings, 2002). However, the available findings suggest that negative and positive outcomes are independent from each other (Hastings, Beck, & Hill, 2005).

That is, mothers can experience positive experiences as they raise children diagnosed with ASD as well as experience challenges.

Mothers also discussed more negative aspects of raising children with ASD. Most specifically, mothers discussed the discrepancy between the life the parents' envisioned and the life that they encountered when their children were diagnosed with ASD.

You can read about it [having a child with special needs] but when it's actually happening to you, it's like, basically the way I see it is we've gone from being, you know, we're white, middle class, well-educated and then suddenly we're thrust into this different world, and as was Hugo [target sibling].... Suddenly we are in this world of disabilities... [exposed to] people in a less comfortable [social and economic] position. (Monica).

It is this terrible clichéd story that goes around with Down syndrome, and I think it's called something like *Living in Holland*, or some terrible name like that. And it is about somebody who goes on a journey and they think they are going to, say, France and they get off at the other end and, 'Hey, this isn't France. This is Holland.' So they are in a place where nothing is as they expected it to be, and that is what it is like to find, 'Hang on, I've got a kid with a disability. This isn't what I signed up for.' (Fiona).

Despite being thrust into a world that none of the mothers expected, the general attitude was that one had to deal with the challenges they encountered, an example of the mothers' attempt to cope with the stressor (Dunkel-Schetter et al., 1992). "I mean, there's good and bad to every situation, I think you just deal with it." (Caitlin); and "I think it's been, you know plenty of times when she [the target sibling] probably wished

she didn't have to but you know, you deal with what you've got, don't you? You have to, there's nothing you can do about it, you just have to deal with it." (Lisa).

Some mothers clearly demonstrated that their own experiences impacted on the experiences of the target siblings. Mothers did not keep to themselves the attitude of acceptance along with the insight they had gained through their experience. Rather, mothers actively tried to pass their new found perspective on to the target siblings. "I said to Belle people [need] to realise that sometimes with the autism and siblings and parents, that it's not all doom and gloom but there're a lot of funny and happy times as well." (Barbara); and "I do try to highlight the positives as well that, you know, and it's not all hard work, and it's not all the struggles." (Lorna). The perceptions of the mothers, particularly when they actively try convey these to the targets siblings, can be one of the factors that accounts for the target siblings' own attitudes regarding their experiences as target siblings.

As it can be seen, mothers discussed their own experiences as parents raising children with ASD even though the study focused on the experiences of the target siblings. This occurrence is to be expected when considering that from a phenomenological perspective the way mothers perceive and interpret the experiences of the target siblings is based on their own experiences. Consistent with a very limited body of literature (Hastings, Beck, et al., 2005; Taunt & Hastings, 2002) mothers did not focus solely on the negative aspects of parenting children with ASD, but they also focused on the gains they had experienced, and how they tried to pass on this insight to the target siblings. As a consequence of this it can therefore be argued that the target siblings' own experiences of living with brothers or sisters with ASD can be shaped by their mothers' experiences of raising children with ASD. Again, this highlights that the

experiences of the target siblings play out against the backdrop of the experiences of their parents and family unit.

Being a Target Sibling

It is well recognised in the literature that when children are diagnosed with ASD this tends to affect all members of the family, including any typically developing siblings (Randall & Parker, 1999; Strohm, 2001). There is, however, some debate regarding whether the impact on the typically developing siblings is predominantly positive or negative (N. Gold, 1993; Kaminsky & Dewey, 2002; Pilowsky et al., 2004; Shivers et al., 2013). Researchers have proposed that some of the discrepancy in the results can be accounted for by numerous factors relating to the target siblings, such as their age or gender; their families, such as parental stress levels; or the research design, such as the constructs measured (Petalas, Hastings, Nash, Lloyd, et al., 2009; Yirmiya et al., 2001). Although the full nature of the experiences of target siblings remains unclear what is evident is that the nature of the experiences of target siblings appears complex and diverse.

The narratives of the mothers in the present study reflected the complex nature of the target siblings' experiences as mothers perceived positive and negative aspects to their children's experiences. These aspects were classified in three sub-themes. The first sub-theme – reorganisation of resources - depicted the impact that the diagnosis of the children with ASD had had on the family's resources and the impact this in turn had had on the target siblings. The second sub-theme – target siblings' revised roles - described the different roles that the target siblings took on, and which the mothers attributed to having brothers or sisters diagnosed with ASD. The third sub-theme – character

development - described the mothers' perception of how the target siblings' characters had developed as a consequence of their experiences.

Reorganisation of Resources

Researchers have noted a discrepancy between the demands of raising children with ASD and those of raising typically developing children (Benson & Karlof, 2008; E. Johnson & Hastings, 2002). Parents in previous studies have reported that the demands of raising children with ASD tend to be so time consuming that the other children in the family often receive less attention from them (Dellve et al., 2000; Dodd, 2004; Lutz et al., 2012; Opperman & Alant, 2003). Nine of the mothers in the present study described how reorganising the family's resources to meet the demands of the children with ASD signified that the target siblings were often not the primary focus of attention. "He probably misses out on some of my time." (Eva); "And that was where I was thinking again I need to give her a bit more time." (Tamara); "I think it would probably give me a bit more time with her [if her brother did not have ASD]." (Lauren); and "She has always been in the background.... nothing is ever about her." (Stephanie).

The prioritisation of the families' time to meet the needs of the children was common for a number of families, and mothers were aware of the discrepancy between the amount of resources devoted to the children with ASD in comparison to those devoted to the target siblings. However, some mothers also described how they had tried to find a balance in meeting the demands of the children with ASD as well as the needs of the other children. "So Belle [target participant] would've felt a little bit on the outside [when she was younger] and she still says, 'Dan is the favourite' and I go, 'No, Dan is not the favourite, you both are but you both get equal time when I'll worry about

you. You just have to worry about one at a time.” (Barbara). Lorna expressed the parents’ continual awareness of the greater demands created by Isaac’s special needs:

I think he has had to - - Isaac has taken up a lot of our time as parents in terms of getting to different appointments, and trying different therapies, and doing things at home. We have always tried to be conscious of balancing that a bit.

While Stephanie described how she compensated for the impact the reorganisation of resources had on the target sibling.

And every now and then I will sneak in things where the others [children with ASD] don’t see and that. And I guess in some ways it is like trying to make up for, you know, her [target sibling] not having everything that I would like her to have, and also for having to take on such a huge thing [role as carer].

(Stephanie).

One of the reasons why parents devote considerably more time to the children with ASD compared to the target siblings is because children with ASD have complex needs that often require multifaceted and time-consuming treatment programs (Stoner & Angell, 2006; Vismara & Rogers, 2010). Parents of children with ASD do not only have to take children to various appointments but often also take on the role of therapists and teachers (Kidd & Kaczmarek, 2010; Ozonoff & Cathcart, 1998). Parents have identified the cost, whether in terms of time or effort, associated with the care of children with ASD as a considerable burden on their resources that naturally diminishes the resources available to the target siblings (Mackintosh et al., 2012). However, not all mothers attributed the same meaning to the reallocation of resources and its impact on the target siblings.

Some mothers, such as Lorna, did not perceive the impact on the target siblings associated with the reallocation of resources as a significantly negative consequence of having brothers or sisters with ASD. She stated that even children in typically developing families learn that they cannot always be their parents' priority. "I think there have been times where, yeah, he [target sibling] has had to come second in that, but I guess that is normal for any kid." (Lorna). On the other hand, mothers such as Caitlin believed the target sibling's experience was significantly negatively affected by the ASD diagnosis. "I can't say how his [target sibling's] life would be different because there would be so many things that he'd missed out purely because Thomas had autism." (Caitlin). This dichotomous view is reflected in the literature, with some researchers positing that target siblings experience significant losses while others perceiving their experiences as less negative (Dempsey et al., 2012; Giallo et al., 2012; N. Gold, 1993; Griffith et al., 2014; Ross & Cuskelly, 2006; Yirmiya et al., 2001).

A number of factors can contribute to these varying views of the experiences of target siblings. The spectrum nature of ASD could account for some of the discrepancies in the literature and narratives of the families (Abbeduto et al., 2004; Dunn et al., 2001). The degree of coping experienced by the family unit could be another potential factor that might underpin the different perspectives of the mothers, as discussed in chapter 2. Families who have developed better coping mechanisms, and who have adapted to the stressors they have experienced are more likely to report positive aspects to their experiences; on the other hand, families who have less robust coping mechanisms, or who have not adapted as successfully are less likely to be able to identify positive aspects about their experiences (Dunkel-Schetter et al., 1992; Hastings, Beck, et al., 2005; Saloviita et al., 2003). Some theorists would argue that families do not cope as well as others due to the coping strategies they adopt to meet the demands

of the challenges they encounter (Abbeduto et al., 2004; Benson, 2010; Lazarus & Folkman, 1984). More complex explanations of coping would suggest that it is a multifactorial process that is dependent on the interaction between the accumulation of stressors, the resources available to the family, and the meaning attributed to the situation, along with the coping strategies employed; together these factors determine the degree of adaptation families will experience (McCubbin & Patterson, 1983). The narratives of the mothers reflected these more complex models of coping and adaptation as mothers described the various factors and layers that influenced the experiences of the target siblings.

In sum, mothers identified the reallocation of resources within the family, particularly parental time, as a significant factor shaping the experiences of the target siblings. Mothers generally expressed that target siblings had missed out to a greater or lesser degree as the demands of their brothers or sisters had consumed more of the family resources. Another key aspect of the experiences of target siblings related to the roles they performed within the family.

Target Siblings' Revised Roles

Researchers have identified that typically developing siblings of children with special needs, such as ASD, can take on added responsibility, which tends to increase as the target siblings become older (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Dowey, et al., 2009). As parents take on additional roles, such as teachers and therapists, this leads to a change in roles for other family members, including the target siblings (Hoogsteen & Woodgate, 2013). Mothers in the present study identified that the most common roles target siblings adopted were those associated with extra responsibility, and this was irrespective of the age of the target siblings in comparison

to their brothers or sisters with ASD. Carers and teachers were the most common roles described by the mothers in this study. “She likes to teach him,” (Tamara); “I think as Brandon [target sibling] became more aware he became more of the teacher” (Maya); “[In the future] there is still going to be, you know, looking after Scott somehow or being involved in his care [by the target sibling].” (Tamara). While both Lauren and Maya commented on the fact that the target siblings assumed a parental role in relation to their brothers with ASD. “She’s always been -- always helped out with him and been hands on with him because she was old enough to be, and I suppose in a way she’s kind, to both the boys, she’s kind of a bit like a second mother.” (Lauren); “Brandon has always been a parent help with Toby... He is like a third parent to him at times, to be honest.” (Maya).

Stephanie discussed how the target sibling had taken on the role of carer to both of her siblings with ASD from a young age due to the family dynamics created by the separation of the target sibling’s parents. Thus, indicating that the experiences of the target siblings can be shaped by the circumstances of the family unit.

Kirra has become very much a carer and has been from a very, very young age. As a single parent I did a lot of - - I was a nurse and I did a lot of shift work, and especially at night. I worked night duties, so she would have to look after them during the day..... [Now] she quite often will step in and try and help... you know, take on that other parent role, I guess, in a lot of ways. (Stephanie).

Some mothers did not perceive the target siblings’ roles as detrimental to their wellbeing. However, some mothers reflected on the discrepancy between the target siblings’ roles and their perceived expectations. These mothers recognised that the target siblings’ role within the family was likely not what the target siblings would have

wanted. “I think she would like to be spoilt, and I think she probably doesn’t feel spoilt. And occasionally, yeah, that is what she would like.” (Tamara); and “I would say it is all a big compromise. Yeah, I would say an awful lot of his experience in his role in the family is basically a compromise.” (Fiona). Some mothers recognised that the demands placed on the target siblings could be challenging for the target siblings, however, the mothers acknowledged that they did not often think about the significant role target siblings played in order to assist with the functioning of the family unit. “She has always been a very loving and caring, you know, natured girl and, it is always hard for me to remember that, you know, she has taken on such a huge role.” (Stephanie); and “Because sometimes one of the things that I think we do is we forget how we rely on him [target sibling] to help Toby, and we take it for granted sometimes. And that’s probably not fair.” (Maya).

The narratives of the mothers in the present study are consistent with at least two published studies (Myers et al., 2009; Taunt & Hastings, 2002). While it might be intuitive to think that taking on roles of added responsibility can be a risk factor for target siblings not all parents perceive the target siblings’ modified roles as inherently detrimental. Mothers have identified their children’s increased maturity, defined as target siblings taking on roles of greater responsibility, as a positive outcome associated with their experience as target siblings (Taunt & Hastings, 2002). Although this could reflect a misguided believe that significantly greater maturity in childhood and adolescence is a strength, more research is necessary to understand the prevalence and rationale of this perspective.

In the present study mothers identified a discrepancy between the ideal and the actual roles of the target siblings in the family. That is, these mothers reflected that the target siblings at times were expected to take a role of greater responsibility than

would be presumed in other circumstances, or to take a role of less prominence, at least for a time, in order to assist the families in meeting the needs of the children with ASD. The ability for the target siblings to adopt these roles was a critical aspect for the functioning of the family unit as they helped facilitate better family functioning and thus, it reflected the needs of the unit rather than the needs of the target siblings. “We appreciate that he hasn’t got much choice about it [helping care for his brother] ... I think there is an assumption, and I think he buckles under it sometimes.” (Fiona).

Well for Bianca, I guess she sort of felt like she was always being told off.

‘Don’t do this, don’t do that’, and ‘don’t upset him’, and ‘don’t upset him before school’, and all that sort of stuff, wanting to get him somewhere without too much of a fuss. And because she was older, and I suppose because she, in some ways, acted older, even when she was quite little... (Diana).

Likewise, Barbara described how the target sibling had had to adjust to the needs of her brother with ASD in order to assist with family life.

And a lot of time it was ‘Belle just go with the flow. Just do this, this one [time]. He’s not going to back down but can you just do this so we can get out into the car? So we can just do something, can we just do it?’ Because I’d take very often the easy road which meant someone had to give, and quite often it was Belle who had to give. (Barbara).

The quotes above illustrate the way the target siblings were expected by their mothers to adapt in order to assist in the functioning of the family. It has been documented that parents have expressed that when children are diagnosed with ASD these children become the focal point in the family (Hoogsteen & Woodgate, 2013). This focus on the children with ASD can reflect the process of adaptation. That is, when

family units are met with unique demands, such as those generated by raising children with ASD, it creates a need for all members of the family unit to adjust in order to maintain equilibrium within the system. However, this does not signify that the target siblings necessarily experience losses; gains can also be experienced, according to the mothers interviewed.

Character Development

Eleven mothers discussed numerous ways by which the target siblings had demonstrated a positive change in their personalities or maturity levels over time. In the present study mothers described empathy and compassion as common characteristics that were evident in the target siblings. Some mothers described the target siblings being empathic towards individuals with special needs. “His empathy is wonderful for kids like his sister.” (Eva); and “I think the empathy... and it’s not just for people with autism, I think it’s generalised to people with all types of disabilities. (Monica). Other mothers described empathy in a broader sense attributing the target siblings’ empathic nature to their experiences as target siblings rather than due to typical developmental changes experienced by all individuals. “I do think that his level of compassion and understanding has improved because he has a brother with a disability. So, yeah, I think that has definitely helped him develop emotionally.” (Lorna); and “I think he has got a lot of empathy and understanding because of the family that we have.” (Fiona).

Some researchers have documented that target siblings score better or at least no different than normative samples across a number of scales including peer relationships, emotional adjustment, and pro-social behaviours (Hastings, 2003b, 2007; Kaminsky & Dewey, 2001). There are also maternal reports that have described a positive impact on the characters of the target siblings, including increased tolerance, sensitivity, and

maturity (Myers et al., 2009; Taunt & Hastings, 2002). These findings are consistent with the narratives of the present study in that mothers identified positive character development in the target siblings as a positive consequence of their experiences. Moreover, some mothers identified that the target siblings had also learnt patience, and to care for others. “And, you know, we’ve mentioned some of those already in terms of compassion, and caring, and looking out for him” (Lorna); and “I think [if he did not have a brother with ASD] he might not have learnt that gift of patience with helping others.” (Maya).

Another area of the target siblings’ character that some mothers perceived had been impacted by their experiences was the way target siblings viewed the world. Some mothers described how the target siblings had become more tolerant and accepting of diversity. “She’s very, very tolerant of people who have any sort of difference, more accepting with people with differences.” (Diana).

I think she’s had the opportunities to embrace diversity. She has been a lot more tolerant of people with disabilities to the point where she tends to gather them in and look after them because, you know, she’s had to do it with her brother. (Barbara).

Moreover, mothers believed that the target siblings were able to develop skills or knowledge at a younger age. Mothers perceived the adolescents and youths becoming more mature in certain areas due to their experiences as a positive consequence for the target siblings. “I think he’s a lot wiser than a lot of kids his age because of the challenges that we’ve had over the last 12 years prior to his [brother’s] diagnosis.” (Caitlin); “She has learnt a lot of things: empathy, seeing life through someone else’s eyes, which as a child at her age, a lot wouldn’t have to do.” (Barbara); and “I think

when you've got a person in the family with a disability you learn those things [patience and compassion] probably much quicker, much earlier." (Lisa).

In summary, consistent with the findings of previous research (Hornby, 1992; Taunt & Hastings, 2002) mothers in the present study reported that the target siblings developed positive personality traits and pro-social behaviour as a result of their experiences. Mothers perceived these developments to occur at a younger age, believing that the target siblings behaved more maturely than their peers. Another significant aspect of the experiences of the target siblings related to their interpersonal relationships both inside and outside the family unit.

Target Siblings' Interpersonal Relationships

Having a sibling who has been diagnosed with ASD can have an impact on the social development of the other children in the family (Pilowsky et al., 2004). Researchers have indicated that having brothers or sisters diagnosed with ASD can impact relationships inside and outside the family unit (Hastings, 2003a; Kaminsky & Dewey, 2001). Conflicting evidence is available regarding the social skills of target siblings; with some researchers arguing target siblings have social deficits when compared to individuals whose siblings do not have ASD, while others reporting no such deficits (Macks & Reeve, 2007; Pilowsky et al., 2004; Piven et al., 1990; Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Similarly, conflicting results have also been published regarding the sibling relationship; with some researchers reporting a positive sibling relationship, and others reporting poor quality interactions between siblings (Bågenholm & Gillberg, 1991; Knott, Lewis, & Williams, 1995).

All mothers in the present study discussed the impact they believed having brothers or sisters diagnosed with ASD had on the interpersonal aspects of target

siblings' lives. Mothers related that having brothers or sisters with ASD impacted the target siblings' interpersonal relationships both inside and outside the family unit and consequently this theme was divided into two sub-themes. The first sub-theme – sibling relationship - detailed the mothers' perspective regarding the quality of the sibling relationship. The second sub-theme – social relationships outside the family unit - described the perception of the mothers regarding the impact of having a brother or sister with ASD on the social relationships of the target siblings outside the family unit.

Sibling Relationship

Central to the impact of having siblings with ASD on target siblings' relationships was the effect ASD had on the sibling relationship (i.e., the target sibling and the child with ASD). The sibling relationship is an important familial relationship that can provide all siblings with emotional support, companionship, and practical help (Rodrigue et al., 1993; Seltzer et al., 2005). Researchers have indicated that a chronic condition such as ASD can disrupt the relationship (Petalas, Hastings, Nash, & Duff, 2015; Reid, 1999).

Most mothers in the present study described a positive relationship between the target siblings and their brothers or sisters with ASD. "They've always had a good relationship; she's always been good with him." (Lisa); "She gets on extremely well with both of them [siblings with ASD]." (Stephanie); and "They have a lovely relationship. Hugo [target sibling] is very caring... he is very good with her and very protective." (Monica). Researchers have documented that target siblings report being able to have positive relationships with their brothers or sisters despite the challenges they also experience; thus challenging the notion that the experiences of target siblings

are either positive or negative in nature (Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Dowey, et al., 2009).

Although mothers spoke mostly of positive relationships between the siblings, a small minority described relationships that were less satisfying for the target siblings. “It’s like being an only child, I suppose because you don’t have a lot of - - they don’t have a lot of interaction unless they are watching TV together.” (Diana).

I think Felix [child with ASD] doesn’t fulfil what Patrick [target sibling] would have liked in a brother. So I mean, I would hate to say that he was disappointed in him because that is a nasty way to put it, but, yeah, there’s a void. There’s a gap in what he gets from his big brother. (Fiona).

The mothers raised a significant issue in the experiences of some target siblings, namely having sibling relationships that do not fulfil all of the target siblings’ needs, including interpersonal needs. This has been identified as an important issue in the literature (Orsmond & Seltzer, 2009; Reid, 1999). While target siblings can have relationships with their brothers or sisters that are free from conflict they can nevertheless miss out on some of the intimacy, nurturance, and reciprocity characteristic of the dyads of typically developing children (Bank & Kahn, 1975, 1976; Kaminsky & Dewey, 2001; McHale et al., 2016; Seltzer et al., 2005; Walton & Ingersoll, 2015).

Mothers at times compared the sibling relationship to typically developing sibling dyads, highlighting its differences. “They probably bicker less than the average family.... I would say they have a better relationship than most siblings.” (Eva); and “And she [target sibling] is thinking, ‘I’ve never had a fight with my brother’. So he never fights, if there is an argument it is like he just goes and does something else. He won’t retaliate to her.” (Tamara).

Even though some of the differences appeared to be positive, such as the absence of conflict in the sibling relationship, the differences did not necessarily have a positive impact on the target siblings. The most prominent effect the mothers reflected on was that the target siblings often missed out on a more typical sibling relationship or learning opportunities. “Maybe wishing sometimes she had a normal brother or sister, wondering what it is like.” (Tamara).

I always felt a little bit sorry for her because she didn't have that normal rapport with a brother or sister. Like I had a brother, he was as annoying as he was but he was still someone that you could talk to or you could learn from you know, you could learn to be assertive with. She just didn't develop any of those skills so she was quite unprepared for how she would be treated at school. (Diana).

Parents of children with ASD in the past have expressed mixed feelings about the future (Myers et al., 2009; Taunt & Hastings, 2002). In these studies, parents have expressed a desire for a better future while acknowledging the challenges that lay ahead. In the present research study, the future sibling relationship was another significant area that the mothers believed would be affected by the diagnosis of ASD. Similar to the assessment of the current sibling relationship, mothers' vision of the future relationship between the target siblings and their brothers or sisters with ASD ranged from a close relationship to a distant one. The majority of mothers predicted it was likely the siblings would have a good relationship, with the target siblings most commonly likely to fulfil a caring role in their brothers or sisters' lives. “I think Brandon [target sibling] would still, go and see Toby, and look after him actually.” (Maya); “I would imagine that Finn [target sibling] would always be a bit of a sounding board for Isaac or a point of reference for him, and that he will continue to have that little caretaker role of looking

out for his brother.” (Lorna); and “Kirra will remain connected to both... I see her as being still in that [care giving] role.” (Stephanie).

Future sibling relationships were not always perceived by the mothers as being without their potential difficulties though. A small number of mothers foresaw the siblings growing apart as the target siblings aged, although they hoped it would not be permanent.

What I imagine with the kids, with Hugo [target sibling] is that I think when he’s about 18 I think he will want to escape for a while... I imagine when he’s that age, late teens to early twenties there will be a growing distance as he does his own thing. I am hoping that they will then come together as they grow older. (Monica).

I hope that they will see that there is a point in seeing each other on a regular basis and connecting to each other. I hope that they will feel a pull or a need to do that, because really all they have in common is that they are from the same family, they don’t have any interests in common. (Fiona).

Despite the optimism expressed by many mothers in the present study, some mothers demonstrated insight regarding the discrepancy between what they hoped for the future sibling relationship and what they currently perceived. “Well, how do I see [the future sibling relationship] or how do I hope [the future sibling relationship will be]?” (Fiona). It is possible that mothers choose to remain hopeful about the future as a coping mechanism rather than as a reflection of the current sibling relationship (Dunkel-Schetter et al., 1992; Hastings, Kovshoff, et al., 2005).

Mothers' perceptions of the sibling relationship varied greatly from very positive appraisals to quite negative appraisals. The variance described by the mothers reflected the literature. That is, based on the literature available it cannot be said with certainty whether the quality of the sibling relationship when an individual has ASD is significantly poorer or similar to that of typically developing sibling dyads (Kaminsky & Dewey, 2001). However, the mothers in the present study indicated that the siblings' relationship seemed to be predominantly defined by the target siblings' role as carer for their brothers or sisters with ASD, a role that would likely continue to define the sibling relationship in the future. Another aspect that mothers perceived to have been impacted by the experiences of the target siblings was their relationships outside their immediate families.

Social Relationships Outside the Family Unit

The social relationships of target siblings outside the family unit can also be impacted when they have brothers or sisters with ASD (Shivers et al., 2013). There is evidence that indicates that target siblings are more likely to experience a range of social issues, including social dysfunction and isolation, have limited relationships outside the family, as well as suffer from impaired play and conversational skills, although it must be noted that the results are inconsistent (Piven et al., 1990; Piven et al., 1997). Embarrassment was the most prominent social issue for the target siblings occurring outside the family unit as described by the mothers in the present study. "I think at times he can get embarrassed by Isaac, especially when he is getting angry at someone or overreacting to a certain situation in a public place" (Lorna) and "I would say having a weird brother—and that's a term that he might use—might be a bit embarrassing at times." (Fiona); and "I think it is that sometimes he is embarrassed by her behaviour." (Monica).

For many target siblings the emergence of self-consciousness towards their brothers or sisters' behaviour coincided with early adolescence, as perceived by the mothers. "When she went off to high school she went to a different high school and I think it [her peers finding out about her brother's diagnosis] was a bit of an issue for her." (Lisa); and "I wonder sometimes if she's been a bit embarrassed. She used to have friends over when she was a bit younger but she rarely does since she has been at high school." (Diana). Monica, whose typically developing son was 12-years-old at the time of the interview, also identified adolescence as the time when his embarrassment regarding his sister's atypical behaviour appeared to emerge: "I think this embarrassment is a new thing, so that being publicly aware of her not being normal."

Researchers have reported that target siblings can feel angry, embarrassed or rejected due to the reactions of those outside the family unit towards the children with ASD and these emotions can provoke social difficulties for the target siblings (Moyson & Roeyers, 2012; Petalas, Hastings, Nash, Dowey, et al., 2009). Moreover, self-consciousness is a developmental phenomenon that occurs as children mature and it peaks during adolescence due to the adolescents' greater awareness of what is socially acceptable and desirable (Saarni, 2011). The growing awareness of the discrepancy between socially acceptable behaviours and the unusual behaviours associated with ASD can help explain the embarrassment described by the mothers in the present study. However, the developmental changes associated with adolescence, such as increased independence, also helped to decrease some of the social challenges. "I don't think there're too many social challenges these days because Kyle's [target sibling] just kind of hit that next level of maturity where they [the target sibling and the child with ASD] don't really spend a great deal of time out and about." (Caitlin). Therefore,

developmental factors played an important role both in exacerbating and ameliorating the social issues the target siblings in the present study experienced.

Having brothers or sisters with ASD posed other social challenges for the target siblings. In some cases, the target siblings were victims of bullying. “I think he did get teased a bit because of the way Thomas [child with ASD] was but he never verbalised it, it’s just instances that I got from hearing from other people.” (Caitlin); and “There was bullying going on [at school]. Some of it was related to him having a sibling with autism.” (Maya). For other target siblings, social difficulties outside the family unit emerged as limitations in social opportunities. “However, there are certain things which are made a lot more difficult. For example, she rarely has friends over because both of the boys - not just Fletcher [child with ASD] but it did start with Fletcher - make it very difficult.” (Lauren); and “I would say she probably feels a bit isolated, again.” (Tamara). When Diana was asked if she thought her daughter’s life would be different if she did not have a sibling with ASD she responded positively, explaining: “But yeah, maybe she would’ve been a bit more outgoing.”

In sum, the excerpts above illustrate the various ways that having brothers or sisters with ASD impacted on the social relationships of target siblings. Mothers perceived the target siblings to experience feelings of self-consciousness as they entered adolescence. Mothers predominantly spoke of the negative impact having brothers or sisters with ASD had had on the target siblings’ social relationships outside the family. The negative accounts of social experiences outside of the family unit are consistent with some of the literature (Yirmiya et al., 2001) and indicate that a central aspect of the being target siblings, as perceived by their mothers, is the effect the target siblings’ experiences have on their social lives. However, the narratives of the mothers indicated that developmental factors influenced the social difficulties experienced by the target

siblings. The last theme evident in the narratives of the mothers regarding the experiences of the target siblings related to the phenomenon of maturation, and the impact this had had on the experiences of the adolescents and youths.

Developmental Maturation

According to the mothers, the experiences of the adolescents and youths changed over the course of time; thus, suggesting that developmental maturation is a factor that should be considered when exploring the experiences of target siblings. Mothers described that over time the target siblings matured, became more independent from the family unit, and learnt to adjust to the demands posed by having brothers or sisters diagnosed with ASD. One way in which the impact of developmental maturation on the experiences of the target siblings was at times reflected was in the relationship they had with their brothers or sisters with ASD.

Mothers such as Caitlin described how the sibling relationship had improved as the siblings aged. In this particular case, the ASD diagnosis precipitated a change in the target sibling that led to greater understanding.

[Kyle's relationship with Thomas has been] Much better over the last two years, again since Thomas's been diagnosed, there's a lot more understanding there. Prior to that it was pretty horrible.... I can remember Kyle saying that Thomas had ruined his life a couple of times just by things he [Thomas] had done and said, and how much he [Kyle] hated him [Thomas], that kind of thing, just purely through lack of understanding more than anything, and his [Kyle's] frustration. He still gets frustrated with Thomas but he's managed to kind of distance himself from Thomas' actions, and just explain that's just the way his autism works instead of taking it on a personal front. (Caitlin).

Although from Caitlin's perspective the diagnosis itself played a significant role in the target sibling's attitude towards his brother, other mothers described an improvement in the sibling relationship over time not attributed to the diagnosis itself. When asked if there had been changes in the sibling relationship Barbara replied: "Yes, [they are] a lot more tolerant of each other, a lot more supportive of each other." Similarly, Fiona stated: "I think it is more understanding from Patrick's [target sibling] point of view. I think they are more tolerant of each other. He [target sibling] is a smart guy and as he gets older I think he sees 'this is just how it is; I had better just learn to live with it'." While Lisa described a change in the target sibling's attitude towards her brother particularly during adolescence: "There's obviously been times when, you know, she hasn't been happy having a brother with a disability... it changes obviously with their age like I say, the teens were probably more difficulty, you know, I'm sure she's been more than embarrassed at times with him." (Lisa).

A number of mothers related that the target siblings at times felt self-conscious about their brothers or sisters with ASD. However, mothers such as Monica believed her son's current self-consciousness regarding his sister's diagnosis was due to his developmental stage, and it would be transitory.

Again, I think, I assume, I hope that when he gets into those mid-20s or you know, early 20s that it will not bother him so much anymore, and that you know it won't be an issue. But I think for the next couple of years he won't be telling people. (Monica).

For some mothers, adolescence marked a change in the level of responsibility the target siblings took on. "If anything he has probably taken on a bit more responsibility" (Lorna); and "Like I say, school holidays and things when she [target

participant] was older she was asked to look after him and take him to the movies. She's much more accepting of that now that she's a bit older but I'm sure that wasn't what she wanted to do when she was a teenager" (Lisa). The changes in the experiences of the target siblings over time, as described by the mothers, can be explained by two perspectives, namely; developmental and adaptation models.

Developmental models propose that as individuals' age their cognitive, emotional, and social skills develop, and this maturation is reflected in changes to their understanding, attitudes, and relationships. In the present study, the target siblings, as described by their mothers, demonstrated changes to their ability to understand and cope with the demands associated with having brothers or sisters with ASD as they matured. Likewise, target siblings also demonstrated positive changes in the relationships or attitudes, which can be an indicator of successful adaptation, as described in chapter 2 (Patterson, 1988, 2002; Walsh, 2003, 2006). Models of adaptation emphasise that adaptation is a process that occurs over time rather than being a one-off event (Lutz et al., 2012; Patterson, 1988). Similarly, coping has been conceptualised as a continuous change in behaviours and cognitions in order to adjust to internal or external demands (Lazarus & Folkman, 1984). Consequently, the gradual adaptation in the target siblings to the challenges they experience is consistent with both developmental models and coping and adaptation models, and could be considered to continue to evolve throughout the target siblings' lives.

The target siblings changing and adapting to the demands of their experiences are not only supported by theoretical frameworks but also by researchers such as Bayat (2007) who reported that families of children with ASD are able to develop coping strategies to handle the demands associated with raising children with special needs. In addition, target siblings themselves have hinted to the significance of developmental

maturation in terms of their experiences. Petalas, Hastings, Nash, Reilly, and Dowey (2012) reported that adolescent target siblings viewed the relationships with their brothers or sisters with ASD more positive at the time of the study than when they were younger. It is possible this is a reflection of their ability to cope and adapt to the demands of their brothers or sisters, and thus enabling them to form more positive relationships (Taunt & Hastings, 2002). Despite the limited empirical evidence available regarding target siblings' adaptation, there are theoretical frameworks that support the premise that target siblings are able to cope and adapt to the unique demands they encounter particularly as they mature. Consequently, developmental maturation seems to be an important factor in the lives of these families and this aspect requires further research.

In sum, mothers identified developmental maturation as an important construct in the experiences of the target siblings. It was evident that the experiences of the target siblings were not static, but changed over time. A number of theories, concepts, and studies (Lutz et al., 2012; Patterson, 1988; Petalas, Hastings, Nash, Reilly, et al., 2012) indicate that families and individuals are able to adjust to the challenges associated with having brothers or sisters with ASD, a process that is clearly dependent on time and that requires further investigation.

Summary

The results of the semi-structured interviews that were analysed with the use of IPA revealed a number of key themes and related sub-themes about how mothers perceived the experiences of the adolescents and youths as target siblings. The narratives of the mothers indicated that the experiences of the target siblings were imbedded within the experience of the family unit. That is, mothers described how ASD

impacted the entire family unit as families had to adjust to the unique, and at times complex, demands of the children with ASD. The experiences encountered by the mothers often led to positive changes in the mothers' perspective on life as well as what it meant to have special needs. Mothers tried to pass on these newly developed attitudes to the target siblings. As the experiences of the families directly impacted on the experiences of the target siblings it is therefore important that researchers contextualise the experiences of the target siblings within those of the family unit.

A common theme across the interviews with the mothers related to how they perceived the target siblings had been affected when the family reallocated its resources to cope with the demands of raising children with ASD. The shift in resources led to the target siblings taking on a number of different roles, such as carers and teachers. Mothers did not perceive these roles as intrinsically negative although they did recognise that the target siblings could miss out on opportunities as well as feel burdened by the additional responsibilities. Mothers often perceived that the experiences of the target siblings led to the development of positive character traits such as empathy, tolerance, and maturity. Having brothers or sisters diagnosed with ASD was also identified as impacting on the social relationships of the target siblings both inside and outside the family unit. While the sibling relationship was generally positive despite significant deficits, social issues outside the family unit were common, with embarrassment being most evident during early adolescence and diminishing as the target siblings grew older.

Finally, mothers identified that the experiences of the target siblings were not static. That is, the target siblings changed, developed, and learnt to adjust to the challenges they encountered. Therefore, it can be said that mothers identified a number of challenges in the experiences of the adolescents and youths as siblings of individuals

diagnosed with ASD that not only affected the target siblings directly but also impacted the family unit. However, overall mothers perceived the experiences of the target siblings and the family units as largely positive, and having provided all family members with opportunities for growth.

The following chapter concludes the dissertation by providing a general discussion of the results of stage one and stage two of the study. In addition, the limitations, and areas of further research are identified. Finally, the applications and implications of the present study are discussed.

Chapter 9

General Discussion

Chapter Overview

In this chapter the results from stage one and stage two of the research study are summarised. The significance of the results along with the scholarly, methodological, and clinical implications are discussed. Lastly, the limitations of the current research study as well as areas of further study are identified.

Chapter 9

General Discussion

Stage One Summary

Researchers investigating the impact that living with children with ASD can have on the family unit have generally reported that families tend to experience considerable stress and adjustment issues (Benson, 2006; Benson & Karlof, 2008; Davis & Carter, 2008; Dunn et al., 2001; Lutz et al., 2012). In more recent times, researchers have also investigated the impact ASD can have on typically developing siblings (Benderix & Sivberg, 2007; N. Gold, 1993; Hastings, 2003b; Macks & Reeve, 2007). The results of previous research regarding the psychological adjustment of the target siblings have been diverse and it cannot be said with certainty whether target siblings experience greater psychological distress, particularly when compared to other clinical and community sibling groups (Griffith et al., 2014; Tomeny et al., 2012; Verte et al., 2003).

Methodological issues such as including children, adolescents, and youths within a single study, the composition of the comparison groups, or the type and number of informants have impacted on the available findings regarding the psychological adjustment of target siblings. In addition, the impact of protective factors, such as family functioning and psychological resilience on the psychological adjustment of target siblings has not been sufficiently researched. Thus, stage one of the current study had two main aims; first, to investigate if group differences were evident between target participants (adolescents/youths and their mothers) and community participants (adolescents/youths and their mothers) on measures of the adolescents/youths' psychological resilience and psychological distress, as well as family functioning.

Second, stage one aimed to explore the relationship between the target siblings' psychological distress and psychological resilience and family functioning from the perspective of the target siblings and their mothers. In order to address the first aim, 52 target siblings and their mothers completed questionnaires measuring the psychological distress of the target siblings, the target siblings' level of psychological resilience, as well as the functioning of the family. The target participants were compared to 34 community siblings and their mothers in order to answer the first two research questions.

Research question 1: How do the reports of target siblings differ from the reports of community siblings on the measures of psychological resilience, psychological distress, and family dysfunction?

Research question 2: How do the reports of target mothers differ from the reports of community mothers regarding the psychological resilience and psychological distress of participating siblings, and the degree of family dysfunction?

The results indicated that when compared to adolescents and youths whose brothers or sisters were typically developing, target siblings reported being less resilient only. In the domains of psychological distress and family functioning, target siblings reported comparable outcomes to those of community samples. According to the target mothers, the target siblings displayed lower levels of psychological resilience and greater levels of psychological distress when compared to the reports of community mothers regarding the community siblings. However, target mothers reported comparable family functioning to that reported by community mothers.

Preliminary analyses detected no differences between the reports of the adolescents/youths and their mothers, irrespective of group membership, on any of the

scales. That is, no significant informant differences were detected on measures of psychological resilience, family functioning, or psychological distress. When the clinical cut-offs denoting unhealthy functioning on the family functioning scales were considered, the reports of the target siblings and their mothers were considerably different. While the reports of mothers on the scales of roles and affective involvement associated with family functioning reached the clinical cut-off point, target siblings' reports reached the clinical cut-off on all scales except for behaviour control.

Research question 3: To what extent are family dysfunction and psychological resilience, as reported by the target siblings and the target mothers, associated with psychological distress in target siblings after controlling for informant type (target siblings vs. target mothers) and the target siblings' age and gender?

Family functioning and psychological resilience were identified as having a unique and large impact on the psychological distress of target siblings in the present study. The demographic variables of gender and age were not identified as significant predictors in the present sample. The type of informant (i.e., target sibling or target mother) was also not a significant predictor of the target siblings' psychological distress. The results of the present study indicate that the psychological adjustment of target siblings can be explained by factors other than having brothers or sisters with ASD, such as psychological resilience and the functioning of the family unit. Therefore, the experience of target siblings is bound to be better understood within a risk and protective factors framework that accounts not only for the impact of living with brothers or sisters with ASD (the risk context) but also for protective factors related to the target siblings (e.g., demographic variables or psychological resilience) and protective factors relating to their environment (e.g., family functioning).

Stage Two Summary

The number of qualitative studies regarding the experiences of target siblings who are adolescents or youths is small in comparison to the number of quantitative studies; however, the qualitative data provide insight into the experiences of target siblings not otherwise available in quantitative data. In particular, qualitative data allow researchers to examine in detail aspects of the target siblings' experiences not as easily captured in quantitative results, such as the processes of coping and adaptation. The aim of stage two of the current study was to explore the factors that impacted the experiences of a subgroup of target participants that had participated in stage one of the research study, thus providing contextual information to better understand the findings currently available. Twelve target siblings and their mothers took part in individual one-off semi-structured interviews. The aim of the interviews was to answer two research questions.

Research question 4: How do adolescents and youths perceive their experiences as siblings of individuals diagnosed with ASD?

The interviews with the adolescents and youths indicated that the experiences of the target siblings are not static; the target siblings reflected that their experiences had evolved as their families, their brothers and sisters with ASD, and the target siblings themselves had changed. In particular, target siblings described how over time they believed their characters and their understanding of ASD had evolved. Target siblings identified a range of difficulties they experienced, including witnessing aggressive behaviour from their brothers or sisters, social difficulties, and concerns about the future. Target siblings also identified their role within the family unit as carers, particularly of their brothers and sisters with ASD. The role of the target siblings as

carers at times reflected the needs of the family. That is, target siblings would care for their brothers or sisters in order to assist their parents and facilitate the functioning of the family. Therefore, the narratives of target siblings contained themes depicting challenges and potential risks (e.g., feeling embarrassed about atypical behaviour, having to care for their brothers or sisters with ASD, or being exposed to aggressive behaviour) but also examples of more typical sibling experiences or even opportunities for positive self-growth (e.g., shared enjoyment with their brothers or sisters or developing empathy and compassion).

Research question 5: How do mothers perceive the experiences of the adolescents and youths as siblings of individuals diagnosed with ASD?

The interviews with the mothers identified that the experiences of target siblings occurred within the context of the family unit and this set the backdrop against which the experiences of these adolescents and youths could be understood. Mothers detailed how the target siblings had been impacted by the reorganisation of resources as well as by the changes in the target siblings' roles. In addition, the experiences encountered by the target siblings had an impact on their characters. The mothers discussed the interpersonal impact on the target siblings both with their brothers or sisters with ASD, as well as with individuals outside the family unit. Lastly, the mothers perceived that the experiences of the target siblings were contextualised within the phenomenon of developmental maturation. That is, the target siblings, their brothers or sisters with ASD, and their families changed and developed over time, thus their experiences were not static. Mothers described a positive change over time as target siblings and their families adjusted to the needs precipitated by the children diagnosed with ASD.

Table 9.1

Summary of the Stage One and Stage Two Results

Stage	Research question	Results
One	RQ 1: How do the reports of TS differ from the reports of CS on the measures of psychological resilience (READ), psychological distress (DASS), and family dysfunction (FAD)?	READ: TS < CS, $p = .001^*$, $d = .57$ DASS: TS > CS, $p = .22$, $d = .28$ FAD: TS > CS, $p = .19$, $d = .3$
	RQ 2: How do the reports of TM differ from the reports of CM regarding the psychological distress (DASS) and psychological resilience (READ) of participating siblings and the level of family dysfunction (FAD)?	READ: TM < CM, $p = .01^*$, $d = .67$ DASS: TM > CM, $p = .005^*$, $d = .58$ FAD: TM > CM, $p = .07$, $d = .4$
	RQ 3: To what extent are family dysfunction (FAD – GFS) psychological resilience (READ total) as reported by the target siblings and the target mothers associated with psychological distress (DASS total) in TS after controlling for informant type (TS vs. TM) and the TS' age and gender?	FAD – GFS: $B = 13.30$, $\beta = .29$, $p < .001^*$ READ: $B = -18.66$, $\beta = -.42$, $p = .002^*$
Two	RQ 4: How do adolescents and youths perceive their experiences as siblings of individuals diagnosed with ASD?	Evolving experiences Awareness of ASD Character development “It’s difficult sometimes” Aggressive and violent behaviour from the sibling with ASD Social challenges Time spent worrying Target siblings as carers Present-day caring Caring in the future
	RQ 5: How do mothers perceive the experiences of the adolescents and youths as siblings of individuals diagnosed with ASD?	Family unit Families managing ASD Mothers’ own experience Being a target sibling Reorganisation of resources Target siblings’ revised roles Character development Target siblings’ interpersonal relationships Sibling relationship Social relationships outside the family unit Developmental maturation

Note. TS = target siblings; CS = community siblings; TM = target mothers; CM = community mothers.

When the results of the interviews with the target siblings and their mothers are considered together the following themes are evident. First, the experiences of the target siblings were not described as being static. Rather, the target siblings, their brothers and sisters with ASD, and their families experienced changes, which impacted on the reported experience of the target siblings. Moreover, mothers reflected how developmental maturation affected the target siblings' experiences. Second, despite normalising the experiences of the target siblings, both mothers and target siblings reported numerous challenging, and at times distressing aspects of being a target sibling (e.g., aggressive behaviour from the children with ASD). Third, target siblings and their mothers believed that the target siblings' experiences had precipitated personal growth in the adolescents and youths. Fourth, the narratives of the target siblings and their mothers illustrated the influence family factors (e.g., the family's resources) can have on the target siblings' experiences. The target siblings and mothers described how the target siblings had to adopt certain roles in order to assist the family's functioning. Mothers described how the needs of the family unit were at times prioritised above those of the target siblings' needs, while the target siblings' narratives reflected their acceptance of this family dynamic. Fifth, target siblings and their mothers described the sibling relationship as being characterised by the care target siblings offered their brothers and sisters. This dynamic was predicted to be one of the key features of the siblings' relationship in the future. In sum, the results of stage two provide information that can assist in understanding the complex and diverse experiences of target siblings. Consequently, the results of stages one and two will be considered together next.

Overall Summary

The impact of living with brothers or sisters with ASD on the target siblings' experiences, as perceived by the target siblings and their mothers, can be summarised

into three areas: psychological, interpersonal, and familial. A summary of the results of stage one and stage two can be seen in Table 9.1. The findings indicated that the target mothers reported greater psychological distress in the target siblings when compared to the reports of community mothers. In addition, target siblings and their mothers reported lower levels of psychological resilience in the target siblings than those in the community group. Lower levels of psychological resilience suggest that target siblings can be at greater risk of succumbing to the stressors they are exposed to (Anyan & Hjemdal, 2016; Bellin & Kovacs, 2006; Moreira et al., 2015). In the qualitative stage target siblings reported having considerable worries about their brothers or sisters with ASD that caused them varying degrees of concern. Target siblings also reported feeling distressed by their brothers or sisters' aggressive behaviour.

The current study provides evidence that adolescents and youths can experience distress as a result of their experiences as target siblings. The findings of the current study also indicate that the distress target siblings experience can be conveyed differently. That is, mothers reported their perception of the target siblings' distress in the quantitative (when compared to community siblings) and qualitative stages of the study. On the other hand, target siblings reported experiencing distress in the qualitative stage of the study but similar psychological distress as community siblings in the quantitative stage. In light that target siblings were identified to have fewer resources to draw on when faced with challenges due to lower levels of psychological resilience the current findings provide evidence that the perception of distress can be different for target siblings and mothers and thus conveyed differently.

Target siblings and their mothers also reported that the interpersonal experiences of the target siblings had been affected in several ways by having brothers or sisters

with ASD. The target siblings particularly, identified negative social consequences associated with having brothers or sisters with ASD, especially interpersonal relationships outside the family unit. Both mothers and target siblings identified that learning to cope with social challenges was a central aspect of the experiences of the target siblings. Similarly, target siblings and mothers identified that having brothers or sisters with ASD impacted the sibling relationship in both positive and negative ways. These results suggest that while the interpersonal lives of target siblings can be impacted by their experiences, the effects of the challenges are likely to be dependent on the specific social domains under investigation. For example, while target siblings can be victims of bullying, they may develop greater empathy at a younger age. Moreover, the target siblings' family lives are also affected by their experiences.

Although the discrepancy between the family functioning reports of target siblings and their mothers and those of the community participants did not reach statistical significance, clinically significant dysfunction were identified in the reports of the target siblings and the target mothers. In the interview phase, target mothers expanded on the challenges their families had to negotiate in order to meet the demands of the children with ASD, such as reorganising the family's resources and roles. These adjustments signified that, at times, target siblings received less attention from their parents, or had to take roles of greater responsibility, such as caring for their brothers or sisters with ASD. Despite target participants identifying that raising children with ASD created a number of challenges for the family unit, target mothers in particular, were also able to discuss positive outcomes, thus, indicating that coping and adaptation were possible outcomes for these families. Consistent with the Double ABCX model (Pakenham et al., 2005; Saloviita et al., 2003) adaptation to stressors occurs on a continuum and can change over time. Indicators of adaptation were reported by the

target siblings and/or their mothers including: comparable levels of psychological distress and family dysfunction to those of community participants, the development of empathy and tolerance in the target siblings, and identification of positive experiences associated with their brothers or sisters with ASD.

In sum, the findings of the current research study indicate that having brothers or sisters with ASD predisposes target siblings to experience increased distress in a number of areas, including in psychological, social, and familial domains. The increased distress that they experience can translate into increased risk of poor psychological wellbeing when compared to community siblings. Moreover, the distress and risk experienced by target siblings may be clinically significant even if it does not reach statistically significant levels. Consequently, target siblings and their families are likely to benefit from clinical support in order to foster and strengthen protective factors, such as psychological resilience and family functioning, which can continue to buffer the target siblings from the stressors they are exposed to.

The importance of contextualising the experiences of the target siblings within the experiences of their family units is further highlighted by the target siblings' role as carers. The interviews with the mothers and target siblings indicated that target siblings were prone to internalising their parents' expectations, especially regarding caring for their brothers or sisters in the future. That is, the expectations of target siblings who stated they would likely become their brothers or sisters' carers once their parents were unable to do so often paralleled the narratives of their mothers who indicated that the responsibility of caring for the individuals with ASD in the future would rest on the target siblings. This suggests that the experiences of target siblings, particularly during childhood, adolescence, and early adulthood when the target siblings are most likely to still be dependent on their families of origin, would be best understood within the

context of the experiences, including degree of coping and adaptation, of their family units (Andolfi & Mascellani, 2013; Cree, 2003).

Contributions of the Current Research Study

As it can be seen the findings of the current study suggest that having brother or sisters with ASD can have positive and negative impacts on target siblings across numerous domains. In the next section the contributions of the current research will be discussed. The contributions to the literature, methodology, and clinical practice will be discussed in turn.

Contributions to Literature

The results of the present study have helped clarify the impact of having brothers or sisters with ASD across the developmental phases of adolescence and early adulthood in isolation from childhood. Even though other studies researching the experiences of target siblings have included adolescents and youths in their samples, researchers rarely analyse if differences exist between the results of younger target siblings and those of older target siblings (e.g., N. Gold, 1993). A focus of this study was to provide data that specifically applied to adolescents and youths who had a sibling diagnosed with ASD. Moreover, the study provided both quantitative and qualitative data for the same sample of adolescents and youths thus allowing for a mixed methods investigation of one group of target siblings that increased the richness of the findings. The current study provided some findings regarding how typical developmental factors (e.g., the development of embarrassment) can interplay with the unique aspects of being a target sibling (e.g., atypical behaviour from their brothers or sisters with ASD), and together shape the experiences of target siblings.

The present study also contributed knowledge regarding predictors associated with the psychological wellbeing of target siblings. Researchers have identified that some demographic variables such as age and gender can impact on the psychological adjustment of target siblings although the results are inconsistent (Di Biasi et al., 2016; Giallo et al., 2012; N. Gold, 1993; Macks & Reeve, 2007; Orsmond & Seltzer, 2009; Rodrigue et al., 1993; Walton & Ingersoll, 2015). However, the findings of the present study indicated that the variables of family functioning and psychological resilience are significant factors in the experience of psychological distress of target siblings. The identification of psychological resilience as being negatively associated with psychological distress adds to the growing body of knowledge that indicates that psychological resilience is a significant protective factor for psychological adjustment (Masten & O'Dougherty Wright, 2010; Ungar, 2005). In particular, the current study provides data on psychological resilience in a population which had not yet been investigated. Additionally, while a small number of researchers have examined the relationship between family functioning and the target siblings' outcomes, family functioning has only been measured from the parents' perspective (Benson & Karlof, 2008; Mohammadi & Zarafshan, 2014). Consequently, the current research study provides findings exploring the relationship between the target siblings' psychological wellbeing and family functioning from the perspective of the target siblings themselves.

The identification of familial and personal factors associated with the psychological adjustment of target siblings increases our understanding of the experiences of target siblings and it also increases the support for conceptualising their experiences within the risk and protective factor framework. That is, having brothers or sisters diagnosed with ASD may precipitate a number of processes that in combination with other risk or protective factors leads to positive or negative psychological

adjustment for the target siblings. As more risk and protective factors associated with the experiences of target siblings are identified it will assist researchers in developing better conceptual models for researching and understanding this population.

The degree of congruence in the reports of the mothers and adolescents/youths is another contribution to the literature. There is evidence to indicate the reports of informants can depend on factors such as the roles they play within the family unit (Davis & Carter, 2008; Gua et al., 2012; Lutz et al., 2012). However, in the present study mothers and adolescents/youths reported similar results in terms of the participating siblings' psychological wellbeing and psychological resilience, as well as family functioning. This finding suggests that, at least in the current study, mothers can accurately report on their children's personal attributes or experiences. However, clinical differences were detected between target siblings and their mothers on the scales of family functioning, with target siblings reporting clinically significant family dysfunction in more areas than their mothers. This finding suggests that mothers and target siblings perceive family functioning differently even if these differences are not statistically significant. Therefore, the results of the present study indicate that the use of multiple informants can allow for a richer understanding of the phenomenon under investigation.

In stage two, the findings indicated that developmental maturation impacts on the experiences of the target siblings, an aspect not evident in quantitative research. While these findings could be examined in longitudinal studies, longitudinal studies are not common in this area of research. Overall, both target siblings and their mothers reflected on the dynamic nature of the target siblings' experiences as the target siblings had matured. In addition, mothers explained how they tried to explicitly shape the perspectives of the target siblings as the target siblings matured by focusing the target

siblings' attention on the positive aspects of their experiences. The findings of the current study thus provide a basis for contextualising research on target siblings within a developmental framework.

Contributions of the Methodology

The present study utilised a mixed methods design with quantitative and qualitative components to investigate the experiences of target siblings. The majority of studies in this area of research use only one methodology, either quantitative or qualitative, consequently, the methodology of the current study has contributed to the findings. The combination of both types of methodologies has provided a new perspective to the findings of the current study. One of the benefits of utilising mixed methods in research studies is that it can help overcome the limitations of individual methodologies, namely the loss of contextual information in quantitative studies, and the lack of generalisability in qualitative research (Creswell & Plano Clark, 2011). By combining both methodologies in this study the quantitative data were reported with some contextual information. In particular, stage two was able to provide an in-depth exploration of a portion of the target participants of stage one, thus expanding on the data that had already been collected in stage one. Reporting data within their original context allowed particular aspects of the target siblings' experiences that were not captured in stage one to be explored in stage two. In particular, the qualitative results seemed to cast some doubt over the degree of adjustment reported in the quantitative data. That is, the narratives of the target siblings and their mothers indicated that target siblings experienced considerable challenges, missed out on the family resources, and took on roles of greater responsibility. In combination with lower levels of psychological resilience target siblings would be expected to carry a considerable psychological burden.

Likewise, the use of multiple informants, namely siblings and mothers, provided convergent information, consequently increasing the reliability and validity of the data. Increasing the number of data collection points, in this case the use of multiple informants, increases the richness of the data collected (T M Achenbach, 2006; De Los Reyes et al., 2015; De Los Reyes, Thomas, Goodman, & Kundey, 2013; Oltmanns & Turkheimer, 2009). The lack of significant discrepancies on the scales indicates that maternal reports can be an acceptable source of information about the children in the family and the family's functioning. However, target siblings reported more areas of clinically significant family dysfunction than mothers. Therefore, methodologically, including multiple informants is likely to assist researchers in drawing the most accurate and informative conclusions, including being able to explore differences in perspectives between informants.

The methodology of the current study allowed for the exploration of risk and protective factors and the dynamics between these factors. The current study provided evidence to support the risk and protective factor framework as an approach for exploring the experiences of target siblings. That is, the results of the present study indicate that the experiences of target siblings are influenced by factors other than having brothers or sisters with ASD. Consequently, the findings derived from the study's methodology enables researchers to build clinical interventions that highlight both protective and risk factors.

The methodology adopted in the present study also allowed for a broader exploration of the facets that impact the experiences of the target siblings. Exploring positive aspects associated with the experiences of the target siblings and their families is a characteristic rarely addressed in other studies (Taunt & Hastings, 2002), thus signifying an important contribution made by the study. Target mothers, in particular,

appeared predisposed to discuss positive aspects of their experiences since they were aware of the bias in the literature and the general populations towards highlighting difficulties when children are diagnosed with ASD. Therefore, it is important that methodologies are adopted that allow for an exploration of all aspects of the experiences of target siblings and their families, not only their hardships.

Contributions to Clinical Practice

The results of the present study provide evidence that target siblings can present with lower levels of psychological resilience when compared to community siblings. Also, target siblings can experience greater psychological distress than community siblings; however, clinicians should consider that the degree of distress reported can be affected by the type of informant, and discrepancies can emerge when the reports of multiple informants are examined. In addition, target siblings seem to engage in compensatory behaviours in an attempt to maintain family functioning and cope with the demands associated with having brothers or sisters with ASD. Thus, they are more likely to require additional formal and informal support and clinical interventions to assist them with their experiences, particularly developing skills that foster psychological resilience. Currently, support services for target siblings in Australia vary from state to state. While target siblings are able to engage privately-funded services, such as psychologists or counsellors, Carers Australia and Siblings Australia are the only national support services that adolescents and young adults can access (Carers Australia, 2019; Siblings Australia Inc., 2019).

The results of the present study will contribute toward supporting target siblings by allowing clinicians to focus on the areas that target siblings find most difficult to cope with. In the present study target siblings identified aggressive and violent

behaviour, worries, and their concerns about the future as key areas of distress. On the other hand, the changes in the family unit and the implications for the target siblings were highlighted as key areas of concern for the mothers. In addition, both target siblings and mothers identified areas of family dysfunction that were of clinical significance. Identifying the key areas of concern allows clinicians to provide tailored support to families and target siblings. In addition, the different areas of concern identified by the target siblings and their mothers highlight the value to clinicians of exploring the experiences of target siblings from multiple perspectives, as well as considering that the experiences of the target siblings do not occur in isolation from the experiences of the family unit.

The present study identified factors that were associated with the psychological wellbeing of the target siblings. Psychological resilience was identified as an important influencing factor in the psychological adjustment of target siblings. Even though psychological resilience has already been identified as a protective factor when individuals face adversity, the data available from the current research study further strengthen the value of clinicians fostering psychological resilience in target siblings. Fostering psychological resilience in target siblings may be of particular importance as the findings of this study indicated that target siblings can have lower levels of psychological resilience than community siblings. Identifying protective factors as well as fostering those already present will help minimise the adverse effects associated with being target siblings.

Family functioning was also identified as a significant contributor to the psychological adjustment of the target siblings. Moreover, target participants (both mothers and siblings) reported unhealthy adjustment in more areas of family functioning than community participants. An important intervention for families of

individuals with ASD is therefore finding ways to improve family functioning. Given the discrepancy in the problem areas identified by mothers and siblings, it is thus important that family functioning be considered from the perspective of all family members. Clinicians will then be able to support the families in improving family functioning in the areas that each family member perceives as being of greatest need by providing families with the necessary tools to successfully adapt to and negotiate the demands associated with raising children with ASD.

Another clinical contribution of the present study relates to the challenges experienced by the target siblings. Target siblings identified that they could find their brothers or sisters' aggressive or violent behaviour difficult to manage or even distressing; therefore, helping target siblings cope with violent or aggressive behaviours is an important clinical application. Assisting target siblings in understanding their brothers or sisters' behaviour within the context of the disorder would be beneficial but most importantly target siblings need tools and strategies for managing these situations. In addition, some target siblings and their families may need assistance in exploring the safety of all family members, and pets, as well as in developing adequate safety plans and behavioural management strategies.

Target siblings described the role that knowledge about ASD played in their acceptance of their brothers or sisters, as well as their ability to understand their atypical or aggressive behaviour. Consequently, the results of the present study will help support the evidence suggesting that target siblings benefit from receiving age-appropriate information about ASD, including its clinical features, aetiology, and life-course (Lobato & Kao, 2002). In particular, based on the narratives of the participating target siblings, it may be most important to help target siblings understand behaviours they find distressing in terms of the disorder. The narratives of the target participants

indicated that an important aspect of understanding and accepting their brothers or sisters' disorder included being able to manage social situations, such as being able to explain to strangers their brothers or sisters' atypical behaviour. Target siblings would thus benefit from receiving tools and information to navigate these kinds of social scenarios.

The narratives of the target sibling and their mothers explored the role target siblings played as carers, in particular caring for their brothers or sisters with ASD. While most target siblings appeared to accept this role, some discussed how it interfered with their own activities or how it would influence their future decisions (e.g., whether or not to have children). Consequently, it is important for clinicians to help the target siblings and their parents negotiate appropriate levels of care-giving responsibility that help maintain family functioning but more importantly, that ensure that target siblings are not burdened with this responsibility. Likewise, since ASD is a developmental disorder the responsibility for the care of the individuals with ASD in adulthood can be a source of worry for target siblings. Thus, target siblings are likely to benefit from being able to address their questions about the future with their parents, and clinicians can facilitate these conversations. As it can be seen, the present study has contributed in a number of ways to the current understanding regarding what it means to be a target sibling. However, the present study is not without its limitations.

Limitations and Future Research

The results of the present study should be considered within a number of limitations. The results of the present study could be affected by selection bias of the sample; that is, participants in both the clinical and the community groups volunteered themselves. It is possible that participants in the clinical group in particular, could have

come from families that had better functioning or more positive experiences to report, thus providing a biased understanding of the experiences of target siblings. However, self-selection is a common limitation in most studies in this area of research and therefore, the data can still provide valid information regarding the experiences of target siblings, even if care should be taken when generalising the results. Moreover, the study aimed at reducing selection bias by advertising in a variety of settings (e.g., university, schools, support services, and research centres). Another issue regarding self-selection bias relates to the motivation of the participants to take part in the study. Participants who chose to volunteer may have had distinct experiences they were interested in sharing. Moreover, the methodology of the present study stipulated that both the participating siblings and their mothers were to participate in both phases of the study thus, excluding data from potential participants whose children or mothers did not wish to participate. Also, the target participants spanned a relatively large age range and this could have confounded variables relating to the participants' age and developmental stage. Future studies could consequently investigate narrower age spans.

As the current study was cross-sectional in nature, it was not possible to analyse the target siblings' experiences over time. The findings of the current study can be considered a snapshot of the target siblings' at a specific point in time. The discussion pertaining to the target siblings' futures should be considered suppositional while the issues regarding their past are retrospective accounts. Therefore, longitudinal studies should validate the evolving natures of the target siblings' experiences.

The findings of stage one had a number of specific limitations. The brothers or sisters of the community siblings were significantly older than the brothers or sisters of the target participants. The discrepancy in the ages of the siblings' brothers or sisters

could be a confounding variable and should be considered when interpreting the results. In addition, limited demographic data on the mothers were gathered, and consequently this can limit the generalisability of the results.

There were also some limitations to the findings of stage two. Most of the interviews were conducted within a few weeks of the stage one data having been collected. However, the time lapse between the collection of data of stages one and two may be considered a potential limitation of the current study. It is possible that significant events occurred between the two points of data collection that would influence the data collected in stage two and could pose as a confounding variable. Nevertheless, a time delay is a common constraint in studies that consist of multiple phases of data collection.

In addition, all the interviews were conducted and analysed by a single researcher. The biases inherently held by all individuals are bound to influence any work one carries out, particularly influencing interpretative and analytical type tasks, such as analysing qualitative data. The researcher attempted to minimise this issue by keeping an audit trail, which included self-reflections. In addition, a sub-sample of participants were provided with the preliminary results and asked to consider whether the results accurately reflected their experiences thus, reducing the researcher's bias in the reporting of the final results. Moreover, an independent researcher to the study confirmed the themes and sub-themes of stage two, a technique that can also minimise the influence of the primary researcher's biases on the results. Therefore, the interpretation of the results should be considered within the limitations noted above.

There are a number of areas that future research studies can address. It is suggested that future research could explore the role the severity of impairment has on

the experiences of target siblings, such as when the target siblings' brothers or sisters are diagnosed with ID plus ASD. It has been proposed that since ASD is a spectrum disorder the severity of symptoms as well as the degree of impairment, including cognitive impairment, can vary greatly from individual to individual, consequently the impact on the rest of the family is bound to be different despite the shared diagnosis of ASD (Frith, 2003). The present study initially set out to determine whether the presence of ID would have a significant impact on the target siblings' wellbeing, however, preliminary analyses indicated that no significant differences were present between target siblings whose brothers or sisters had been diagnosed with ASD and with ID, and those whose siblings did not have the additional diagnosis of ID. Nevertheless, the potential role that the severity of symptoms could have on the target siblings needs to be researched further as a potential risk factor for the wellbeing of the target siblings, especially given the published data that suggest a relationship between the severity of ASD and the target siblings' adjustment (Abbeduto et al., 2004; Benson & Karlof, 2008; Petalas, Hastings, Nash, Lloyd, et al., 2009; Sullivan et al., 2012).

Future studies could also expand on the current results by exploring psychological resilience in greater detail. The simultaneous nature of the research design of the present study limited the ability to investigate psychological resilience across both stages. A staggered research design would increase the exploration of psychological resilience.

Future research studies could also expand on the current results by focusing on adults as target siblings. ASD, a developmental disorder, requires management across the lifespan and this reality was evident in the narratives of the target siblings. The target siblings reflected on the issues that they believed would impact them once they and their brothers or sisters were older. In particular, target siblings considered their role

caring for their brothers or sisters in adulthood. Even though some research studies have focused on adult target siblings (Orsmond, Kuo, & Seltzer, 2009; Orsmond & Seltzer, 2007) by sampling adult target siblings, researchers would be able continue to investigate the impact of developmental changes on the experiences of target siblings across the lifespan. Likewise, by adopting a longitudinal methodology developmental factors across the target siblings' lifespan could continue to be examined.

Future research studies could also include fathers as additional informants, thus collecting data from both parents and the target siblings. Increasing the number of informants would consequently increase the richness and depth of the data available. Including fathers would also permit a more accurate investigation of how the experiences of other family members impact on the experiences of target siblings while allowing differences in their perspectives to be identified and analysed.

Final Conclusions

As the incidence of ASD has risen, researchers have focused their interests on the experiences of typically developing siblings whose brothers or sisters have been diagnosed with ASD (Frith, 2003; N. Gold, 1993; Hastings, 2003b). Despite this increased interest, the findings regarding the experiences of target siblings currently available remain complex and diverse (Giallo et al., 2012; Kaminsky & Dewey, 2002; Petalas, Hastings, Nash, Lloyd, et al., 2009). The present study expanded the current understanding of what it means to be a target sibling by investigating the experiences of adolescent and young adult target siblings using a mixed methods multi-informant approach. Exploring the experience of target siblings has first, increased the understanding of this population; second, identified protective factors that impact on the

target siblings' experiences; and last, identified a framework for providing target siblings and their families support.

The results of the current study indicate that the experiences of target siblings are complex, multi-faceted, and ever-changing. Target siblings when compared to community siblings reported lower levels of psychological resilience. Moreover, target siblings were perceived to experience greater psychological distress by their mothers but not themselves, when they were compared to a community sample. However, target siblings and their mothers reported comparable levels of family functioning when compared to the community participants. The target siblings' psychological resilience and family functioning were identified as the most significant predictors of their psychological distress indicating that factors relating to the target siblings and their families impact on the psychological adjustment of target siblings. In addition, target siblings and their mothers described how changes in the family unit, interpersonal issues outside the family, and developmental issues all shaped the experiences of the target siblings in positive and negative ways.

Overall, the findings of the current study suggest that living with children with ASD has a broad impact on the experiences of target siblings. Conceptualising the experiences of target siblings within a risk and protective factor framework can assist clinicians to develop support strategies that will acknowledge the complex interplay of risk and protective factors that each target sibling is exposed to. In addition, including systemic issues within the risk and protective factor model will allow clinicians to identify the unique characteristics of the family environment that affect, either positively or negatively, each target sibling. Thus, by providing target siblings a framework of support that accounts for the various factors that can impact on their experiences, including personal and familial factors, clinicians will be better able to

foster the development of protective factors while reducing the impact of risk factors, and thus increase the psychological wellbeing of this population.

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Appendix A

Demographic Information

Dear Mother/Guardian, as part of the study we are interested in collecting some additional information about your family. Please answer as many of the questions below as possible. Some questions require you to place a tick or cross in the box next to the response that best suits you. Some questions require you to write a response in the space provided. (If you require more space feel free to attach additional pages. Be sure to label carefully the question you are answering). The answers you provide are strictly confidential.

1) **Your name:** _____
First name *Surname*

2) **Adolescent's name:** _____ **Gender:** []M []F
First name *Surname*

3) **Adolescent's Date of Birth:** __/__/____ (DD/MM/YYYY)

4) **Names, ages and gender of adolescent's siblings:**

For example: Mary, 9 years, female; Ben, 21 years, male.

		[]M []F
Name	Age	Gender
		[]M []F
		[]M []F
		[]M []F
		[]M []F
		[]M []F

5) **Name of child(ren) with disability:**

For example: Mary, Asperger's Disorder, 2001; Ben, Type 1 diabetes, 1997

Name of child	Name of disorder	Severity (if known)	Year of diagnosis

Appendix B

Resilience Scale for Adolescents - Mothers' version

Please think about how the last month has been for your adolescent/young adult son or daughter. Their thoughts and how they have felt about themselves and important people in their life. Please mark the option that best describes the thoughts and feelings you believe they had. There are no right or wrong answers. (For example, do you think your son/daughter has felt they are able to reach their goals if they work hard?) **Remember: you must indicate how you think your son/daughter would answer these statements.**

(Developed by Odin Hjemdal & Oddgeir Friborg)

Name: _____

Today's date: _____

Age: _____

Gender: _____ Girl/Boy

	Totally agree	Agree	Average	Disagree	Totally disagree
1. I reach my goals if I work hard	D	D	D	D	D
2. I am at my best when I have clear aims and objectives aims and objectives	D	D	D	D	D
3. I have some friends/family members that usually encourage me	D	D	D	D	D
4. I am satisfied with my life up till now	D	D	D	D	D
5. In my family we share views of what is important in life	D	D	D	D	D
6. I easily make others feel comfortable around me	D	D	D	D	D
7. I know how to reach my goals	D	D	D	D	D
8. I always make a plan before I start something new	D	D	D	D	D
9. My friends always stick together	D	D	D	D	D
10. I feel comfortable with my family	D	D	D	D	D
11. I easily find new friends	D	D	D	D	D

12. When it is impossible for me to change certain things I stop worrying about them	D	D	D	D	D
13. I am good at organizing my time	D	D	D	D	D
14. I have some close friends/family members that really care about me	D	D	D	D	D
15. In my family we agree on most things	D	D	D	D	D
16. I am good at talking to new people	D	D	D	D	D
17. I feel competent	D	D	D	D	D
18. In my family we have rules that simplify everyday life	D	D	D	D	D
19. I always have someone that can help me when I need it	D	D	D	D	D
20. When I have to choose between several options I almost always know what will be right for me	D	D	D	D	D
21. My family view the future as positive, even when very <u>sad</u> things happen	D	D	D	D	D
22. I always find something fun to talk about	D	D	D	D	D
23. My belief in myself gets me through difficult times	D	D	D	D	D
24. In my family we support each other	D	D	D	D	D
25. I always find something comforting to say to others when they are sad	D	D	D	D	D
26. When things go badly I have a tendency to find something good that can come out of it	D	D	D	D	D
27. In my family we like to do things together	D	D	D	D	D
28. I have some close friends/family members that value my qualities	D	D	D	D	D

Appendix C

Depression Anxiety Stress Scales-21 Items - Mothers' version

DASS		Name:			
		Date:			
<p>Please read each statement and indicate how much you think each statement applied to your adolescent/young adult over the past week. There are no right or wrong answers. Do not spend too much time on any statement. (For example, do you think your adolescent/young adult found it hard to wind down? Do you think he/she was aware of dryness in their mouth?) Remember: you must indicate how you think your son/daughter would answer these statements.</p>					
<p><i>The rating scale is as follows:</i></p>					
<p>0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time</p>					
1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I felt I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the reaction of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

Appendix D

Family Assessment Device

Instructions

This assessment contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.

For each statement there are four (4) possible responses:

- (1) Strongly agree (SA) Check SA if you feel that the statement describes your family very accurately.
- (2) Agree (A) Check A if you feel that the statement describes your family for the most part.
- (3) Disagree (D) Check D if you feel that the statement **does not** describe your family for the most part.
- (4) Strongly disagree (SD) Check SD if you feel that the statement **does not** describe your family at all.

These four responses will appear below each statement like this:

41. *We are not satisfied with anything short of perfection.*

The answer spaces for statement 41 would look like this.

_____SA_____A_____D_____SD_____

For each statement, there is an answer space below. Do not pay attention to the blanks at the far right-hand side of each space. They are for office use only.

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have difficulty, answer with your first reaction. Please be sure to answer *every* statement and mark all your answers in the space provided *below* each statement.

1. Planning family activities is difficult because we misunderstand each other.

_____SA_____A_____D_____SD_____

2. We resolve most everyday problems around the house.

_____SA_____A_____D_____SD_____

3. When someone is upset the others know why.

_____SA_____A_____D_____SD_____

4. When you ask someone to do something, you have to check that they did it.

_____SA_____A_____D_____SD_____

5. If someone is in trouble, the others become too involved.

__SA_____A_____D_____SD_____

6. In times of crisis we can turn to each other for support.

__SA_____A_____D_____SD_____

7. We don't know what to do when an emergency comes up.
__SA__A__D__SD__
8. We sometimes run out of things that we need.
__SA__A__D__SD__
9. We are reluctant to show our affection for each other.
__SA__A__D__SD__
10. We make sure members meet their family responsibilities.
__SA__A__D__SD__
11. We cannot talk to each other about the sadness we feel.
__SA__A__D__SD__
12. We usually act on our decisions regarding problems.
__SA__A__D__SD__
13. You only get the interest of others when something is important to them.
__SA__A__D__SD__
14. You can't tell how a person is feeling from what they are saying.
__SA__A__D__SD__
15. Family tasks don't get spread around enough.
__SA__A__D__SD__
16. Individuals are accepted for what they are.
__SA__A__D__SD__
17. You can easily get away with breaking the rules.
__SA__A__D__SD__
18. People come right out and say things instead of hinting at them.
__SA__A__D__SD__
19. Some of us just don't respond emotionally.
__SA__A__D__SD__
20. We know what to do in an emergency.
__SA__A__D__SD__
21. We avoid discussing our fears and concerns.
__SA__A__D__SD__
22. It is difficult to talk to each other about tender feelings.
__SA__A__D__SD__
23. We have trouble meeting our financial obligations.
__SA__A__D__SD__
24. After our family tries to solve a problem, we usually discuss whether it worked or not.
__SA__A__D__SD__
25. We are too self-centered.
__SA__A__D__SD__
26. We can express feelings to each other.
__SA__A__D__SD__
27. We have no clear expectations about toilet habits.
__SA__A__D__SD__

28. We do not show our love for each other.
__SA__A__D__SD__
29. We talk to people directly rather than through go-betweens.
__SA__A__D__SD__
30. Each of us has particular duties and responsibilities.
__SA__A__D__SD__
31. There are lots of bad feelings in the family.
__SA__A__D__SD__
32. We have rules about hitting people.
__SA__A__D__SD__
33. We get involved with each other only when something interests us.
__SA__A__D__SD__
34. There is little time to explore personal interests.
__SA__A__D__SD__
35. We often don't say what we mean.
__SA__A__D__SD__
36. We feel accepted for what we are.
__SA__A__D__SD__
37. We show interest in each other when we can get something out of it personally.
__SA__A__D__SD__
38. We resolve most emotional upsets that come up.
__SA__A__D__SD__
39. Tenderness takes second place to other things in our family.
__SA__A__D__SD__
40. We discuss who are responsible for household jobs.
__SA__A__D__SD__
41. Making decisions is a problem for our family.
__SA__A__D__SD__
42. Our family shows interest in each other only when they can get something out of it.
__SA__A__D__SD__
43. We are frank (direct, straightforward) with each other.
__SA__A__D__SD__
44. We don't hold to any rules or standards.
__SA__A__D__SD__
45. If people are asked to do something, they need reminding.
__SA__A__D__SD__
46. We are able to make decisions about how to solve problems.
__SA__A__D__SD__
47. If the rules are broken, we don't know what to expect.
__SA__A__D__SD__
48. Anything goes in our family.
__SA__A__D__SD__

49. We express tenderness.
__SA__A__D__SD__
50. We confront problems involving feelings.
__SA__A__D__SD__
51. We don't get along well together.
__SA__A__D__SD__
52. We don't talk to each other when we are angry.
__SA__A__D__SD__
53. We are generally dissatisfied with the family duties assigned to us.
__SA__A__D__SD__
54. Even though we mean well, we intrude too much into each other's lives.
__SA__A__D__SD__
55. There are rules in our family about dangerous situations.
__SA__A__D__SD__
56. We confide in each other.
__SA__A__D__SD__
57. We cry openly.
__SA__A__D__SD__
58. We don't have reasonable transport.
__SA__A__D__SD__
59. When we don't like what someone has done, we tell them.
__SA__A__D__SD__
60. We try to think of different ways to solve problems.
__SA__A__D__SD__

The End

Appendix E

Resilience Scale for Adolescents – Adolescent/Youth Version

Please think about how the last month has been for you. Your thoughts and how you have felt about yourself and important people in your life. Please mark the option that best describes your thoughts and feelings. There are no right or wrong answers.

(Developed by Odin Hjemdal & Oddgeir Friberg)

Name: _____ Age: _____

Today's date: _____ Gender: _____ Girl/Boy

	Totally agree	Agree	Average	Disagree	Totally disagree
1. I reach my goals if I work hard	D	D	D	D	D
2. I am at my best when I have clear aims and objectives	D	D	D	D	D
3. I have some friends/family members that usually encourage me	D	D	D	D	D
4. I am satisfied with my life up till now	D	D	D	D	D
5. In my family we share views of what is important in life	D	D	D	D	D
6. I easily make others feel comfortable around me	D	D	D	D	D
7. I know how to reach my goals	D	D	D	D	D
8. I always make a plan before I start something new	D	D	D	D	D
9. My friends always stick together	D	D	D	D	D
10. I feel comfortable with my family	D	D	D	D	D
11. I easily find new friends	D	D	D	D	D
12. When it is impossible for me to change certain things I stop worrying about them	D	D	D	D	D
13. I am good at organizing my time	D	D	D	D	D
14. I have some close friends/family members that really care about me	D	D	D	D	D

15. In my family we agree on most things	D	D	D	D	D
16. I am good at talking to new people	D	D	D	D	D
17. I feel competent	D	D	D	D	D
18. In my family we have rules that simplify everyday life	D	D	D	D	D
19. I always have someone that can help me when I need it	D	D	D	D	D
20. When I have to choose between several options I almost always know what will be right for me	D	D	D	D	D
21. My family view the future as positive, even when very <u>sad</u> things happen	D	D	D	D	D
22. I always find something fun to talk about	D	D	D	D	D
23. My belief in myself gets me through difficult times	D	D	D	D	D
24. In my family we support each other	D	D	D	D	D
25. I always find something comforting to say to others when they are sad	D	D	D	D	D
26. When things go badly I have a tendency to find something good that can come out of it	D	D	D	D	D
27. In my family we like to do things together	D	D	D	D	D
28. I have some close friends/family members that value my qualities	D	D	D	D	D

Appendix F

Depression Anxiety Stress Scales-21 Items – Adolescent/Youth Version

DASS		Name:				Da			
Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i> . There are no right or wrong answers. Do not spend too much time on any statement.									
<i>The rating scale is as follows:</i>									
0 Did not apply to me at all									
1 Applied to me to some degree, or some of the time									
2 Applied to me to a considerable degree, or a good part of time									
3 Applied to me very much, or most of the time									
1	I found it hard to wind down	0	1	2	3				
2	I was aware of dryness of my mouth	0	1	2	3				
3	I couldn't seem to experience any positive feeling at all	0	1	2	3				
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3				
5	I found it difficult to work up the initiative to do things	0	1	2	3				
6	I tended to over-react to situations	0	1	2	3				
7	I experienced trembling (eg, in the hands)	0	1	2	3				
8	I felt that I was using a lot of nervous energy	0	1	2	3				
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3				
10	I felt that I had nothing to look forward to	0	1	2	3				
11	I found myself getting agitated	0	1	2	3				
12	I found it difficult to relax	0	1	2	3				
13	I felt down-hearted and blue	0	1	2	3				
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3				
15	I felt I was close to panic	0	1	2	3				
16	I felt I was unable to become enthusiastic about anything	0	1	2	3				
17	I felt I wasn't worth much as a person	0	1	2	3				
18	I felt that I was rather touchy	0	1	2	3				
19	I was aware of the reaction of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3				
20	I felt scared without any good reason	0	1	2	3				
21	I felt that life was meaningless	0	1	2	3				

Appendix G

Consent Form – Stage One

CONSENT FORM**Title of Project: Living with Autism: The Experience of Developmentally Healthy Adolescents and Youths who have a Sibling Diagnosed with an Autism Spectrum Disorder**

- I have been provided with a letter explaining the research project and I understand the letter.
- I have been given the opportunity to ask questions and all my questions have been answered to my satisfaction.
- I am aware that I can contact Doctors Elizabeth Kaczmarek or Craig Harms or Ms Kim Gifkins if I have any further queries, or if I have concerns or complaints. I have been given their contact details in the information letter.
- I give permission for the data to be used in the process of completing a Doctor of Philosophy-Clinical Psychology degree and acknowledge that it may be published.
- I understand that participating in this project will involve me and my son/daughter and completing questionnaires.
- If applicable, I understand that my son/daughter and I may be asked to participate in one interview each. I am aware that we are free to not answer any questions and may withdraw at any time.
- If applicable, I consent for the interviews to be audio recorded and understand that once the study is completed the recordings will be deleted.
- I understand that all information will be kept confidential and my identity or that of my children will not be disclosed without my consent.
- I understand that we can withdraw from the research at any time without explanation or penalty. We may also choose to remove our data.
- I freely agree for my son/daughter and I to participate in this project:

 Name: Mother/Guardian

 Signed: Mother/Legal Guardian

 Date

 Name: Young adult

 Signed: Participant (Young adult)

 Date

 Email address

 Contact number

Appendix H

Information Letter to Mother/Female Guardian Participants - ASD

Dear Potential Participant,

Thank you for taking an interest in my research. My name is Jessica Michel and I am a Doctor of Philosophy-Clinical Psychology student at Edith Cowan University. As part of my course I am required to conduct a research study. This study has been approved by the Human Research Ethics Committee of Edith Cowan University. All information collected during the study will remain confidential and no identifying information will be included in the completed project.

The aim of the study is to explore the experience of young people who have at least one sibling who has been diagnosed with an autism spectrum disorder. By taking part in the study your son/daughter and you will have an opportunity to share your unique accounts of living in a family with a child who has been diagnosed with an autism spectrum disorder.

To be included in this study you must have: **1) a child between 12 and 24 years of age who DOES NOT have an intellectual disability or an autism spectrum disorder; 2) at least one child of ANY AGE who has been formally diagnosed with autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); 3) the agreement of your adolescent or youth to also take part in the study.**

Young people will be asked to complete three questionnaires about their family functioning, themselves and their mental health and emotional wellbeing. This should take between 20 to 35 minutes. You will be asked to complete the same three questionnaires regarding your adolescent's well-being and your family. This will take about 20 to 35 minutes. Following this you and your adolescent *may* be asked to take part in an audio recorded interview lasting approximately 30 to 45 minutes. The interview will consist of answering questions about your adolescent's experience regarding having a sibling who has been diagnosed with an autism spectrum disorder. The interviews will be audio recorded so they can be transcribed; then the recording will be deleted. You may choose not to take part in the interview or withdraw from the interview at any time.

If you or your family would like to speak to someone after taking part in the study there are a number of counselling services you can contact. If you have any questions about the study feel free to contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 6304 5715). If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

If you would like to take part in the study, please contact me using the details below and I will supply you with further details. Your participation in the study and that of your child are entirely voluntary and you may withdraw at any time without any penalty and remove your data if you so wish. Your participation in the study will by no means affect the services offered to you by your service provider/s. If you are interested in the

outcome of the project, I can be contacted after the proposed date of completion, December 2014.

To participate in the study:

If you are interested in participating in the study (or have any questions) you can contact me on jmichel@our.ecu.edu.au and I will provide you with further details.

Yours sincerely, Jessica Michel

Appendix I

Information Letter to Adolescent/Youth Participants - ASD

Dear Potential Participant,

Thank you for your interest in my research. My name is Jessica Michel and this study is part of my PhD in Clinical Psychology. This research has been approved by the Human Research Ethics Committee of Edith Cowan University.

Why do I need your help?

I want to find out what it is like to be the brother or sister of a person who has been diagnosed with autism, Asperger's syndrome or PDD-NOS. By taking part in this study you will have an opportunity to share your unique experiences and to help others understand what it is like to be the sibling of an individual who has been diagnosed with an autism spectrum disorder.

What do you have to do?

To be included in this study you must: 1) be aged between 12 and 24 years of age; 2) you **MUST NOT** have been diagnosed with an intellectual disability or an autism spectrum disorder; 3) have at least one sibling of ANY AGE who has been formally diagnosed with autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); 4) have the agreement of your mother/female guardian for her to also take part in the study.

I will ask you to fill out three questionnaires about your family functioning, yourself and your mental health and emotional wellbeing. This will take about 20 to 35 minutes. By participating you will go in the draw to win one of two \$50 Westfield gift cards.

Then, you *may* be asked to do a short interview which will last less than an hour. The interview will ask you to talk about what it is like to be the brother or sister of someone who has been diagnosed with autism. There are no right or wrong answers; I am just interested in finding out what you think. Your mother/female guardian will also be asked to fill in the same questionnaires and to do a similar interview. The interviews will be done separately. You can choose not to do the interview or to withdraw from the interview or the study at any stage.

Who will see what you say?

All the information you share is confidential which means that I am the only person who will see or hear what you say. I will record the interview digitally so I can listen to it later and type up what you have said, then I will delete the recording. No one will know your name or the name of your sibling.

If you are less than 18 years and report to be particularly stressed about issues in your life I may have to discuss this with your parents/guardians and I will let them know of places to contact so you can speak with someone and share your concerns.

It is entirely up to you if you take part in the study. You can ask to stop at any time without penalty. This study will not affect the services your family may be receiving from any agency that you may be connected for family support. If you want to talk to someone after taking part in the study there are places I can help you and your parents/guardians contact.

If you have any questions about the study you can talk to your parents/guardians or contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 6304 5715). If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

How do I participate?

If you are interested in being involved in this study you can contact me on jmichel@our.ecu.edu.au and I will provide you with further information.

Yours sincerely, Jessica Michel

Appendix J

Information Letter for Mothers/ Female Guardians - Community

Dear Potential Participant,

Thank you for taking an interest in my research. My name is Jessica Michel and I am a Doctor of Philosophy-Clinical Psychology candidate at Edith Cowan University. As part of my course I am required to conduct a research study. This study has been approved by the Human Research Ethics Committee of Edith Cowan University. All information collected during the study will remain confidential and no identifying information will be included in the completed project.

The aim of the study is to explore the experiences of young people who have a sibling who has been diagnosed with an autism spectrum disorder (ASD) compared to the experiences of young people whose siblings have not been diagnosed with an ASD. By taking part in this study your son/daughter and you will have an opportunity to share your unique experiences and help others understand differences in the experiences of siblings of individuals diagnosed with an ASD and those young people whose siblings have not been diagnosed with an ASD.

To be included in this study you must have 1) a child between 12 and 24 years of age who DOES NOT have an autism spectrum disorder or an intellectual disability; 2) at least one other child of ANY AGE who has NOT been formally diagnosed with autism, Asperger's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or a condition that causes an intellectual disability; 3) the agreement of your adolescent or youth to also take part in the study.

Young people will be asked to complete three short questionnaires about their family functioning, themselves and their mental health and emotional wellbeing. This should take between 20 to 35 minutes. You will be asked to complete the same three questionnaires regarding your adolescent/youth's well-being and your family. This should take about 20 to 35 minutes.

If you would like to take part in the study, please contact me using the details below and I will provide you with a consent form and the questionnaires. Your participation in the study and that of your child are entirely voluntary and you may withdraw at any time without any penalty and removing your data if you so wish. If you are interested in the outcome of the project, I can be contacted after the proposed date of completion, December 2014.

If you or your family would like to speak to someone after taking part in the study there are a number of counselling services you can contact. If you have any questions about the study feel free to contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 63045715).

If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

To participate in the study:

If you are interested in participating in the study (or have any questions) you can contact me on jmichel@our.ecu.edu.au and I will provide you with further details.

Yours sincerely, Jessica Michel

Appendix K

Information Letter for Adolescent/Youth Participants - Community

Dear Potential Participant,

Thank you for your interest in my research. My name is Jessica Michel and this study is part of my PhD in Clinical Psychology. This research has been approved by the Human Research Ethics Committee of Edith Cowan University.

Why do I need your help?

I want to find out what it is like to be the sibling of an individual who has been diagnosed with an autism spectrum disorder (ASD). In order to do this I need to know what it is like to be the sibling of an individual who has not been diagnosed with an ASD. By taking part in this study you will have an opportunity to share your unique experiences. Also you will help me understand how the experiences of young people whose siblings have been diagnosed with an ASD are different from the experiences of those whose siblings have not been diagnosed with an ASD.

What do you have to do?

To be included in this study you must 1) be aged between 12 and 24 years of age; 2) you MUST NOT have been diagnosed with an intellectual disability or an autism spectrum disorder; 3) have at least one sibling of ANY AGE who has NOT been diagnosed with an autism spectrum disorder or an intellectual disability; 4) the agreement of your mother/female legal guardian for her to also take part in the study.

I will ask you to fill out three questionnaires about your family functioning, yourself and your mental health and emotional wellbeing. This should take about 20 to 35 minutes. Your mother will also be asked to fill in the same questionnaires.

Who will see what you say?

All the information you share is confidential which means that I am the only person who will see what you say. No one will know your name or the name of your family.

If you are less than 18 years and report to be particularly stressed about issues in your life I may have to discuss this with your parents and I will let them know of places to contact so you can speak with someone and share your concerns.

It is entirely up to you if you take part in the study. You can ask to stop at any time without penalty. If you want to talk to someone after taking part in the study there are places I can help you and your parents contact.

If you have any questions about the study you can talk to your parents/guardians or contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 6304 5715). If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

How do I participate?

If you are interested in being involved in this study you can contact me on jmichel@our.ecu.edu.au and I will provide you with further information.

Yours sincerely,

Jessica Michel

Appendix L

Counselling Services-WA

Kids Helpline

Free, confidential counselling service

Web page: www.kidshelp.com.au/teens/

Ph: 1800 55 1800

Lifeline

Confidential counselling services

Ph: 13 11 14

Crisis Care

Confidential counselling services

Ph: 13 16 11

Kinway

Relationship counselling

Web page: <http://www.kinway.org.au/>

Ph: 1800 812 511

Headspace

Counselling and support services for 12-25 year olds

Centres found throughout Australia

Web page: www.headspace.org.au

Ph: contact details available on website

ECU Psychological Services Centre

Psychological counselling services 8 Davidson Terrace

Joondalup WA 6027

Ph: 9301 0011

Autism Association of Western Australia

Web page: www.autism.org.au

Ph: 9489 890

Kids Helpline

Free, confidential counselling service <http://www.kidshelp.com.au/teens/>

Ph: 1800 55 1800

Amaze (Autism Victoria)

Information and advice for individuals and families with an ASD

Web page: <http://www.amaze.org.au/>

Email: info@amaze.org.au

Ph: 1300 308 699

Lifeline

Confidential counselling services

Ph: 13 11 14

Headspace

Counselling and support services for 12-25-year olds

Centres found throughout Australia

Webpage: <http://www.headspace.org.au>

Ph: contact details available on website (depending on location)

Carers Victoria

Counselling and information for carers

Web page: <http://www.carersvic.org.au/>

Ph: 1800 242 636

Parentline

Advice and information for parents and children

Ph: 13 22 89

Kids Helpline

Free, confidential counselling service

<http://www.kidshelp.com.au/teens/>

Ph: 1800 55 1800

Autism Queensland

Information and advice for individuals and families with an ASD

Web page: <http://www.amaze.org.au/>

Email: admin@autismqld.com.au

Ph: (07) 3273 0000

Lifeline

Confidential counselling services

Ph: 13 11 14

Headspace

Counselling and support services for 12-25-year olds

Centres found throughout Australia

Webpage: <http://www.headspace.org.au>

Ph: contact details available on website (depending on location)

Carers Queensland

Counselling, support, information, education and advocacy for carers

Web page: <http://carersqld.asn.au/>

Ph: 1800 242 636

Anglicare Southern Queensland

Counselling and education services for adults, families and carers

Email: info@anglicaresq.org.au

Ph: (07) 3028 4600

Appendix M

Information Letter to Schools

Dear Principal,

Thank you for taking an interest in my research. My name is Jessica Michel and I am a Doctor of Philosophy-Clinical Psychology student at Edith Cowan University. The study has been approved by the Human Research Ethics Committee of Edith Cowan University.

I am interested in discussing how your school may be able to assist me in recruiting adolescents/young adults and their mothers/female guardians for the study. Your school is one of 27 schools that will be asked to assist in the recruitment of participants. The aim of the study is to explore the experience of developmentally healthy young people who have at least one sibling who has been diagnosed with an autism spectrum disorder. The study will compare the experiences of young people whose siblings have been diagnosed solely with an autism spectrum disorder to the experiences of young people whose siblings have been diagnosed with an autism spectrum disorder and an intellectual disability. Both of these groups will be compared to a third group (young people whose siblings have been diagnosed with neither an autism spectrum disorder nor an intellectual disability). The individual diagnosed with autism will not participate in the study.

The study will benefit participants by allowing them to reflect on their experiences and the experiences of their children as siblings of individuals who have been diagnosed with a developmental disorder. In addition, if the participants report significant distress they will be assisted in finding support services which will contribute towards better psychological outcomes and overall wellbeing. Furthermore, it is anticipated that the study will contribute to literature by expanding the knowledge of risk and protective factors associated with young people who have a sibling who has been diagnosed with an autism spectrum disorder. The study will also contribute towards understanding the unique challenges and opportunities which these young people encounter. This in turn, will help to provide a framework for appropriate support and interventions for these young people.

Potential families must meet the following criteria to participate in the study:

Group One:

1) have a child aged between 12 and 24 years who does not have an intellectual disability or an autism spectrum disorder; 2) have at least one child, of any age, who has been formally diagnosed with autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) with or without an additional diagnosis of intellectual disability; 3) both the mother and the young person must agree to participate in the study.

Group Two:

1) have a child aged between 12 and 24 years who does not have an intellectual disability or an autism spectrum disorder; 2) have at least one child, of any age, who has not been formally diagnosed with autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) **OR** intellectual disability; 3) both the mother and the young person must agree to participate in the study.

Young people will be asked to complete three questionnaires (printed or online) about their depressive symptomatology, their resilience and the functioning of their families. The mothers of the young people will be asked to complete the same three questionnaires regarding their son/daughter's depressive symptomatology, resilience and the functioning of their families. The completion of the surveys should take about 20 to 35 minutes. Following this the young persons in Group One and their mothers *may* be asked to take part in an audio recorded interview lasting approximately 30 to 45 minutes. The interview will consist of answering questions about the young people's experiences regarding having a sibling who has been diagnosed with an autism spectrum disorder. Families will be made aware that their participation is voluntary and their participation (or lack thereof) will by no means affect their current or future service provision.

Any assistance your school may be able to offer in the recruitment process will be greatly appreciated.

Please do not hesitate to contact me on 0421 240 487 or 0416 423 050 or jmichel@our.ecu.edu.au if you would like to discuss how your school can support the recruitment of participants.

Yours sincerely,

Jessica Michel

PhD (Clinical Psychology) Candidate.

Project supervisors:

Doctor Elizabeth Kaczmarek

Email: e.kaczmarek@ecu.edu.au

Phone: (08) 6304 5193

Doctor Craig Harms

Email: c.harms@ecu.edu.au

Phone: (08) 6304 5715

Research Ethics Office:

Ms Kim Gifkins

270 Joondalup Drive

JOONDALUP, WA 6027

Phone: (08) 6304 2170

Fax: (08) 6304 2661

Email: research.ethics@ecu.edu.au

Appendix N

Call for Target Participants - Flyer

Do you have a brother or sister who has been diagnosed with an Autism Spectrum Disorder?

As part of my PhD in Clinical Psychology at Edith Cowan University I want to find out what it is like to be the brother or sister of a person who has been diagnosed with an autism spectrum disorder.

Who is eligible for the study?

Young adults aged between 12 and 24 years who:

- have NOT been diagnosed with an intellectual disability or an autism spectrum disorder;
- have at least one sibling (of any age) who has been formally diagnosed with Autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) with or without an additional diagnosis of intellectual disability.
- have mothers/female guardians willing to also participate in the study.

What will you be asked to do?

You will be asked to fill out three questionnaires about your family functioning, yourself and your mental health and emotional wellbeing. Your mother/female guardian will be asked to complete the same questionnaires. Following this you and your mother/female guardian *may* be asked to do a short interview. The interviews will be done separately. You may choose not to do the interview. All responses are confidential.

How long will it take?

The questionnaires should take about 20 to 35 minutes. The interview should last less than an hour.

Do you want more information or want to volunteer?

Email Jessica Michel: jmichel@our.ecu.edu.au

Appendix O

Call for Target Participants – Newsletter

Living with Autism Study

As part of my PhD in Clinical Psychology at Edith Cowan University I am interested in finding out about the experiences of developmentally healthy young people aged 12-24 who have at least one sibling who has been diagnosed with an autism spectrum disorder. The aim of the study is to find out what it is like to be the brother or sister of a person who has been diagnosed with autism, Asperger's syndrome or PDD-NOS. The study involves young people completing 3 questionnaires about their family functioning, themselves and their mental health and emotional wellbeing. The mothers/female guardians of these young people will complete the same questionnaires. This should take 20-35 minutes. Following this, participants may be asked to take part in a one-off interview. The interview should take 45-60 minutes. Participants may decline the interview. To participate in the study or for more information email Jessica Michel: jmichel@our.ecu.edu.au

Appendix P

Call for Community Participants – Online Advertisement

*Would you like to be part of a **Research Study**?*

As part of my PhD in Clinical Psychology at Edith Cowan University I am interested in finding out about the experiences of developmentally healthy young people who have at least one sibling who has been diagnosed with an autism spectrum disorder. In order to do this I need to find out what it is like to be the sibling of someone who has not been diagnosed with an autism spectrum disorder. Developmentally healthy young people aged 12-24 who have at least one sibling, of any age, can participate. Siblings must not have been diagnosed with an autism spectrum disorder or an intellectual disability. The study involves young people completing 3 questionnaires about their family functioning, themselves and their mental health and emotional wellbeing. The mothers/female guardians of these young people will complete the same questionnaires. This should take 20-35 minutes. To participate in the study or for more information email Jessica Michel: jmichel@our.ecu.edu.au

Appendix Q

Call for Community Participants –Flyer

Would you like to participate in research?

Are you aged between 12 and 24?

As part of my PhD in Clinical Psychology at Edith Cowan University I want to find out what it is like to be the brother or sister of a person who has been diagnosed with an autism spectrum disorder. To do this I need to find out what it is like to be the sibling of someone who *has not* been diagnosed with an autism spectrum disorder.

Who is eligible for the study?

Young adults aged between 12 and 24 years who:

- have NOT been diagnosed with an intellectual disability or an autism spectrum disorder;
- have at least one sibling (of any age). Siblings MUST NOT have been formally diagnosed with Autism, Asperger's syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or an intellectual disability.
- have mothers/female guardians willing to also participate in the study.

What will you be asked to do?

You will be asked to fill out three questionnaires about your family functioning, yourself and your mental health and emotional wellbeing. Your mother/female guardian will be asked to complete the same questionnaires. All responses are confidential.

How long will it take?

The questionnaires should take about 20 to 35 minutes.

Do you want more information or want to volunteer?

Email Jessica Michel: jmichel@our.ecu.edu.au

Appendix R

Adolescent/Youth Interview Schedule

Tell me about yourself /Tell me about your family

- What things do you do together?

Tell me about _____ (sibling.)

- Do you believe _____ has any opportunities/strengths?
- Do you believe _____ faces any challenges?
- What do you like most about _____ (sibling)?
- What do you like the least about _____ (sibling)?
- What kind things do you do together?

Can you recall growing up with your sibling? What do you remember?

- Some young people have talked about how their relationship with their siblings was different because they often couldn't do some of the things other siblings did such playing together or arguing and that they wished they could've fought with their brothers/sisters when they were younger, did you ever feel this way?
- What was it like in primary school? (In relation to sibling) In high school? Post school/uni?
- Did/do your friends know _____ has autism?
- When did you decide to tell them?
- What did you tell them?

Tell me what it is like to be _____'s (sibling) brother/sister.

- Are there positives to having _____ (sibling) as a brother/sister? Explain.
- Are there challenges to having _____ (sibling) as a brother/sister? Explain.
- Has anyone helped you cope with the challenging aspects of having a sibling with autism? How?
- Tell me something you have learnt from living with your sibling.
- Some young people have said they care for their siblings with autism. Do you care for _____? In what ways do you care for him/her?
- Some young people have said it's hard to have their sibling with autism as a role model because perhaps they don't behave or think the way most people their age do. Do you consider your sibling a role model? [if participant younger than ASD]

- What advice would you give to other brothers/sisters of siblings with autism?
- What things would be different if your sibling didn't have ASD? Would some things be better or worse? Explain.
- If you had the power to change anything in your life is there something you would change? Explain.

What do you do when you face difficult times?

- Who do you talk to?
- What helps you when things get difficult?
- What makes it difficult to cope with stressful situations?
- Can you tell me about a time when you faced a difficult situation? How did you deal with it?
- What does your family do in difficult times?
- Can you tell me about a time when your family faced a difficult situation how it dealt with it?

What are your hopes for the future?

- Can you tell me about what you think will happen in the future?
- What do you think will happen with your sibling (name)?

Is there something we haven't talked about that you would like to discuss?

Sometimes things can change once you've talked about them. Do you feel there is anything that has changed by what we've been talking about?

Appendix S

Mother Interview Schedule

Tell me about your family. (Ask for genogram).

- How would you describe your family?
- What activities do you do as a family?

Tell me about_(child with autism).

- How would you describe him/her?
- Does_(child with autism) face any challenges? Explain.
- Does_(child with autism) have strengths? Explain.

Tell me about_(participant).

- How would you describe him/her?
- Describe the relationship between__(child with autism) and _____ (participant).
- Has the relationship changed from when (participant) was younger? Explain.
- What was primary school like for (participant)?
- What was high school like?
- What is it like now?

What do you think it is like for (participant) to be the sibling of (child with autism)?

- Do you believe (participant) faces challenges as the sibling of (child with autism)? Explain
- Do you believe (participant) has opportunities as the sibling of (child with autism)? Explain.
- Some mothers discuss that their children (without autism) care for their brother/sister with autism. Does/has_care for_____? How does he/she care for sibling?
- Tell me something (participant) has learnt by being (child with autism's) sibling.
- Some mothers have discussed that they have tried to make up or compensate because perhaps they can't spend as much time as they'd like with the child without autism or

because they feel the child might be missing out due to the demands associated with having a child with autism. Did you try to do anything to compensate?

- What things would be different for (participant) if brother/sister did not have ASD? Would some things be better or worse? Explain.
- Some mothers have discussed that they can feel socially isolated at times, can you relate to this?

What does ___(participant) do when he/she faces difficult times? Example

- Who does he/she talk to?
- What helps__when things get difficult?
- What makes it harder for his/her to cope with stressful times?
- What does your family do in difficult times?
- Can you tell me about a time when your family faced a difficult situation, how did it deal with it?

What are your hopes for your children in the future?

- What do you think will happen in the future? (for participant).
- What do you think will happen with (child with autism)?

Is there something we have not talked about that you would like to discuss?

Sometimes things can change once you've talked about them. Do you feel there is anything that has changed by what we've been talking about?

Appendix T

Information Letter for Interview for Mother Participants

Dear Participant,

Thank you for your participation in my study which has been approved by the Human Research Ethics Committee of Edith Cowan University. The aim of the study is to look at the experience of young people who have a sibling who has been diagnosed with an autism spectrum disorder. You and your son/daughter have been selected as potential participants in the last phase of the study. By taking part in the study your son/daughter and you will have an opportunity to share your unique accounts of living in a family with a child who has been diagnosed with an autism spectrum disorder.

This part of the study involves you and your adolescent completing one interview that will last approximately 30 to 45 minutes each. In the interview I will ask questions about your child's experience as a sibling of someone who has been diagnosed with an autism spectrum disorder. The interviews will be done separately. After the interview you *may* be contacted to briefly discuss the themes present in the interview. This will ensure that the interviews are analysed accurately and will only take a few minutes.

If you would like to participate in the study, please contact me using the details below and we will set up a time and place for the interviews. Before the interview you will have to read and sign a consent form, which also gives permission for the interview to be audio recorded for later analysis. The recording will be destroyed once the study has been completed. Your participation is completely voluntary and you may withdraw at any time. All information you share will remain confidential and no one will know your name or your children's names. If you are interested in the results of the study, I can be contacted after December 2014.

If you would like to talk to someone after having taken part in the study there is a list of services you can call. If you have any questions about the study contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 6304 5715). If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

To participate in the study:

If you are interested in participating in the study (or have any questions) you can contact me on jmichel@our.ecu.edu.au and we will arrange a time and location for the interviews to take place.

Yours sincerely,

Jessica Michel

Appendix U

Information Letter for Interview for Adolescent/Youth Participants

Dear Participant,

Thank you for helping me with the last part of my research which has been approved by the Human Research Ethics Committee of Edith Cowan University.

Why do I need your help?

I want to find out what it is like to be the brother or sister of a person who has been diagnosed with an autism spectrum disorder. By taking part in this study you will an opportunity to share your unique experiences and to help others understand what it is like to be the sibling of an individual who has been diagnosed with autism, Asperger's syndrome or PDD-NOS.

What do you have to do?

I am going to ask you to do one short interview. It will last less than an hour. The interview will ask questions about you, your family and your sibling who has been diagnosed with autism. There are no right or wrong answers; I am just interested in finding out what you think. Your mother will also be asked to do a similar interview. The interviews will be done separately.

Who will see what you say?

Your interview will be confidential which means that I am the only person who will see or hear what you say. I will record the interview digitally so I can listen to it later and type up what you have said; then I will delete the recording. No one will know your name or the name of your sibling.

If you are less than 18 years and express that you are particularly stressed about issues in your life I may have to discuss this with your parents and I will let them know of places to contact so you can speak to someone about your concerns.

It is entirely up to you if you take part in the interview. You can ask to stop at any time without penalty. If you want to talk to someone after taking part in the interview there are places I can help you and your parents contact.

If you have any questions you can talk to your parents/guardians or contact myself or my supervisors, Dr. Elizabeth Kaczmarek (e.kaczmarek@ecu.edu.au; 6304 5193) or Dr. Craig Harms (c.harms@ecu.edu.au; 6304 5715). If you want to speak with an independent person you can contact:

Ms Kim Gifkins, Research Ethics Office

P: (08) 6304 2170

270 Joondalup Drive, JOONDALUP WA 6027

F: (08) 6304 2661

Email: research.ethics@ecu.edu.au

How do I participate?

You or your mother can contact me on jmichel@our.ecu.edu.au and we will arrange a time and place for the interview to take place.

Yours sincerely,

Jessica Michel

Appendix V

Consent Form – Stage Two

INTERVIEW CONSENT FORM**Title of Project: Living with Autism: The Experience of Developmentally Healthy Adolescents and Youths who have a Sibling Diagnosed with an Autism Spectrum Disorder**

- I have been provided with a letter explaining the research project and I understand the letter.
- I have been given the opportunity to ask questions and all my questions have been answered to my satisfaction.
- I am aware that I can contact Doctors Elizabeth Kaczmarek or Craig Harms or Ms Kim Gifkins if I have any further queries, or if I have concerns or complaints. I have been given their contact details in the information letter.
- I give permission for the data to be used in the process of completing a Doctor of Philosophy-Clinical Psychology degree and acknowledge that it may be published.
- I understand that participating in this project will involve my son/daughter and me taking part in a one-off interview.
- I understand the interviews will be conducted separately.
- I consent for the interviews to be audio recorded and understand that once the study is completed the recordings will be deleted.
- I understand that all information will be kept confidential and my identity or that of my children will not be disclosed without my consent.
- I understand that we are free not to answer any questions and may withdraw at any time without explanation or penalty. We may also choose to remove our data.
- I understand that the researcher may contact me or my son/daughter to briefly discuss the themes present in the interview.
- I freely agree for my son/daughter and I to participate in this project:

Name: Mother

Signed: Mother/Legal Guardian

Date

Name: Young adult

Signed: Young adult

Date

Appendix W
t-test analyses

Table 10

Dependent Samples t-tests Comparing Siblings and Mothers on Measures of READtotal, DASStotal, and FAD – GFS

	<i>M (SD)</i>	<i>t</i>	Degrees of freedom	Significance
READ young adult – READ mother	-.03 (.47)	-.67	5	.50
DASS young adult – DASS mother	3.19 (21.90)	1.37	85	.18
FAD – GFS young adult – FAD – GFS mother	.18 (.51)	3.35	85	.00