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The lived experiences of adolescents with autism spectrum disorder: a personal constructivist and family systems approach

Elizabeth Kate Cridland
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**UNIVERSITY OF
WOLLONGONG**



Faculty of Social Sciences

**The Lived Experiences of
Adolescents with Autism Spectrum Disorder:
A Personal Constructivist and Family Systems Approach**

Elizabeth Kate Cridland

Bachelor of Psychology (Hons)

**This thesis is presented in partial fulfilment of the requirements for the award
of Doctor of Philosophy (Clinical Psychology) in the School of Psychology,
University of Wollongong**

August 2014

CERTIFICATION

I, Elizabeth Cridland, declare that this thesis, submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy (Clinical Psychology), in the School of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Elizabeth Cridland

August 2014

ABSTRACT

Individuals with Autism Spectrum Disorder (ASD) experience persistent and significant social communicative impairments, as well as restricted and repetitive behaviours and/or interests. There is currently a dearth of literature investigating the experiences of adolescents with ASD, despite research findings indicating adolescence is a particularly challenging period for these individuals. In addition to the significant influence of ASD on the individual, having a family member with the condition can have chronic and pervasive effects on individual family members and the family unit as a whole. However, research investigating the experiences of families who have an adolescent member with ASD is scarce.

The overall aim of this thesis is to investigate the lived experiences of adolescents with ASD and their families. More specifically, the studies explore the positive and challenging aspects of adolescence; the coping strategies used by family members; and the distribution of roles and responsibilities within the family and their impact on individual and family functioning. A qualitative approach was used to interview multiple family members, including adolescents with ASD, mothers, fathers, and adolescent siblings.

The thesis is informed by Family Systems and Personal Constructivist frameworks. Chapters 2 and 3 examine these frameworks in relation to understanding adolescents with ASD and their families. Conceptual and methodological components of these frameworks were used to guide subsequent qualitative investigations, which are presented in Chapters 4-7.

More specifically, Chapters 4 and 5 focus on the experiences of adolescent boys and girls with ASD, respectively; Chapter 6 investigates the experiences of parents; and Chapter 7 identifies issues pertinent to adolescent neurotypically developing siblings. The findings of these qualitative investigations highlight a range of adolescent-specific issues, covering physical, cognitive, emotional, social, and sexual domains, which may provide guidance to clinicians, researchers, and family members supporting adolescents with ASD and their families.

Chapter 8 utilises Personal Constructivist methodology to investigate the dependency patterns of adolescents with ASD. Findings indicate that the adolescents had various ways of dispersing their dependencies amongst resources and differed in the types of support most utilised. Additionally, by including family members, the study was able to investigate family awareness of the adolescents' preferences. The findings presented in this chapter offer a novel approach to understanding the experiences of families living with ASD, given the adoption of the combined Family Systems and Personal Constructivist framework.

The thesis concludes with a synthesis of the key findings of the conceptual and qualitative investigations. It considers research limitations of the studies conducted and discusses implications for future research and clinical practice. Overall, the thesis findings address an important gap in literature and have the potential to make significant contributions to the field of clinical psychology by directly informing clinical interventions for adolescents with ASD and their families.

KEY ABBREVIATIONS

Asperger's Syndrome	AS
Autism Spectrum Disorder	ASD
Family System	FS
High Functioning Autism	HFA
Interpretative Phenomenological Analysis	IPA
Neurotypically developing	NTD
Personal Construct Theory	PCT

“Sometimes when you are in a crowded room the best way to be heard is to yell.

But the best way to be understood is to explain yourself.”

Carly Fleischmann¹

¹ Fleishmann, A., & Fleishmann, C. (2012). *Carly's Voice: Breaking Through Autism*. New York, Touchstone.

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The importance of understanding adolescents with ASD within their family system is reverberated throughout this thesis. So too is it necessary to recognise the system within which this thesis was grounded ~

This thesis would not have been possible without the willingness and openness of the families who participated. Thank-you for trusting me to share your very personal stories- your experiences have moved me both professionally and personally.

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THESIS PUBLICATIONS

- Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2013). Understanding high functioning autism during adolescence: A personal construct theory approach. *The Journal of Intellectual and Developmental Disability*, 39(1), 108-118. DOI: 10.3109/13668250.2013.87033.
- Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A., (accepted August 2014). The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology and family systems perspective. *Journal of Intellectual and Developmental Disabilities*.
- Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders*, 44, 1261–1274. DOI: 10.1007/s10803-013-1985-6.
- Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2014). Qualitative research with families living with autism spectrum disorders: Recommendations for conducting semi-structured interviews. *Journal of Intellectual & Developmental Disability*, Advanced online edition. DOI: 10.3109/13668250.2014.964191. (Appendix A)
- Cridland, E. K., Jones, S.C., Magee, C.A., & Caputi, P. (2013). Family focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, 18(3), 213-222. DOI: 10.1177/1362361312472261.
- Cridland, E.K., Jones, S.C., Stoyles, G., Caputi, P., & Magee, C.A. (accepted November 2014). Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. *Focus on Autism and Other Developmental Disabilities*.

THESIS MANUSCRIPTS UNDER REVIEW

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Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (under review). Experiences of parents of adolescents with and without autism spectrum disorder: Roles, responsibilities, challenges, and coping strategies. *Focus on Autism and Other Developmental Disabilities*.

STATEMENT OF VERIFICATION

This statement verifies that the greater part of the work in the previously stated publications/manuscripts are attributed to the candidate. Elizabeth Cridland, under the guidance and supervision of her supervisors, took primary responsibility for the design of each study, all data collection and analysis, prepared the first draft of each manuscript, and prepared the papers for submission to relevant journals. Co-authors, who were also supervisors to the candidate, contributed to the thesis by providing guidance on the design and structure of each study, and provided editorial suggestions for every paper.

Elizabeth Cridland (PhD Candidate)

A handwritten signature in dark ink, appearing to read "P. Caputi".

Associate Professor Peter Caputi (Primary Supervisor)

OTHER CONTRIBUTIONS ARISING FROM THESIS

- Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2013, July). *Understanding high functioning autism during adolescence: A personal construct theory approach*. Paper presented at the 20th International Congress on Personal Construct Psychology, Sydney, Australia. (Appendix B)
- Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2013, October). *Puberty blues? The experience of adolescence for individuals with Asperger's syndrome and their families*. Presented at the University of Wollongong Three Minute Thesis Finals Competition, Wollongong, Australia. (Appendix C)
- Cridland, E.K., Caputi, P., Walker, B., Jones, S.C., & Magee, C.A. (2014, September). *The use of dependency grids when working clinically with families living with autism spectrum disorder*. Workshop presented at the 49th Australian Psychological Society Annual Conference, Hobart, Australia. (Appendix D)
- Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2013, December). *Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence*. Paper presented at the 22nd Annual PsychDD Conference, Homebush, Australia. (Appendix E)

CHAPTER 1: INTRODUCTION

1.1 Preamble

‘Everyone with Asperger’s Syndrome feels frustrated when people do not understand them.’

(Michael², adolescent with Autism Spectrum Disorder)

There is currently a dearth of literature focusing on the lived experiences of adolescents with Autism Spectrum Disorder (ASD) (Holiday-Willey, 2003; Jensen & Spannagel, 2011; Levy & Perry, 2011). This thesis aims to address this significant research gap by investigating the positive and negative experiences of adolescents with ASD and their families. The research uses a qualitative approach, permitting unique and detailed insights into the experiences of these individuals. The thesis is positioned in the theoretical and methodological frameworks of Family Systems (FS) (Bowen, 1978; 1995) and Personal Constructivist (Kelly, 1955; 1966) approaches. The research findings have the potential to directly inform evidence-based clinical interventions targeted at adolescents with ASD and their families.

1.2 Autism Spectrum Disorder

Autism Spectrum Disorder is one of the most common neurodevelopmental conditions, with an estimated prevalence of 1 in 1000 individuals (Duchan & Patel, 2012; Fombonne, 2003). The prevalence of ASD is comparable across most countries for which data are available, including the United States (Centers for Disease Control and Prevention, 2012; Duchan & Patel, 2012; Rice, 2009); England (Baron-Cohen et al., 2009; Brugha et al., 2011; Ryszard, 2011); China (Sun & Allison, 2010; Wong & Hui,

² Participants’ names have been changed throughout thesis to preserve anonymity.

2008); and Australia (Australian Advisory Board on Autism Spectrum Disorders [Autism Australia], 2007; Buckley, 2013; Williams, MacDermott, Ridley, Glasson, & Wray, 2008). In Australia, an estimated 125 000 individuals have ASD and over half a million families are affected by the condition (Autism Australia, 2007).

The precise aetiology of ASD remains unclear, but it is generally agreed that the condition is related to a dysfunction in the central nervous system (Kabot, Masi, & Segal, 2003). Individuals with ASD experience persistent and significant social communicative impairments, as well as restricted and repetitive behaviours and/or interests (American Psychiatric Association [APA], 2013) (see Appendix F for diagnostic criteria of ASD). In addition to these core impairments, individuals with ASD often experience a range of sensory sensitivities, gastrointestinal issues, immune system irregularities, and sleep disturbances (Attwood, 2007; Solomon & Chung, 2012). These combinations of significant social impairment coupled with physical issues exacerbate the challenging nature of this condition (Gray, 2003; Jensen & Spannagel, 2011; Seltzer et al., 2003).

Adolescents with Autism Spectrum Disorder

Adolescence is a critical period of development, involving a range of social, emotional, physical, and cognitive changes (Damon & Hart, 1982; Erikson, 1982; Levesque, 2011). The scope of these developmental changes often results in adolescence being a particularly challenging period for individuals with ASD (Levy & Perry, 2011; McGovern & Sigman, 2005; Samson, Phillips, Parker, Shah, Gross, & Hardan, 2014; Stoddart, 1999). For example, during adolescence the complexity of social interactions increases (Carrington, Templeton, & Papinczak, 2003; White & Roberson-Nay, 2009), the importance of ‘fitting-in’ and conforming to social norms is

heightened (Barnhill & Myles, 2001; Bolick, 2001; Boushey, 2007), and exposure to and involvement in a broader range of social roles is encouraged (Levesque, 2011).

These developmental changes are coupled with heightened societal expectations of social functioning (Barnhill & Myles, 2001). Many of the social peculiarities often exhibited by individuals with ASD, such as unusual eye-contact, emotional bluntness, self-centredness, and minimal reciprocity, are more likely to be viewed more negatively during adolescence than during childhood years (Barnhill & Myles, 2001; Smith & Simpson, 1998). Additionally, compared to younger individuals with ASD, adolescents are likely to become aware of their social difficulties, their distinction from peers, and the realm of interpersonal relationships they find elusive (Fullerton & Coyne, 1999; Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014; White & Roberson-Nay, 2009). This growing awareness is understood to contribute to the high rates of anxiety, depression, low self-esteem, and behavioural difficulties experienced by adolescents with ASD (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Samson et al., 2014; White & Roberson-Nay, 2009).

Families living with Autism Spectrum Disorders

Having a family member with a disability³ reverberates throughout all aspects of family life including meals, toileting, sleep, play, travel, education, and work (Solomon & Chung, 2012). Compared to other conditions, ASD poses a range of distinct challenges for families, such as management of inflexible daily routines, unique intolerances, quick mood changes, and taking on unique roles such as mediator in social

³ In some contexts, ASD is considered a disability (National Disability Insurance Scheme, 2014). More commonly, however, ASD is considered a condition (Attwood, 2007; Seligman & Darling, 2007). Following this, and in respect for the participants involved in this research, ASD will be referred to as a condition henceforth throughout the thesis.

situations (Attwood, 2007; Heiman & Berger, 2007; Macks & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005).

Adolescence is one of the most challenging developmental stages for families living with ASD. Some key challenges during this period include management of behavioural problems and sexual development; ongoing coping with the social and emotional deficits inherent to the condition; managing the increased academic, social, and cognitive demands of high school; and planning for future residential, vocational, and leisure services (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hendricks & Wehman, 2009; Humphrey & Lewis, 2008; Kring, Greenberg, & Seltzer, 2009; Seltzer et al., 2003; Shattuck et al., 2007).

The range of distinct challenges inherent to living in a family with ASD has led some researchers and clinicians to suggest that having a family member with ASD is a chronically stressful experience (Carrillo, 2012; Heiman & Berger, 2007; Macks & Reeve, 2007; Pakenham et al., 2005). However, improved understanding of the nature of co-existing stress and enrichment has led to greater acknowledgment of the positive effects of having a family member with ASD (Meadon & Stoner, 2010; Phelps, McCammon, Wuensch, & Golden, 2009b; Strecker, Hazelwood, & Shakespeare-Finch, 2014; Taunt & Hastings, 2002). Such positive effects include, but are not limited to, strengthened relationships, improved communication, and personal growth (Davis & Gavidia-Payne, 2009; Higgins, Bailey, & Pearce, 2005; Phelps, Hodgson, McCammon, & Lamson, 2009a; Rivers & Stoneman, 2003). This thesis aims to explore both challenging and positive experiences of having an adolescent family member with ASD.

1.3 Conceptual framework

This thesis is informed by two approaches; Family Systems (FS) (Bowen 1978; 1985) approaches and Personal Construct Theory (PCT) (Kelly, 1955; 1966). A brief overview of each approach follows, including a discussion of the rationale for using the two approaches in conjunction.

Family Systems approaches

Family Systems approaches emphasise the importance of understanding individuals in relation to their family (Bowen, 1978, 1995; Hales & Glasscock, 1998; Klein & White, 1996). In describing FS, Seligman and Darling (2007) proposed that “the family is the primary and most powerful system to which a person will ever belong” (p.18). From a FS perspective, families are considered to be distinct, interactive social systems within which individual members have roles and responsibilities that guide their behaviour and the functioning of the overall system (Edwards, 2011; Seligman & Darling, 2007). Family Systems approaches consider there to be semi-independent systems, or ‘subsystems’, operating within the FS. Traditional subsystems include ‘parental’ (parents and child), ‘spousal’ (husband and wife), and ‘sibling’ (child and child) (see Appendix G for further description of these subsystems).

Family functioning is a central concept in FS approaches. In this context, family functioning is understood to involve the complex interplay of various elements, such as emotional closeness, cognitive engagement, physical health habits, social connectedness, communication, expectations, and interactions within a FS. Each family has its own pattern of functioning (Carrillo, 2012). However, there are several factors commonly used to measure family functioning, such as role dispersion and clarity, functioning of boundaries within and outside of the FS, level of cohesion among family

members, and adaptability of the FS. These factors are discussed in more detail in Chapter 2.

Family Systems approaches offer a suitable conceptual framework for researching families living with ASD given the complexity and heterogeneity of this condition and the influences it has on all family members (Johnson, Frenn, Feetham, & Simpson, 2011; Lozzi-Toscano, 2004; Morgan, 1988; Seligman & Darling, 2007). Additionally, the methodologies inherent to FS approaches are useful for understanding ASD as they utilise the perspectives and experiences of various family members (Henry, Sager, & Plunkett, 1996; Puig, Koro-Ljungberg, & Echevarria-Doan, 2008; Turnbull, Summers, & Brotherson, 1984).

Utilising a FS approach for investigating the experiences of families living with ASD during adolescence may be particularly efficacious considering the range of changes in the family that generally occur during developmental transitions (Carrillo, 2012; Seligman & Darling, 2007; Turnbull, Summers, & Brotherson, 1986). That is, whilst adolescence is traditionally considered in relation to the individual only, FS approaches consider such developmental stages as family transition periods (Bray & Hetherington, 1993; Fulmer, Medalie, & Lord, 1982). During such transition periods the FS undergoes changes in structure and functioning as family members experience adjustments to roles, boundaries, goals, level of cohesion, and expectations of one another (Bray & Hetherington, 1993; Seligman & Darling, 2007). Family functioning during transition periods is influenced by the management of, and adjustment to, these changes. The functioning of families who have an adolescent family member with ASD has not yet been adequately investigated (Dew, Balandin, & Llewellyn, 2008; Orsmond & Seltzer, 2007).

Personal Construct Theory

Personal Construct Theory is an approach to understanding human thought and action that is derived from the clinical and theoretical work of George Kelly (1955). Personal Construct Theory is grounded in the assumption that individuals construct a subjective model of their world based on objective reality (Kelly, 1955; 1966). Referred to as ‘personal constructs’, these individualised models of reality guide the way people process and interpret their world.

Personal constructions are considered to develop over time from both direct and anticipated experiences and interactions, meaning there are diverse ways in which people can construe the world (Kelly, 1955; 1966). Furthermore, the philosophy of constructive alternativism recognises that individuals have the capacity to change their constructions through reconstruing processes. This capacity to change ways of viewing the world promotes an optimistic outlook for individuals who hold ineffective or maladaptive constructions and is the basis of PCT grounded therapy (Badzinski & Anderson, 2012; Button, 1985; Epting & Amerikaner, 1980). Kelly (1955; 1966) outlined the key concepts of PCT in a Fundamental Postulate and eleven corollaries (see Appendix H).

Preliminary steps towards applying PCT and methodologies for understanding individuals with ASD have suggested its utility for both research and clinical interventions (Hare, Jones, & Paine, 1999; Procter, 2000, 2001; Sharma, Winter, & McCarthy, 2012). The benefits of utilising a PCT framework with this population include eloquent explanations about the construing processes of individuals with ASD (Procter, 2000), and use of methodologies which suit the processing styles of individuals with ASD (e.g., their general preference for structure, order, and sequence) (Hare, 1997; Hare et al., 1999; Hare, Searson, & Knowles, 2011; Sharma et al., 2012).

However, more work is needed to validate PCT with this population, especially amongst adolescents and their families (Procter, 2001).

A combined Family Systems and Personal Construct Theory framework

There are various factors supporting the use of FS approaches and PCT in conjunction. First, FS and PCT approaches are philosophically consistent as they are both grounded in constructivism. This epistemological position emphasises that people construct a subjective meaning of the world based on their experiences with objective reality (Alexander & Neimeyer, 1989; Feixas, 1990; Giblin & Chan, 1995). When applied to families, the constructivist position proposes that families develop shared meanings and assumptions of the world resulting from shared experiences (Feixas, 1990; Procter, 1981; 1985; 1996).

Second, both FS and personal constructivist approaches recognise that having a family member with ASD influences the FS, as both approaches acknowledge the influence individual family members have on each other and on the FS in general (Ferrari & Sussman, 1987; Procter, 2000, 2001; Seligman & Darling, 2007). Similarly, both approaches recognise developmental periods as critical times. More specifically, PCT considers developmental periods important due to the extensive revisions and elaborations of personal and familial construct systems during these periods (Procter, 1985; 1996; Walker, Oades, Caputi, Stevens, & Crittenden, 2000). Family System approaches consider developmental periods important due to the significant changes in the organisation and functioning of the system as members adjust to alterations in roles, boundaries, goals, and levels of cohesiveness which occur during transition periods (Gavazzi & Sabettelli, 1990; Henry et al., 1996; Turnbull et al., 1986)

1.4 Thesis aims

The overarching aim of this thesis is to better understand adolescents with ASD and their families using FS and Personal Constructivist frameworks. Therefore, the general aims of the thesis are to address the following research questions:

- i. How can FS conceptual and methodological approaches help us better understand the experiences of adolescents with ASD and their families?
- ii. How can personal constructivist conceptual and methodological approaches help us better understand the experiences of adolescents with ASD and their families?

In investigating the experiences of adolescents with ASD, the second Phase of research uses qualitative methodology to capture the perspectives of the adolescents themselves and family members (mothers, fathers, and adolescent siblings). More specifically, this Phase of the research aims to answer the following research questions:

- iii. What are the lived experiences of adolescents with ASD?
- iv. What are the lived experiences of parents of adolescents with ASD?
- v. What are the lived experiences of adolescent siblings of adolescents with ASD?

Some of the challenges experienced by adolescents with ASD highlighted by the qualitative investigations will be used to inform the third Phase of research. More specifically, Phase Three will investigate the ways adolescents with ASD seek help from their family members and the types of support they prefer. Phase Three uses a combined FS and personal constructivist approach and aims to answer the following research questions:

- vi. What are the dependency patterns of adolescents with ASD? More specifically, on whom do the adolescents rely on and what types of support do they prefer?
- vii. What levels of awareness do family members have of the adolescents' dependency patterns?

1.5 Thesis structure

This thesis is presented as a collection of manuscripts prepared for publication; with each chapter presenting a manuscript written for a specific journal. The structure of each manuscript is consistent with the style used by the journal for which it is written. References to Appendices have been included in the manuscripts for the reviewers' convenience. In keeping with journal preferences, different terms have been used throughout the thesis to reference ASD. This issue was compounded with the introduction of the DSM-V (APA, 2013) mid-way through thesis production, and the resulting elimination of diagnostic sub-categories within the autism spectrum (See Appendices I, J, and K for DSM-IV-TR diagnostic criteria).

In addressing the thesis aims, the chapters relate to the various Phases of research. The first two manuscripts (Chapters 2 and 3) outline the conceptual and methodological application of FS approaches and PCT, respectively, for understanding adolescents with ASD. The following four manuscripts (Chapters 4, 5, 6, and 7) present the qualitative investigations of the experiences of adolescents with ASD and their family members. Each manuscript focuses on a specific individual or subsystem within the FS, whilst utilising the perspectives of various family members. Specifically, Chapters 4 and 5 outline the experiences of adolescent boys and girls with ASD, respectively. Chapter 6 focuses on the experiences of parents, with particular attention to the roles undertaken and the coping strategies used when parenting an adolescent with ASD. Chapter 7 focuses on the experiences of adolescent neurotypically developing (NTD) sisters, with particular attention to the roles and responsibilities they undertake at home and school, and the influence this has on their wellbeing and family functioning.

Chapter 8 presents the third Phase of the thesis research, which involved a combined personal constructivist and FS approach to investigating the dependency

patterns of adolescents with ASD. More specifically, participants completed a series of dependency grids which provided insights regarding whom the adolescents depended on in a range of challenging situations and what types of support they sought. The investigation also included family members to explore their level of awareness of the adolescents' dependency preferences. Findings are considered in relation to both research and clinical implications.

Chapter 9 summarizes the findings from the three Phases of research. This chapter also considers thesis implications and limitations, and is followed by recommendations for future research and overall thesis conclusions.

1.6 Significance and originality

This research is novel in its conjunctive use of FS and personal constructivist approaches for investigating the experiences of adolescents with ASD and their families. Understanding ASD in the context of these conceptual frameworks is significant as it offers a unique perspective into the experiences of adolescents with ASD and their families. Such relational family research is important given the pervasive effect this disorder has on families and the dearth of literature to date focusing on this topic.

There is a need for evidence-based clinical approaches targeted specifically at adolescents with ASD, given the range of new experiences and challenges these individuals face during adolescence (Bradford, 2010; Carrillo, 2012; Griffith, Totsika, Nash, & Hastings, 2011; Solomon & Chung, 2012). The research findings presented in this thesis have the potential to make significant contributions to clinical psychology by directly informing clinical interventions for adolescents with ASD and their families. Further, by investigating the experiences of various family members, the research

findings have the potential to inform clinical approaches targeted at systemic, subsystemic, and individual levels within the FS.

1.7 References

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CHAPTER 2: FAMILY-FOCUSED AUTISM SPECTRUM DISORDER RESEARCH: A REVIEW OF THE UTILITY OF FAMILY SYSTEMS APPROACHES

Cridland, E.K., Jones, S.C., Magee, C.A., & Caputi, P. (2013). Family focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism, 18*(3), 213-222. DOI: 10.1177/1362361312472261.

2.1 Abstract

A family member with an autism spectrum disorder presents pervasive and bidirectional influences on the entire family system, suggesting a need for family-focused autism spectrum disorder research. While there has been increasing interest in this research area, family-focused autism spectrum disorder research can still be considered relatively recent, and there are limitations to the existing literature. The purpose of this article is to provide theoretical and methodological directions for future family-focused autism spectrum disorder research. In particular, this article proposes Family Systems approaches as a common theoretical framework for future family-focused autism spectrum disorder research by considering theoretical concepts such as Boundaries, Ambiguous Loss, Resilience and Traumatic Growth. We discuss reasons why these concepts are important to researching families living with autism spectrum disorder and provide recommendations for future research. The potential for research grounded in Family Systems approaches to influence clinical support services is also discussed.

Family focused autism spectrum disorder research:

A review of the utility of family systems approaches

2.2 Introduction

Autism spectrum disorders (ASD) describe a variety of lifelong and pervasive developmental disorders that affect individuals and, importantly, their family in a variety of ways (Macks & Reeve, 2007; Reichman et al., 2008). For this reason, families who have a member with ASD can be referred to as families living with ASD (Neely-Barnes et al., 2011). Family-focused ASD research is critical for increasing our understanding of the impact of these disorders and informing clinical support services for these families. Such research is becoming more common, exploring issues such as the challenges and benefits ASD has on families, ways to support families living with ASD and the impact of ASD on siblings. However, the area of family-focused ASD research still remains underdeveloped as we are only beginning to understand the intricate, reciprocal influences between an individual with ASD and other family members (Orsmond & Seltzer, 2007).

This article briefly reviews key areas of existing family-focused ASD research to highlight the need for a common theoretical framework in this area. We propose that Family Systems (FS) approaches represent such a framework. Greater utilisation of FS approaches for future research is not intended to be a solution to all limitations of research in this area; however, these approaches could drive and inform future research. Our call for greater utilisation of FS approaches in this area is not recent (e.g. Trute & Hauch, 1988; Morgan, 1988) or in isolation (e.g. Jensen & Spannagel, 2011) but is necessary to bring more attention to this issue. In proposing FS

approaches, we discuss the theoretical and methodological advantages of these approaches and discuss research and clinical implications.

2.3 Family-focused ASD research to date and its limitations

It is recognised that having a family member with ASD poses a range of distinct challenges on family members. Such challenges include, but are not limited to, accommodation of inflexible daily routines, lack of spontaneity, management of unique intolerances and sudden mood changes, and being mediators in social interactions (Attwood, 2007; Heiman & Berger, 2007; Macks & Reeve, 2007; Pakenham et al., 2005). Additionally, approximately one-third of individuals with ASD require assistance with self-care, mobility, communication and cognitive or emotional tasks on a daily basis; the majority of this care is provided by family members (Australian Bureau of Statistics, 2011; World Health Organization, 2005). Due to these and other issues, many families living with ASD experience more stress than families with both neurotypically developing children and children with other disabilities (Altiere & Von Kluge, 2009; Hastings, 2003b; Johnson et al., 2011; Miodrag & Hodapp, 2010; Rao & Beidel, 2009). Additionally, some families living with ASD report negative outcomes on family functioning, evidenced by higher levels of psychological problems, greater emotion rather than problem-focused coping strategies and higher family conflict (Meadon & Stoner, 2010; Phelps et al., 2009b).

Many studies focus on the challenges for families living with ASD, and although these findings are useful, they can be limited by basic research designs, which often overlook the complexity of the FS. For example, ‘stress’ is often

examined in a fragmented manner as studies rarely synthesise the broad range of contributing factors, such as dispersion of responsibilities, boundaries between family members and personal meanings of having a family member with ASD (Lecavalier et al., 2006; Miodrag & Hodapp, 2010). Another important limitation is that there is reliance on maternal perspectives as representative of the whole family (Phelps et al., 2009b; Smith et al., 2010). Maternal perspectives are important but may not necessarily reflect those of other family members (Seligman & Darling, 2007). Guite et al. (2004), for instance, compared responses of mothers and siblings of individuals with developmental disabilities and found some discordance, with mothers reporting more sibling adjustment problems compared to the sibling self-reports. Available research highlights the limitations of basic research designs in attempting to explore the complex interplay of factors contributing to the challenges for families living with ASD.

A comprehensive understanding of the challenges for families living with ASD also warrants investigation of coping and support mechanisms. Research in this area highlights the importance of both formal and informal supports for providing information: a means to communicate experiences, feelings, frustrations, expectations and achievements and practical help such as finances and respite (Heiman & Berger, 2007; Phelps et al., 2009b). While there has been research interest focusing on the best types of support for families living with ASD (Hastings, 2003a; Luther et al., 2005; Müller et al., 2008), there remains minimal understanding of the ways different family members provide support for each other (Seligman & Darling, 2007). For example, preliminary research suggests mothers and fathers differ in the types of support they provide for their families (emotional versus

practical support, respectively) (Seligman & Darling, 2007). Research focusing *within* families is critical for developing an understanding of how to best support families living with ASD. Furthermore, there is limited research focusing on the influence of support from extended family, despite preliminary research highlighting the unique contributions of such support on family functioning (Blackledge & Hayes, 2006; Davis & Gavidia-Payne, 2009; Hastings, 2003b; Rao & Beidel, 2009). For example, Davis and Gavidia-Payne (2009) found extended family member's support influenced parenting satisfaction and quality of family interactions.

Existing research also recognises the positive influences of ASD on family functioning, including psychological and emotional strength, improved communication skills and higher levels of empathy and patience (Bayat, 2007; Davis & Gavidia-Payne, 2009; Pakenham et al., 2011). For example, many mothers report various psychological benefits attributed to parenting a child with ASD including selflessness, compassion, peace during time of uncertainty and a refocus of energy (Bauminger, 2002; Bayat, 2007; Phelps et al., 2009b). Research into the positive impacts of ASD on families is encouraging but is only relatively recent. Furthermore, there are a range of areas that would benefit from further research, such as Resilience, Traumatic Growth, family connectedness, spiritual development, appreciation of life and enrichment of relationships (Brewin et al., 2008; Phelps et al., 2009a). This recommendation is in line with previous calls for positive psychology approaches within developmental disabilities research (Bayat, 2007; Hastings & Taunt, 2002; Pakenham et al., 2011).

The impact of having a sibling with ASD on neurotypically developing individuals has been another predominant research area. Research findings have

indicated mixed results, with some reporting positive effects in areas such as self-concept and self-competence (Macks & Reeve, 2007; Rao & Beidel, 2009), and others reporting negative effects such as embarrassment (Mascha & Boucher, 2006; Orsmond & Seltzer, 2007) and increased emotional and behavioural issues (Dew et al., 2008; Meadon & Stoner, 2010). On the other hand, some researchers report no differential impact in areas such as self-concept, self-efficacy and locus of control (Meadon & Stoner, 2010; Vliem, 2009). These mixed results have been interpreted in various ways. For example, that having a sibling with ASD has positive, neutral or negative influences on neurotypically developing siblings. Alternatively, the mixed findings could reflect the varied and dynamic nature of sibling relationships, suggesting that a straightforward ‘cause–effect’ explanation is too simplistic (Seligman & Darling, 2007). Additionally, the mixed findings can be attributed to factors not accounted for in research designs, such as age, sex or birth order of siblings; comparison group used (e.g. neurotypically developing dyads vs dyads with other developmental disorders); information source; family size; parental relationships and a range of demographic factors such as socio-economic status, nationality and location (Ross & Cuskelly, 2006). These inconsistent findings and interpretations continue because studies are generally interpreted in isolation (Stoneman, 2005; Swanson, 1988).

2.4 Common theoretical framework

Although previous research addresses various important issues for families living with ASD, the literature lacks a common theoretical framework. The benefits of a theoretically driven body of work include utilisation of common terminology to

improve communication of findings, research methodologies grounded in theoretically sound concepts and greater synthesis of results from various individual research studies allowing for detection of emerging patterns (Swanson, 1988).

Without appropriate theoretical frameworks, studies are more likely to be influenced by extraneous factors such as social consensus, samples of convenience, opportunities for immediate applications and researcher preferences (Siegel, 1988; Swanson, 1988; Waterhouse, 2008).

Family System approaches

Systems theories are derived from General Systems Theory, an interdisciplinary approach that has been conceptualised as a *Weltanschauung* or ‘unique worldview’ (Von Bertalanffy, 1950). General Systems Theory upholds the importance of interpreting events, situations and people within their environment rather than in isolation (Becvar & Becvar, 1982; Von Bertalanffy, 1950, 1974; Whitchurch & Constantine, 1993). From this perspective, the application of General Systems Theory to individuals involves understanding them in relation to the other people in their life.

Applications of systems approaches to families are referred to as FS approaches. FS approaches consider families as unique interactive and reactive units, with their own basic social system of rules, values and goals (Edwards, 2011). There is no single systems theory about families (Cox & Paley, 1997; Klein & White, 1996); therefore, throughout this article, the various FS theories will be referred to as FS approaches. These approaches encompass a wide variety of concepts and variables. Rather than discussing all of these in detail, Table 2.1 provides an overview of some of the main FS concepts, which are relevant to family-focused ASD research.

Table 2.1: *Definitions of family systems concepts*

Theoretical Concept	Definition
Family System	In general, describes all individuals a family counts on over time for comfort, care, nurturance, support and emotional closeness.
Family Functioning	Complex interplay of various elements, such as emotional closeness, cognitive engagement, physical health habits, social connectedness, communication, expectations and interactions. Degree of functioning ranges from positive to negative.
Macroscopic approach	A FS approach that focuses on the FS in relation to other systems.
Microscopic approach	A FS approach that focuses on subsystems <i>within</i> the family.
Subsystem	Semi-independent systems operating <i>within</i> the FS. Common subsystems include; ‘maternal’ (mother and child), ‘paternal’ (father and child), ‘parental’ (both parents with child), ‘marital’ (husband and wife), and ‘sibling’ (child and child). Subsystems are also referred to as dyads when referring to two person relationships.
Boundaries	Hypothetical borders between and within a FS and its environment. The External Boundary defines the family in relation to other systems. Internal Boundaries determine who is included and excluded in the subsystems. Individuals within a FS also have Personal Boundaries.
Permeability	Degree of difficulty or ease that information and system members have in crossing the Boundaries. Ranges from open to closed. Open systems can be ‘weak’ as boundaries are loosely defined resulting in confusion about family roles, identities and goals. Closed systems can be rigid and restrict information permitted into system, limiting physical, psychological and social growth.
Boundary Ambiguity	Confusion about roles and responsibilities experienced by family members resulting from poorly regulated boundaries.
Ambiguous Loss	Complicated or unclear loss resulting from either physical loss of a person whilst retaining their psychological presence (eg; missing person) or the physical presence of a person whilst experiencing a loss or change in their psychological state (family member with ASD).
Resilience	Ability to cope with challenging life circumstances. Includes physical, psychological, emotional, and social resilience.
Traumatic Growth	An extension of Resilience where coping involves positive change as a result of challenging life circumstances. Such as increases in appreciation of life, personal strength, family solidarity, and quality of relationships.
FS: Family Systems; ASD: Autism Spectrum Disorder.	

Macroscopic and microscopic FS approaches. FS approaches vary with regard to the scope of their focus. Macroscopic FS approaches (Table 2.1) focus on the ways families interact with other systems, such as the community, other families, schools and social groups (e.g. Turnbull et al., 1984, 1986). Microscopic FS approaches (Table 2.1) examine relationships *within* the family, such as maternal, marital and/or sibling subsystems (e.g. Bowen, 1995; Bowen & Kerr, 1988). Both macroscopic and microscopic approaches are important when researching families living with ASD, as they focus on different aspects of family functioning. For example, Brewin et al. (2008) examined parents' perspectives regarding factors contributing their child's quality of school experience. Major themes were identified across various systems including presentation of ASD in the child, classroom factors, school factors and institutional factors in the education system (Brewin et al., 2008). Importantly, without utilising FS approaches, previous research has rarely explored relationships *between* subsystems. This is important for addressing key research areas such as ways in which the marital relationship influences the functioning of sibling relationships or the ways in which a maternal relationship differs from a paternal relationship. This distinction is important given that relations *within and between* subsystems affect family functioning (Hastings, 2003b; Meadon & Stoner, 2010).

Boundaries. According to FS approaches, the concept of Boundaries (Table 2.1) is central to understanding family functioning (Becvar & Becvar, 1982; Carroll et al., 2007) and is therefore relevant to researching families living with ASD (Seligman & Darling, 2007). The functioning of Boundaries is measured by their permeability (Table 2.1). Permeability of boundaries is necessary for families to manage life events such as job changes and moving house (Seligman

& Darling, 2007). Optimally functioning families develop a balance between open and closed boundaries (Becvar & Becvar, 1982; Seligman & Darling, 2007). For example, Bayat (2007) reported that the most resilient families living with ASD in their study were able to be flexible in role and responsibility changes as well as communicate with each other about personal needs.

Poorly regulated boundaries can impact family functioning in various ways. According to FS approaches, two such ways are experiences of Boundary Ambiguity and Ambiguous Loss (Table 2.1). These experiences may be particularly important for families living with ASD due to the range of ongoing adjustments associated with ASD (O'Brien, 2007). For example, Boundary Ambiguity may result when neurotypically developing siblings become involved in some household and care-giving responsibilities usually reserved for parents (Smith, 2000). Boundary Ambiguity can also occur when the identities of individuals become enmeshed (Carroll et al., 2007). For instance, parents who are preoccupied with their child's ASD may have difficulty viewing their own life as independent from their child's experiences (O'Brien, 2007).

Families may also be more vulnerable to Boundary Ambiguity during transition periods (such as developmental changes), as these periods normally involve large adjustments of roles and expectations for all family members (Bray & Hetherington, 1993; Seligman & Darling, 2007). When considering families living with ASD, there are likely to be unique transition periods related to ASD such as the period of diagnosis (Phelps et al., 2009b; Seligman & Darling, 2007). Additionally, 'universal' transition periods, such as adolescence, are likely to involve different issues for individuals with ASD and their families (Phelps et al.,

2009b). Such transition periods have not yet been adequately mapped (Phelps et al., 2009b).

Ambiguous Loss may be particularly relevant to families living with ASD (Boss, 1994). For example, family members may perceive the family member with ASD as physically present yet psychologically absent (Boss, 2004). This experience may be particularly evident during the period of diagnosis, as it often involves a range of emotions including uncertainty about the clarity and repercussions of the diagnosis (O'Brien, 2007). Other factors that may contribute to vulnerability to Ambiguous Loss in families living with ASD include the unpredictable, heterogeneous and challenging nature of ASD, the high day-to-day variability in functioning, wide ranging patterns of strengths and weaknesses, and broad ranging responses to treatment (O'Brien, 2007). Furthermore, fluctuating emotional experiences ranging from hope for improved functioning (or for some families hope for discovery of a 'cure' for ASD) to feelings of hopelessness or frustration during difficult situations, mixed with feelings of love, pride and joy, may make some families living with ASD vulnerable to Ambiguous Loss (O'Brien, 2007). These experiences may be further complicated by the feelings of guilt when reflecting on the 'negative' emotions mentioned earlier (Boss, 1999, 2004; O'Brien, 2007).

Notably, such reactions are not necessarily long term and do not develop in all families living with ASD. Instead, it appears that *most* families adapt and cope effectively with childhood disability (Seligman & Darling, 2007). The multilevel approaches supported by FS approaches are especially important for understanding *perceived* issues like Boundary Ambiguity and Ambiguous Loss as perceptions may vary across subsystems.

Resilience and Traumatic Growth. Resilience and Traumatic Growth

(Table 2.1) are two positive facets of family functioning outlined in FS approaches. In this context, Resilience is apparent in families who make active efforts to spend time with each other, balance needs of the family member with ASD with needs of other family members, maintain healthy routines, hold shared values, find meaning in challenging circumstances, have flexible roles, utilise support services, openly communicate and have proactive approaches to challenges (Seligman & Darling, 2007).

In recognising the possibility of distress and growth coexisting, Traumatic Growth has been considered particularly suited to the challenging yet rewarding nature of ASDs (Heiman & Berger, 2007). Traumatic Growth is applicable for families living with ASD in a range of ways. As discussed, initially, a diagnosis of ASD for a family member may be perceived as a distressing loss as it involves realisations that they will not develop typically, possible confusion around the individual's identity and re-evaluating expectations and responsibilities of all family members (O'Brien, 2007). However, coupled with this may be experiences of relief, validation and over time understanding and acceptance of having a family member with ASD (Phelps et al., 2009a; Samios et al., 2012)

2.5 Implications for clinical support services

The importance of clinical support services on functioning for families living with ASD has been documented (Bradford, 2010; Seligman & Darling, 2007). Clinical support services are a type of formal social support that increases well-being, knowledge about the disorder, family functioning, Resilience and perceived competence, and reduces subjective distress (Bagatell, 2007; Bradford,

2010; Phelps et al., 2009b; Seligman & Darling, 2007). Therapists may also provide informative and emotional support, help the family respond to grief or confusion, act as role models, improve family capacity building skills (Pinkerton & Dolan, 2007; Russo, 1999; Wetherby & Woods, 2006; Woods & Brown, 2011) and encourage acceptance and even appreciation for an individual's or family's situation (Bagatell, 2007; Bradford, 2010; Seligman & Darling, 2007).

There are several ways family-focused ASD research grounded in FS approaches can directly inform clinical support services, as follows.

1. FS approaches encourage research to focus on various aspects of the FS (e.g., individual, subsystemic and macroscopic). This will result in clinical interventions that can be targeted at individuals, subsystems and the systemic level. Importantly, the interrelations of subsystems can also be targeted.
2. FS approaches encourage inclusive approaches to research designs. Interventions based on such research will encourage all family members to be involved in therapy. This may involve including people outside the traditional scope of 'family therapy' such as extended family, friends or in-home therapists.
3. The utilisation of theoretically grounded FS concepts (such as Boundaries, Ambiguous Loss and Traumatic Growth) means clinical support services will be both theoretically and empirically evidenced based.
4. As FS concepts cover both positive and negative aspects of family functioning, research may inform holistic, strengths-based approaches. Strengths-based approaches help families utilise their own resources and recognise their own capacities for resilience (Bayat, 2007). The efficacy of such approaches is supported in the literature for both families with young and

adolescent children (Allison et al., 2003; Cosden et al., 2006; Early & Glen-Maye, 2000; McGuire, 2009; Sargent, 1991).

5. FS approaches recognise the heterogeneity of families and ASD alike. This recognition promotes individualised clinical support services for each family living with ASD.
6. FS approaches recognise that family functioning changes across time and in response to life events and transition periods. This recognition translates to clinical support services that promote opportunities for improved family functioning, regardless of current challenges.

2.6 Implications for future research

Based on the issues raised in this article, we recommend that the following areas be considered in future research. For each of these areas, we provide examples of research that has been conducted and requires expansion.

1. It is important to embrace flexible and inclusive approaches to researching ‘families’. Such approaches recognise the importance of involving various system members, and in doing so, gain a rich understanding of family functioning. For example, in comparing the efficacy of individual versus family therapy for individuals with Asperger’s syndrome (AS), Stoddart (1999) interviewed individuals with AS, parents and also clinicians in order to understand the issue from all perspectives. The multidimensional perspectives highlighted the multifaceted ways family therapy impacts the FS at various levels (Stoddart, 1999). For example, one family reported that knowledge gained about AS affected their interactions with their family

member with AS and also allowed them to communicate better with extended family members about AS (Stoddart, 1999).

2. Future research would benefit from investigating both positive and negative factors contributing to family functioning. This may include investigation of theoretical concepts grounded in FS approaches, such as Boundaries, Resilience, Traumatic Growth and Ambiguous Loss. For example, one study investigating the lived experiences of mothers reported benefits associated with living with ASD in a range of areas including social opportunities, health, employment and strengthening of family subsystems (Markoulakis et al., 2012).
3. There is a need to design studies targeted at various aspects of the FS (individualistic, subsystemic and macroscopic) to explore complex issues such as stress, coping and supports. For example, Hastings (2003b) explored the interrelationships of psychological well-being between mothers and fathers of children with ASD and found various ways in which the mental health of one individual affected their partner and other family members.
4. FS approaches recognise the importance of researching families during transition periods. Transition periods with minimal research attention include adolescence and young adulthood (Baker et al., 2011; Gerhardt & Lainer, 2011; Griffith et al., 2011; Levy & Perry, 2011). This continues despite preliminary research indicating a range of important issues for families and individuals with ASD during these periods. For example, the transition from primary school to high school requires management of large amounts of unstructured activities (bus rides, changing classes and study periods) (Adreon & Stella, 2001). A common theoretical framework for family-

focused ASD research may help identify transition periods warranting greater research attention.

5. It is important to consider the impact of living with ASD (on individuals and families) across all developmental stages. The predominant focus of research has been childhood (for both individuals with ASD and siblings), with little research focusing on young adulthood and beyond (Baker et al., 2011). Research focusing on ‘childhood’ may also be too broad to identify factors most influential during specific developmental periods (Bauminger et al., 2003; Orsmond & Seltzer, 2007). For example, a meta-analysis of the sibling ASD literature published from 1970 to 2005 indicated that 17 of the 21 studies had participants ranging from age 2 to 18 years (Dew et al., 2008). In recognising the importance of developmental stage, research utilising FS approaches may avoid this limitation.
6. The inclusive nature of FS approaches recognises the importance of involving individuals with ASD (Bayat, 2007). This suggestion may seem self-evident; however, numerous studies examining families living with ASD *do not* include the perspectives of the individual with ASD (Brewin et al., 2008; Dew et al., 2008; Rao & Beidel, 2009). This trend seems well ingrained in disability research. For example, a review of sibling research identified that the individual with a developmental disability was included in only 2 out of 21 studies (Dew et al., 2008).
7. As FS approaches recognise the fluctuating nature of family functioning over time, research grounded in these approaches may utilise longitudinal designs. Preliminary research suggests that the meaning of having a family member with ASD may change over time; however, the nature of such change and the

ways the FS and other systems influence change remain unclear. For example, Altieri and Von Kluge (2009) interviewed parents about their families' meaning-making of living with ASD and found that various changes were reported to have occurred over time such as questioning, devastation, personal struggles, as well as personal, family and child benefits. To date, such research usually relies on recall of experiences rather than tracking participants over time, which may limit the validity of responses. Longitudinal research grounded in FS approaches could be one way of addressing this limitation.

Methodological implications

There are a range of methodological considerations when designing and conducting research with individuals with ASD and their families. Consideration of the range of potential difficulties in conducting research with individuals with ASD and their families is likely to have deterred some researchers from pursuing research in this field. Yet, importantly, the potential difficulty of conducting research in this area does not decrease the need for research with families living with ASD. FS approaches not only provide a theoretically sound framework for conducting research in this area, but also address many of the methodological challenges associated with research in this area.

We propose that the following issues may be considered when conducting research with families living with ASD:

1. Wording of instructions and questions should suit the processing styles of children and individuals with ASD (e.g. concrete and single-faceted

sentences). This may involve including step-by-step, written instructions, rather than complicated verbal instructions.

2. Consider using alternative methodologies to verbal conversations, such as drawings or photographs (Ravenette, 1997, 2005) or multimedia (Wyn & Harris, 2004).
3. Be aware of the potential for linguistic confusions. Misinterpretations may be from the individual with ASD (e.g. literal interpretations of phrases, misunderstanding words with double meanings or difficulty articulating experiences) or the researcher (e.g. misunderstanding an individual's specific meaning of a particular word). To avoid misinterpretations, researchers can involve participants in interpretation of findings (Dockett et al., 2009).
4. Ensure participation of all family members is based on voluntary and informed consent. This may involve asking children and individuals with ASD to describe their understanding of the study's aims and procedures and what they will be asked to do.
5. Attempt to prepare participants for the range of personal experiences that may be focused on during the study. This may also involve managing unexpected or negative reactions related to issues focused on during the study.
6. Consider using qualitative approaches that are supported by FS approaches. Such approaches provide opportunities to capture subjective experiences and understand complex patterns of relationships *between* individuals and subsystems (Carrington & Graham, 2001). Furthermore, qualitative approaches have the potential to capture idiographic, multifaceted issues often present in the families by avoiding predetermined and sometimes restrictive response options of quantitative approaches. Furthermore, qualitative

approaches are useful for conducting research with children (Dockett et al., 2009; Mishna et al., 2004). Notably, there are justifiable reasons for utilisation of quantitative approaches (i.e. standardised measurements and greater opportunity for generalisation). However, these approaches may benefit from being complemented with qualitative sections (i.e. mixed methods approaches) in FS research.

Statistical analysis recommendations

An array of statistical techniques is available to researchers applying FS approaches to individuals with ASD and their families. A comprehensive review of available strategies is beyond the scope of this article. Instead, we briefly comment on some analytic techniques that can be used in future family-focused ASD research utilising FS approaches.

1. It is important to note that FS data are inherently interdependent. For instance, while interested in how a child's characteristics influence his or her behaviour, we may also be interested in how characteristics of a parent influence the child's behaviour. It is appropriate then that the interdependence in dyadic relationships, such as that between parent and child, is modelled and tested using appropriate strategies. Cook and Kenny's (2005) actor-partner interdependence model is an illustration of modelling the concept of interdependence using appropriate techniques. This approach highlights the application of structural equation modelling and multilevel modelling to longitudinal dyadic data (Cook & Kenny, 2005). Campbell and Kashy (2002) provide a more comprehensive review of the actor-partner interdependence model. This approach was used to examine the degree of non-independence in

sense-making and benefit finding between mothers and fathers of children with AS (Samios et al., 2012). Results indicated that overall meaning-making was interrelated between partners (Samios et al., 2012), highlighting the importance of adopting an interpersonal approach to analyse family data.

2. Data from FS research have certain characteristics that need to be considered during analysis. Data are usually nested or hierarchical in nature. For instance, children are members of families – they are nested within families. Studies may also collect inter-generational data. Multilevel models can account for the interdependence inherent in nested data structures evident in FS approaches. It is recommended that researchers use, where appropriate, analytical techniques that model the characteristics of FS data. Examples of applications of multilevel models in family research include Snijders and Kenny (1999) and Jenkins et al. (2005).
3. It is important to consider the ways in which family dynamics may influence the analysis and interpretation of findings. Such considerations may include family size (e.g. number of siblings), sibling ages and genders and blended families.

2.7 Conclusion

There remains limited research focusing on families living with ASD (Orsmond & Seltzer, 2007). This is of concern given the diverse and pervasive impacts these conditions have on families. Of the research that is available, it can be difficult to synthesise findings due to limited use of a common theoretical direction. This article highlights some of the limitations in the existing literature and proposes the efficacy of FS approaches as a guiding framework for future family-focused ASD research. The

benefits of FS approaches involve the inclusion of theoretically sound concepts, balanced focus of both positive and negative factors involved in family functioning and inclusion of all family members in research methodologies. If future family-focused ASD research utilises a common framework, such as FS approaches, then the research findings of individual studies may be synthesised and emerging patterns made more salient. Furthermore, reviewing the findings of past research through a FS lens may lead to further insights and alternate interpretations of some existing research findings. Together, this will result in a deeper understanding of research findings, which will potentially inform evidence-based clinical support services for families living with ASD. All these benefits contribute to our overall goal of learning about the best ways to support families living with ASD.

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CHAPTER 3: UNDERSTANDING HIGH FUNCTIONING AUTISM DURING ADOLESCENCE: A PERSONAL CONSTRUCT THEORY APPROACH

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3.1 Abstract

Background: Personal construct theory (PCT) is a constructivist approach to understanding human thought and action. Preliminary research focusing on applying PCT concepts and methodologies to understanding individuals with high functioning autism (HFA) has suggested its utility for both research and clinical interventions. The developmental period of adolescence has also been outlined according to PCT. However, PCT has not been applied to the more specific subgroup of adolescents with HFA, despite various theoretical tenets suggesting its utility. Conclusions: In addressing this research gap, we considered the following adolescent developmental tasks with particular reference to adolescents with HFA: (a) functioning within the increasingly complex world of adulthood, (b) identity development, and (c) development of higher order processing styles (including abstract thinking and flexible processing). These issues were described using PCT concepts. Finally, we considered ways to support individuals and families living with adolescents with HFA.

Understanding high functioning autism during adolescence:

A personal construct theory approach

3.2 Introduction

Adolescence is a time of many maturational changes, including a range of physical, social, emotional, and cognitive developments, as well as transitions into high school and increasing expectations, roles, and responsibilities. Adjusting to these changes can result in vulnerabilities to stress, anxiety, and other emotional issues (Myles & Simpson, 1998). Adolescents with high-functioning autism (HFA) are not immune to these challenges. Rather, research suggests that adolescents with HFA may be more susceptible to these issues than neurotypically developing (NTD) teens (Barnhill & Myles, 2001; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Myles & Simpson, 1998; White & Roberson-Nay, 2009). Although some adolescents with HFA move through this period easily, for the majority, adolescence is a difficult time (Stoddart, 1999; Willey, 2003). For this reason, understanding the experience of adolescence for individuals with HFA is of high importance for the individuals themselves, their families, and clinicians (Levy & Perry, 2011).

In this paper, we describe how Personal Construct Theory ([PCT]; Kelly, 1955) can be used to understand the experience of HFA during adolescence. PCT has previously been applied to HFA (Procter, 2001) and adolescence (Truneckova & Viney, 2006, 2007, 2012) separately. However, it has not been applied to these subgroups in combination. The rationale for focusing on adolescents with HFA is the dearth of literature attempting to understand the experiences of this subgroup grounded in any theoretical approach (Carrington, Templeton, & Papinczak, 2003; Cridland, Jones, Magee, & Caputi, 2013;

Layne, Wilgosh, & Sobsey, 1993; Vliem, 2009). This lack of research remains despite the range of challenges adolescents with HFA face.

We begin this paper by providing a broad overview of PCT, and then apply some of the key PCT concepts to understanding adolescents with HFA. More specifically, we consider (a) functioning within the increasingly complex world of adulthood, (b) identity development, and (c) development of higher order processing styles (including abstract thinking and flexible processing). These issues are described using the following PCT concepts: fragmentation corollary, individuality corollary, organisation corollary, experience corollary, sociality corollary, and the communality corollary. Throughout the paper the advantages of understanding adolescents with HFA through the lens of PCT and central elements of clinician support for both individuals and their families are discussed. The research in this area is also reviewed and potential areas for future research are outlined.

The term HFA is used in this paper to refer to all individuals at the high-functioning end of the autism spectrum. Consequently, the term HFA is used to refer to individuals who experience the following symptoms: significant social reciprocity difficulties and behaviours and/or interests that are considered unusual and/or repetitive, coupled with no significant impairments in cognitive functioning (American Psychiatric Association, 2013; Jensen & Spannagel, 2011).

3.3 Overview of PCT

PCT derives from the clinical and theoretical work of George Kelly and is a constructivist approach to understanding human thought and action (Kelly, 1955). It assumes that objective reality is not directly accessible; rather, each individual actively

processes or constructs a unique model of her or his world that is based on reality (Fromm, 1995; Steinfeld, 2000).

The central tenet of PCT is that people process and make sense of their world according to “personal constructs.” Kelly (1955) defined personal constructs as “a way in which some things are construed as alike and yet different from others” (p. 105). Personal constructs act as models of a person’s world, guiding perceptions and behaviours, and help to make sense of their experiences. In describing the nature of personal constructs, Kelly posited that “man looks at his world through transparent patterns or templates which he creates and then attempts to fit over the realities of which the world is composed” (p. 7). Personal constructs refer to all distinctions a person makes, and although we generally refer to constructs at a verbal level (such as my construct about teachers who are either “fair” or “unfair”), not all constructs operate at this level.

According to Kelly (1955, 2003), people build up their constructions of the world by functioning like a naïve scientist. That is, like scientists, people build complex networks of hierarchically organised theories that they use to help make sense of the world. If a person’s constructions about a situation do not lead to accurate or helpful interpretation, then they will be motivated to adjust their constructions to more accurate theories (Kelly, 1955). This metaphor of “person as naïve scientist” depicts people as agents who are active in making meaning of a relatively passive world. In this way, Kelly theorised that people do not react to events but to the way events are construed (Feixas, Erazo-Caicedo, Harter, & Bach, 2008).

Constructive alternativism posits that there are diverse ways in which people can construe the world (Kelly, 1955). Such flexibility permits people the freedom to change their constructions; “...all our present perceptions are open to question and reconsideration, and...even the most obvious occurrences of everyday life might appear

utterly transformed if we were inventive enough to construe them differently” (Kelly, 2003, p. 1). The capacity to change ways of viewing the world promotes an optimistic outlook for individuals with ineffective or maladaptive constructions of the world and is the basis of therapy in personal construct psychology (Badzinski & Anderson, 2012).

3.4 Adolescence, HFA, and PCT

Kelly (1955) did not directly address developmental periods in his work (Fransella & Neimeyer, 2005; Vaughn & Pfenninger, 1994). Moreover, Kelly considered people to be forms in motion who are continually developing throughout life (Fransella & Neimeyer, 2005; Walker, 2009). Kelly also posited PCT as a “working” theory, with the aim that it would continually be extended upon and applied to a range of areas and client groups (Winter, 2013). Here, we apply PCT concepts to better understand adolescents with ASD.

Increasing complexity of the social realm

A key developmental task of adolescence is adjusting to dramatic changes in social functioning. Social situations become more complex during this period as adolescents transition from childhood roles, competencies, and responsibilities into those required during adulthood (Levesque, 2011). Associated with this increasing complexity are heightened societal expectations of functioning (Henry, 1994; Levesque, 2011). That is, social competencies acquired in childhood are no longer sufficient during adolescence. This increasing complexity of social interactions, coupled with heightened expectations for social functioning, results in a challenging world for adolescents with HFA (Barnhill & Myles, 2001; Carrington et al., 2003; Harter, 1999; Henry, 1994; Layne et al., 1993; White & Roberson-Nay, 2009). More specifically, social deviances, such as unusual eye contact,

emotional bluntness, self-centredness, and lack of reciprocity, which may be considered curious or unusual in childhood, are more likely to be viewed negatively in adolescence as they do not meet the social expectations now required (Barnhill & Myles, 2001).

From a PCT perspective, these social deviances may be understood as attempts to cope with feeling anxious (Myles & Simpson, 1998; Stanghellini, 2001). According to PCT, anxiety may be experienced when an individual is attempting to make sense of a situation that seems alien and uninterpretable within his or her current construct system (such situations are referred to as “beyond the range of convenience” of the construct system; Katz, 1984; Kelly, 1955; McCoy, 1977; McWilliams, 1979). In an extension of Kelly’s original work, McCoy (1977) proposed several emotion-focused PCT concepts, including the anxiety hypothesis. The anxiety hypothesis states that “a person experiences anxiety to the extent that he perceives a loss of ability to structure his perceptual field. Or equivalently, anxiety is the recognition that the events with which one is confronted lie outside the range of convenience of one’s construct system” (McCoy, 1977, p. 101).

With this interpretation, experiencing anxiety in “unknown” situations is evolutionarily functional, as these situations may be dangerous (Katz, 1984). Although the potential for danger in most social situations is generally minimal, it is an individual’s interpretation of the situation that is of importance in PCT. Given that a central feature of HFA is difficulty understanding social situations, it is reasonable to assume that individuals with HFA would interpret social situations as beyond the range of convenience of their construct systems (thus potentially dangerous), therefore leading to the experience of anxiety. For adolescents with HFA, the increasing complexity of social situations increases the likelihood that they will be beyond the range of personal construct systems, thus leading to an increased likelihood of experiencing anxiety. Truneckova and Viney (2012) applied this conceptualisation of anxiety in their work with troubled NTD

adolescents. Additionally, they perceived anxiety as a precondition necessary for psychological change; that is, it serves as a trigger to facilitate revisions to construction systems (Truneckova & Viney, 2012).

Individuals with HFA may also perceive social situations as alien (and thus anxiety evoking) because of their difficulty understanding that other peoples' experiences of the world may differ from their own. For example, an individual with HFA may find it difficult to recognise that others do not hold the same amount of importance in his or her personal interests as they do. Without this knowledge, individuals with HFA can have difficulty regulating the amount of information they share with others about topics they are interested in. Associated with difficulty understanding how other people feel are challenges in appreciating the ways their own behaviour affects others.

According to PCT, the ability to appreciate that other people's experiences of the world may vary from one's own is a major component of social functioning "...because only through construing another's construing can one have a truly social interaction" (Kelly, 1955, p. 18). The sociality corollary describes this process of relating to and understanding others. According to PCT, people do this by developing constructions about how another person may construe the world. In other words, "to the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person" (Kelly, 1955, p. 66). Essentially, this ability unlocks the social world and permits meaningful relationships to develop. Yet it is precisely this skill of role-taking that individuals with HFA find challenging.

During adolescence, social functioning and "fitting in" attain heightened importance (Barnhill & Myles, 2001; Levesque, 2011). Adolescents with HFA may become increasingly aware of their social difficulties, their distinction from peers, and the realm of peer interpersonal relationships they find challenging (Frith, 1991; Fullerton & Coyne,

1999; Stoddart, 1999). Such awareness has been associated with various psychological problems, including internalising difficulties, such as anxiety and depression, and externalising symptoms, such as aggressive behaviour (Barnhill & Myles, 2001; Levesque, 2011; Levy & Perry, 2011; Myles & Simpson, 1998). As a result, it is not unusual for adolescents with HFA to become emotionally sensitive, have low self-esteem, and become easily stressed (Myles & Simpson, 1998). This relationship is likely to be bidirectional. That is, awareness of inadequate social skills, misinterpretation of social subtleties, isolation, or expectations of social failure may lead to anxiety or depression (Lasgaard et al., 2010; White & Roberson-Nay, 2009), and mental health problems may exacerbate social deficits, which could lead to avoidance of social interactions thereby limiting opportunities to practise social skills (Stoddart, 1999; White & Roberson-Nay, 2009).

Associated with the increasingly complex social world of adolescence is exposure to, and participation in, a broader range of social roles. Employee, drivers licence holder, and partner are examples of some roles commonly adopted during adolescence. The uptake of a new role requires learning the rules, responsibilities, and social etiquette associated with each specific role. Adolescents with HFA may find accommodation of new roles to be confusing as their learning style generally requires “manual learning,” whereas their NTD counterparts rely more on “social learning” (Chan & John, 2012). Social learning allows NTD adolescents to form loosely developed constructs about roles they have observed but not personally been involved in (Chan & John, 2012). For example, a NTD adolescent would have constructs about the role of a waiter (i.e., take orders, clean tables, bring out food, handle money). Although adolescents with HFA may have similar constructs, their ability to apply these constructs to themselves is likely to be limited as they rely on manual learning of how roles apply to them personally. This

conceptualisation highlights the importance of manually teaching adolescents with HFA about the specific tasks a particular social role may involve.

The range of social deficits described above are challenging for family members of adolescents with HFA, as it can be particularly difficult for them to understand the unique presentation of HFA exhibited by their family member. Such behaviour may include inflexible daily routines, lack of spontaneity, unique intolerances, quick mood changes, and difficulty coping in social interactions (Attwood, 2007; Heiman & Berger, 2008; Macks & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005; Procter, 2001; Vliem, 2009). The personal constructivist interpretation offered in this paper may facilitate understanding as to why their adolescent family member with HFA finds social situations and relationships difficult. Clinicians may also benefit from understanding such behaviour according to the PCT lens in their provision of support to families.

Sense-making in complex social situations

Adolescent involvement in the complex social world of adulthood requires efficient interpretation of multifaceted, complicated social situations. For example, a room where two conversations are occurring at the same time, a television show is on, and someone is preparing a meal, is a standard situation interpreted by NTD adults. The interpretation of such a situation requires simultaneous processing of the various elements that are subsumed under a broader picture, in addition to the ability to select out and attend to the most relevant aspects of the situation as a priority (Deruelle, Rondan, Gepner, & Fagot, 2006; Procter, 2001). Such skills in efficiently and coherently synthesising complex situations are not well suited to the processing style of individuals with HFA (Deruelle et al., 2006; Procter, 2001). More specifically, research indicates that when individuals with HFA process complex objects or scenes, they process the various parts (or subordinate

components) of an item as a priority (Deruelle et al., 2006). This processing style is different to the NTD controls, who process the overall objects first (superordinate components) before focusing on the more detailed, subordinate elements (Deruelle et al., 2006). This latter style of processing is considered more efficient as it permits the “big picture” to be realised, decreasing opportunity for misinterpretation.

According to a personal constructivist interpretation, the differing processing styles of NTD individuals and individuals with HFA can be attributed to the organisation of personal constructs. A personal constructivist framework posits the importance of hierarchically organised networks of constructs for effective construing. Such hierarchical organisation of constructions allows us to interpret, understand, and anticipate situations more easily than if each situation was interpreted by its various, individual components. To describe the organisation of personal constructs, Kelly (1955) formulated the organisation corollary. This corollary states: “Each person characteristically evolves, for his convenience in anticipating events, a construction system embracing ordinal relationships between constructs” (Kelly, 1955, p. 39). Ordinal relationships between constructs occur when some constructs become subordinate to, or “under,” other constructs. For example, a construct about seagulls may be considered subordinate to the higher order (or superordinate) construct of birds. In this way superordinate constructs are considered to be more abstract because they incorporate more rules and exceptions to rules (e.g., penguins are still classified as birds despite the fact that most birds fly) than subordinate constructs.

Continuing with the example of entering the busy room, the hierarchically organised constructions utilised by a NTD individual may include consideration of the time of day to anticipate the program playing on the television, knowledge about body language to anticipate the types of mood the people are in and importance of what they are saying, and

past experiences with food to anticipate what meal is being prepared. Conversely, the construct system of an individual with HFA, dominated by a network of isolated, subordinate constructs, will require “manual” interpretation of the numerous “separate” components of the situation from a bottom-up approach.

For adolescents with HFA, development of efficiently organised construct systems may be even more challenging. First, processing superordinate constructs requires abstract thinking skills. Abstract thinking skills facilitate problem-solving abilities, regulation of coping responses, and aptitude to anticipate future events and implications of decisions (Inhelder & Piaget, 1958). Such abstract thinking skills, or formal operations, are still developing throughout adolescence and it is not until late adolescence that these skills become fully developed (Inhelder & Piaget, 1958). Therefore, with the combined effects of underdeveloped abstract thinking skills, and construct systems less efficiently organised than those of NTD adolescents, adolescents with HFA are likely to experience difficulties making sense of complex situations.

Kelly (1955) described that such hierarchical organisation of constructs results from ongoing revision of constructs through validation and invalidation processes. Validation is defined as “compatibility between one’s predictions and the outcome he observes” (Kelly, 1955, p. 158), which Kelly contrasts with invalidation, the “incompatibility between one’s predictions and the outcome he observes” (p. 158). Although Kelly theorised that the validation–invalidation process occurs through the person-as-scientist process of interacting with the world (discussed in Overview of PCT), he also recognised that people may not always engage in the validation cycle effectively. Consequently, people sometimes retain constructs despite invalidation and vice versa (Kelly, 1955). Kelly (1955) proposed that this can occur on varying levels from deliberate ignorance to inadvertent overlooking of facts. In addition, Walker (2002) proposed three conceptual

aspects involved in the validation cycle: the content of construing, the process of construing, and the structure of constructs. She posits that errors in the validation–invalidation process can occur at any of these stages (Walker, 2002). Together, this means there are various ways that people may not engage in effective validation–invalidation processes (Walker, 2002; Walker, Oades, Caputi, Stevens, & Crittenden, 2000).

Mason (2008) used repertory grids (a PCT methodology) to measure psychological change with offenders who have intellectual disability. The repertory grid proved sensitive to measure the impact of psychological treatment in a client group who often make only small gains, and flexible enough to effectively measure idiosyncratic changes over treatment (Mason, 2003, 2008). A key way this was achieved was by showing a general “loosening of construing” (Kelly, 1955) over time, which, according to PCT, is evidence of a general increase in readiness to change. This approach may also be efficacious for working with adolescents with HFA, as it may help others understand the content, process, and structure of their constructions.

Identity development

Identity development, or forming a sense of self, is a central component of adolescence. According to PCT, a person’s identity consists predominantly of higher order constructs called core constructs (Butler, 2006; Kelly, 1955). Kelly (1955) defined core constructs as those that “govern people’s maintenance processes—that is, those by which they maintain their identities and existence” (p. 482). Core constructs, like all others, are understood to be the result of construing and are developed to help us anticipate a particularly important set of events—ourselves (Kelly, 1955). Core constructs are considered to be the most complex superordinate constructs in a person’s personal construct system (Butler, 2006). This complexity arises because core constructs are

developed and influenced by all other lower order construct systems, meaning the precise content of core constructs is usually beyond conscious awareness (Butler, 2006).

Individuals with HFA may have difficulty developing superordinate constructs due to the organisation of their personal construct systems (i.e., minimal use of hierarchical organisation of constructs). For this reason, Procter (2001) theorised that individuals with HFA may experience a poor sense of identity. Given that adolescence is a key period of identity development, it may be assumed that adolescents with HFA will find this period demanding (Cottenceau et al., 2012).

Another reason contributing to difficulties in identity development for individuals with HFA is that it is considered to be a largely social process (Levesque, 2011; Neimeyer & Neimeyer, 1985). More specifically, the social components of identity development involve exposure, experimentation, and sense making of different social roles (Levesque, 2011). Although the specific content of core constructs is considered to vary from person to person, socially dependent common factors underlying core constructs have been theoretically (Rowe, 2003) and empirically (Butler, 2006) proposed. More specifically, Rowe (2003) proposed the common dimension of core constructs of “self-liking” whereby a person’s perception of self is developed from the reactions of others. Similarly, Butler (2006) posited that a common factor of core constructs is “relatedness,” which describes the ways in which our core constructs are embedded in relationships with others.

In support of the social nature of identity development, Walker (1996) proposed that implicit and explicit feedback received by other people is critical for identity development. Family and peers are the two main social groups of people who provide feedback to adolescents, and identity development requires interaction and feedback from both these social groups in a particular manner. That is, as adolescents experiment with different social roles, peers serve as “social stepping stones” for the adolescent to transition from

complete dependence (physical, emotional, and psychological) upon family toward autonomous functioning as an adult (Levesque, 2011). The family's role is to provide a secure support base during this role experimentation. Given that identity development is a highly social process, and that the social world can be challenging for individuals with HFA, identity development is likely to be a challenging process for adolescents with HFA (Artar, 2007; Henry, 1994; Willey, 2003; Ybrant, 2008).

Another factor that contributes to the challenging nature of identity development is experiencing conflict between the various roles the adolescent is attempting to assimilate. Some roles may be seemingly incompatible with, or even in opposition to, other roles. For example, most adolescents experience a degree of tension between their role as a dependent child and as an emerging, independent adult. If these different roles remain separate they are unlikely to create conflict for the individual. However, the roles may become conflicting if they increasingly interfere with each other. In PCT, the fragmentation corollary acknowledges that people can be, and in fact often are, inconsistent within themselves. In explaining this corollary, Kelly (1955) wrote, "a person may successively employ a variety of construction subsystems which are inferentially incompatible with each other" (p. 58). During adolescence, the issue of multiple, fragmented selves becomes more prominent than during childhood due to an expansion of roles and the increasing complexity of newly adopted roles, both of which heighten opportunity for incompatibilities to surface.

The issue of identity development and sense making of fragmented selves has not been examined with adolescents with HFA (Bagatell, 2007; Stocker, 2001). Such approaches, however, are emerging in related fields. For example, Thomas, Butler, Hare, and Green (2011) utilised personal constructivist approaches to explore self-image and identity construction in adolescents with learning disability. Findings indicated these

adolescents construed their self-image hierarchically using psychological constructs over nine different dimensions of self. It remains unclear whether adolescents with HFA have similar multifaceted, hierarchically organised constructions of self or how they perceive the experience of having fragmented, sometimes contradictory, selves. This research gap remains despite this developmental issue being highly relevant to this subgroup.

Individuation of the self develops as a result of adolescent identity formation (Erikson, 1982) and involves development of a strong recognition of one's uniqueness, authenticity, and personal moral and ethical values (Levesque, 2011). These complexities develop in the adolescent from a dynamic interplay of personalised past experiences, opinions, attitudes, and predictions of the future. In PCT, the individuality corollary acknowledges that each individual is unique due to his or her personal construction of reality. Kelly (1955) theorised that people each have individualised constructions because their interpretations of current situations are influenced by their unique past experiences. The importance of individuality may be particularly relevant to adolescents with HFA given both the complex nature of the condition and the complex nature of adolescent development.

Coupled with the sense of individuality is the importance of recognising the commonalities these individuals have with all other people (Procter, 2001). In PCT, this concept is described in the commonality corollary, which acknowledges that, in addition to a person's individualised way of perceiving the world, they also share common constructs with others. This corollary states that "to the extent that one person employs a construction of experience which is similar to that employed by another, his psychological processes are similar to the other person" (Kelly, 1955, p. 63). Essentially this corollary reminds us that despite the different way individuals with HFA perceive and experience the world, they have the same desire for acceptance as everybody else.

Recognising this commonality is critical during potentially challenging periods such as adolescence. Simultaneously, recognising that every adolescent with HFA has a unique way of making sense of the world may allow family members and clinicians to be more understanding of these individuals. Hare and colleagues (Hare, 1997; Hare, Searson, & Knowles, 2011) applied PCT methodologies when working with adolescents and adults with intellectual disability. Their work demonstrated how PCT-based approaches effectively capture the rich and idiosyncratic ways individuals with intellectual disability make sense of their world in a nonthreatening, person-centred way (Hare, 1997; Hare et al., 2011). Such approaches are likely to also be efficacious when working with adolescents with HFA, and their families.

Developing flexible processing styles

Sense-making of an increasingly complex social world is a critical task during adolescent development. A facilitating factor for processing complex, social information is flexible, reflexive processing. This style of processing allows for reflection, revision, and elaboration of constructions through validation and invalidation of the construal process. Kelly (1955) considered such “trial and error” learning as central to the development of coherent personal constructs and described it in PCT via the experience corollary. This corollary posits that “a person’s construction system varies as he successively construes the replication of events” (Kelly, 1955, p. 50). For example, if the garbage is collected every Monday morning we expect it to continue to be collected on Monday mornings. Importantly, when things do not happen the way they have in the past, we learn to adapt or re-construe the situation. In this way, constructs are continually revised and elaborated.

Therefore, new experiences alter our future anticipations. Continuing with the example, if one day the garbage is not collected until midday we learn that the garbage is

usually collected on Monday mornings but sometimes it is collected later in the day. Kelly (1955) considered it was the succession of events over time that continually subjects a person's construction system to a validation process:

“The constructions one places upon events are working hypotheses, which are about to be put to the test of experience. As one's anticipations or hypotheses are successively revised in the light of the unfolding sequence of events, the construction system undergoes a progressive evolution.” (p. 51)

This style of reflexive processing is likely to be difficult for adolescents with HFA. A central characteristic of HFA is a tendency for rigid thought processing styles. Individuals, including adolescents with HFA, can become upset when situations do not follow preconceived constructions. For example, having lunch inside rather than outside the classroom because of rainy weather may invalidate their constructions about lunch at school. This process of making sense of new or varied situations can be very upsetting to individuals with HFA due to inflexibility in re-construing. For an adolescent with HFA, the potential to experience distress due to invalidation of constructions may be increased due to the variety of new situations that they are exposed to during this period. For example, the transition from primary school into high school requires exposure to a variety of new situations. Whereas NTD adolescents generally assimilate such changes into their constructions of school, an adolescent with HFA may find this adaptation more challenging.

Expecting events to occur in the same way in the future as in the past is not considered to be unhealthy from a personal constructivist position. Moreover, Kelly (1955) considered this anticipation through replication to be in line with the rational nature of people. He also considered such anticipation to help protect people from the uncertainty of the future. Yet importantly, Kelly highlighted the value of balancing anticipation of

replication with a flexibility in expectations, since retaining constructions in spite of invalidation is considered maladaptive. In this way, rigid thought processing styles that retain constructs despite invalidation are considered to be less efficient than flexible, reflexive processing styles because the individual may uphold constructs that have not evolved through the validation and invalidation processes.

Individuals with HFA may be particularly prone to retaining invalidated constructs as a result of their rigid processing styles. To illustrate, consider the tendency of an individual with HFA to adhere to self-imposed strict rules, and uphold expectations that other people will adhere to these rules as well. For example, an individual with HFA may learn the “rule” that if you tell someone “thank you,” he or she will respond with “you’re welcome,” and expect that this sequence will be followed in every circumstance. This individual may become distressed if someone does not respond, or responds differently, when he or she expresses gratitude. Using a PCT framework, such rule-governed behaviour can be accounted for in an understanding and empathetic way. First, strict adherence to “one-size-fits-all” rules may be the result of relying on subordinate constructs, rather than superordinate constructs that more easily permit “exceptions to the rule.” Second, strict adherence to rules, and the associated preference for routine, familiarity, and order, may be understood as an attempt to reduce uncertainty in the future (which is anxiety provoking).

Another reason for the increased rigidity exhibited during adolescence by some individuals with HFA is their tendency to develop negative attribution styles (Barnhill & Myles, 2001). Adolescents with HFA often have a tendency to attribute errors (such as misunderstandings in social situations) to some stable, internal inadequacy (Barnhill & Myles, 2001). This way of thinking is in comparison to a more functional attribution style that would be to attribute errors to an external factor or to reframe a challenging situation

as a learning opportunity. Further, adolescents with HFA are more likely to generalise negatively beyond a current situation and perceive that they are unable to master a situation rather than make adjustments to their construing of the situation (Barnhill & Myles, 2001). This tendency to internalise, rather than externalise, blame further accounts for why adolescents with HFA tend to be self-critical and have low self-esteem concerning social situations (Myles & Simpson, 1998).

Understanding these negative attribution styles according to PCT may foster more empathetic understandings of adolescents with HFA as it interprets such behaviour as coping mechanisms rather than inflexibility. Further, given the increasingly complex, and therefore anxiety-provoking, world of adolescence, it is understandable that these behaviours sometimes increase in frequency or intensity during this period. It is important for family members and clinicians to keep an open mind when considering individuals with HFA. For example, Hare and colleagues (Hare, 1997; Hare et al., 2011) used PCT methodologies to explore the reasons behind “negative” behaviour exhibited by individuals with intellectual disability. The outcome of this work helped families and clinicians take the perspective of the individual and understand the complex reasons for the behaviour, where they had previously attributed it solely to the individuals’ “diagnoses” (Hare, 1997; Hare et al., 2011). Similarly, the application of PCT approaches for adolescents with HFA will help family members and clinicians understand the individual as a whole rather than based solely on their disability.

3.5 Supporting adolescents with HFA and their families

Helping adolescents with HFA learn about their condition through the lens of PCT concepts may result in greater awareness of variations in the way people experience the world (Carrington et al., 2003; Procter, 2001; Stoddart, 1999). Such awareness is likely to

be particularly beneficial during adolescence due the heightened importance of social functioning and the vulnerabilities often associated with adolescence. Helping families of adolescents with HFA understand the condition according to PCT concepts may increase their understanding of their family member. Understanding and acceptance from family members is likely to protect the adolescent with HFA from the often harsh world of adolescence and help them embrace the fact that they are different not defective.

The provision of clinical support services to individuals with HFA is essential, and of particular importance during adolescence (Carrington et al., 2003; Layne et al., 1993; Myers & Johnson, 2007). Central elements of clinician support for adolescents with HFA involve helping make sense of one's thoughts, feelings, and perceptions; facilitating awareness of the impact of one's behaviours on others; providing support during unique life-stage issues (such as identity development issues); and attempting to understanding the individual's worldview (McGorry, 2007; Stoddart, 1999). In addition, the efficacy of clinical support services involving whole families living with HFA has been well documented (Beresford, 1994; Bradford, 2010; Davis & Gavidia-Payne, 2009; Seligman & Darling, 2007). Family-focused support has been shown to increase wellbeing, knowledge about HFA, family functioning, resilience, and perceived competence, and to reduce subjective distress (Bagatell, 2007; Bradford, 2010; Phelps, McCammon, Wuensch, & Golden, 2009; Seligman & Darling, 2007). The use of family-focused support is in line with the call for more research utilising family systems approaches (Cridland et al., 2013; Jensen & Spannagel, 2011; Seligman & Darling, 2007). Therapists may also provide informative and emotional support, help the family respond to grief or confusion, act as role models, and encourage acceptance and even appreciation of having a family member with HFA (Bagatell, 2007; Beresford, 1994; Bradford, 2010; Seligman &

Darling, 2007). Support during developmental periods, such as adolescence, may be particularly important (Layne et al., 1993; Myers & Johnson, 2007).

Further, support utilising a PCT approach is likely to be beneficial both for adolescents with HFA and for their families. For example, Ijaz and Mahmood (2012) used repertory grids with adolescents with low reading ability to depict their “mental map” of family relationships. The method proved a sensitive means of exploring these individuals’ perceptions about psychological closeness and distance of relationships within the family (Ijaz & Mahmood, 2012). Additionally, Hare and colleagues (Hare, 1997; Hare et al., 2011) found sharing grids developed by individuals with intellectual disability in a clinical setting with their families to be highly beneficial. More specifically, they found it facilitated understanding of the individual’s actions and fostered empathy and tolerance, as well as understanding the person as a whole rather than based solely on their disability (Hare, 1997; Hare et al., 2011). The PCT methodology of repertory grids may be particularly efficacious for individuals, including adolescents, with HFA given their flexibility within a set structure and reliance on number, order, and sequence (Hare et al., 1999).

The application of PCT to understanding and working with adolescents with HFA needs further empirical research. Areas of research may include PCT-orientated psychotherapy with adolescents with HFA and their families and the application of PCT methodologies (such as repertory grids) with this group of people. Not only will such research validate the use of PCT approaches with adolescents with HFA, but also help advance our understanding of HFA in general.

3.6 Conclusion

This paper provides preliminary steps toward the application of concepts from PCT toward understanding the experience of HFA during adolescence. In applying these concepts to adolescents with HFA, we considered several developmental tasks associated with adolescence, including (a) functioning within the increasingly complex world of adulthood, (b) identity development, and (c) development of higher order processing styles. We propose that PCT provides an eloquent and in-depth account of developmental issues for adolescents with HFA. However, there are a range of other developmental tasks inherent to adolescence that would be worthy of consideration according to PCT, such as involvement in intimate relationships and individuation from the family.

Understanding adolescents with HFA within a personal constructivist framework may be helpful for adolescents with HFA themselves, their family members, and clinicians. It may facilitate greater awareness of the ways in which their behaviour influences others, the ways that other people's experiences vary from their own, and reasons why they may find social situations challenging. This understanding may encourage increased self-acceptance, which is critical (although often lacking) during adolescence. Understanding HFA according to PCT concepts may help families acknowledge the challenges their adolescent family member faces in areas such as the social realm and identity development. With this understanding, family members may be better equipped to provide safe and accepting home environments. It may also help family members to understand and manage some of the behaviours and reactions exhibited from adolescents with HFA, such as increased rigidity in thinking, anxiety, or social withdrawal. Further, understanding HFA through a personal constructivist framework may help family members become aware of the commonalities between themselves and their family member with HFA. For clinicians, understanding adolescent clients with HFA

through personal constructivism may help their attempts to understand the individual's worldview and from there develop appropriate intervention strategies (Truneckova & Viney, 2006).

Essentially, adolescents with HFA remain authentic individuals with the right to be acknowledged, understood, and respected (Procter, 2001). The authors propose PCT as efficacious in doing justice to the complexity of this condition during the particularly challenging period of adolescence. Understanding these individuals according to PCT approaches may help family members and clinicians to recognise that adolescents with HFA may differ in their constructions of their world, themselves, and others (Truneckova & Viney, 2012). Further, it may facilitate sensitivity to the possible ways in which these differences in meaning-making may affect individuals' mental health and wellbeing.

3.7 References

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CHAPTER 4: THE PERCEPTIONS AND EXPERIENCES OF ADOLESCENT BOYS WITH AUTISM SPECTRUM DISORDER: A PERSONAL CONSTRUCT PSYCHOLOGY AND FAMILY SYSTEMS PERSPECTIVE.

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A., (accepted August 2014). The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology and family systems perspective. *Journal of Intellectual and Developmental Disabilities*.

4.1 Abstract

Background: This study applies Personal Construct Psychology for understanding the experiences of adolescents with Autism Spectrum Disorder (ASD). Method: Semi-structured interviews were conducted with 26 participants from eight families, including adolescent males with ASD, mothers, fathers, and adolescent neurotypically developing siblings. Analysis of interview data was structured according to themes presented in previous theoretical application of Personal Construct Theory (PCT) for understanding adolescents with ASD. Results: Themes included complexity of the adolescent social realm, sense-making in multifaceted situations, identity development, development of flexible processing styles, and understanding and managing physical and emotional changes associated with puberty. Conclusions: The study provides support for the application of PCT for understanding adolescents with ASD. The insights provided by the participants may be helpful for adolescents with ASD, family members, and clinicians.

The perceptions and experiences of adolescent boys with an autism spectrum disorder:

A personal construct psychology and family systems perspective

4.2 Introduction

Adolescent development involves a range of physical, social, emotional, and cognitive changes (Levesque, 2011). Transitioning to secondary school is another significant change for adolescents involving management of complex routines, increased student population, increased academic workload and expectations, more varied and complex subjects and assignments, and exposure to a greater number of teachers (Adreon & Stella, 2001; Carrington & Graham, 2001; Poon et al., 2012). Adjusting to these broad ranging changes can result in vulnerability to stress, anxiety, and other emotional issues for many adolescents (Myles & Simpson, 2003).

A subgroup of adolescents reported to be particularly vulnerable to the negative effects of these developmental changes are those with Autism Spectrum Disorder (ASD) (Barnhill & Myles, 2001; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; White & Roberson-Nay, 2009). Individuals with ASD experience persistent and significant social communicative impairments, as well as restricted and repetitive behaviours and/or interests (American Psychiatric Association [APA], 2013). Whilst several studies report that some individuals with ASD experience improvements during adolescence (in areas such as communication, social interaction, restrictive and repetitive behaviours, and daily living skills) (McGovern & Sigman, 2005; Smith, Maenner, & Seltzer, 2012), other research indicates that many adolescents with ASD experience symptom deterioration in areas such as frequency and intensity of sensory abnormalities, compulsions, self-injurious behaviour and aggression, cognitive rigidity, and inappropriate sexualised behaviour (Kring, Greenberg, & Seltzer, 2009; Levy & Perry, 2011; Seltzer, Shattuck, Abbeduto, &

Greenberg, 2004). For this reason, understanding the experience of adolescence for individuals with ASD is of high importance for the individuals themselves, their families, and clinicians (Levy & Perry, 2011).

Personal Construct Theory

In this study, we apply Personal Construct Psychology (Kelly, 1955, 1966) for understanding the experiences of adolescents with ASD. Personal Construct Theory (PCT) is a constructivist approach to understanding human thought and action, derived from the clinical and theoretical work of George Kelly (1955). Personal Construct Theory is grounded in the assumption that individuals construct a subjective model of their world based on reality (Kelly, 1955, 1966). Referred to as ‘personal constructs’, these individualised models of reality guide the way people process and interpret their world. Personal constructions are considered to develop over time from both direct and anticipated experiences and interactions (Kelly, 1955, 1966). Moreover, a personal constructivist framework posits that individuals develop hierarchically organised networks of constructs. Such hierarchical organisation of constructions allows us to interpret, understand, and anticipate situations more easily than if each situation was interpreted by its various, individual (lower-order or subordinate) constructs.

As construct systems are developed from personal experiences, there are diverse ways in which people can construe the world (Kelly, 1955). Coupled with this perspective, however, is recognition that people with mutual experiences, such as members of a family, often develop some shared constructs (Procter, 2001). Constructive alternativism also recognises that individuals have the capacity to change their constructions through reconstruing processes. This capacity to change ways of viewing the world promotes an

optimistic outlook for individuals who hold ineffective or maladaptive constructions and is the basis of PCT grounded therapy (Badzinski & Anderson, 2012).

The benefits of utilising a PCT framework with this population include eloquent explanations about the construing processes of individuals with ASD (Cridland, Caputi, Jones, & Magee, 2013a; Procter, 2000). From this, understanding the experiences of adolescents with ASD within a personal constructivist framework may be helpful for family members and clinicians to recognise that adolescents with ASD may differ in their constructions of their world, themselves, and others (Cridland et al, 2013a; Truneckova & Viney, 2012). Further, it may facilitate sensitivity to the possible ways in which these constructions may affect individuals' mental health and wellbeing (Cridland et al, 2013a).

The application of PCT for understanding the experiences of adolescents with ASD was previously outlined by Cridland et al (2013a). The aforementioned paper considered various adolescent development tasks using a PCT framework, including, functioning within the increasingly complex world of adulthood; sense-making in complex situations; identity development; and development of flexible processing styles. Cridland et al (2013a) discussed the advantages of understanding adolescents with ASD through the lens of PCT, however, it also highlighted the need for empirical research to validate the application of PCT to this subgroup of individuals. The present study aims to address this recommendation and extend on the areas to which PCT was theoretically applied.

4.3 Aims

The overarching aim of this study was to understand the perceptions and experiences of adolescents with ASD from a personal construct psychology perspective⁴. Qualitative

⁴ The research aims are elaborated in Appendix V, Section 1.

data collection methods and analyses were used to gain detailed perspectives of the lived experiences of adolescents with ASD and their families.

Based on existing literature and the first author's clinical experience, it was hypothesised that the issues highlighted in previous application of PCT for understanding adolescents with ASD (see Table 4.2) would be relevant to the issues discussed by adolescents with ASD and their families. The nature of additional issues raised by participants pertinent to their experience of being an adolescent/having an adolescent family member with ASD was unknown.

4.4 Method

Sample

The sample consisted of 26 participants from eight families. Specifically, the sample included mothers ($n=8$), fathers ($n=7$), adolescent neurotypically developing (NTD) siblings ($n=4$), and adolescents with ASD⁵ ($n=7$). Eligibility criteria for the families included having two parents who identify as the primary caregivers with at least two adolescent children (one NTD individual⁶ and one son with ASD⁷); all family members living at home a minimum of 5 days per week; only one family member formally diagnosed with an ASD; and all family members having knowledge of the ASD diagnosis. Additional sample demographic information is presented in Table 4.1. The rationale for focusing on adolescent males with ASD was based on the current predominance of males

⁵ All participants with ASD were formally diagnosed with Asperger's Syndrome (AS), which according to the DSM-IV (APA, 2000), is a high functioning form of ASD. The term ASD rather than AS is used throughout the paper in order to be consistent with the DSM-V (APA, 2013). However, terms associated with AS (e.g., Asperger's, Aspie) have been retained in direct quotations from participants in order to accurately portray their comments.

⁶ The NTD individuals could be either male or female

⁷ From hereon, the male adolescent participants with ASD will be referred to as 'adolescents' and the NTD adolescent siblings as 'siblings'/'brother'/'sister'.

diagnosed with ASD (Holtmann, Bölte, & Poustka, 2007; Krahn & Fenton, 2012) and previous recommendations to acknowledge the influence of gender on research findings (Card, Stucky, Sawalani, & Little, 2008; Cridland, Jones, Caputi, & Magee, 2014a; Hsiao, Tseng, Huang, & Gau, 2013).

Table 4.1: *Demographic information*

Family identifier	Participating family members				Adolescent age	Adolescent school level	Sibling gender (age)	Estimated annual household income
	Mother	Father	Adolescent	Sibling				
Family 1	Yes	Yes	Yes	Yes	13	Year 8 mainstream school	Female (12)	\$80000
Family 2	Yes	Yes	Yes	Yes	14	Year 8 mainstream school	Male (17)	>\$100000
Family 3	Yes	Yes	Yes	No	16	Year 10 mainstream school	Male (18)	\$80000
Family 4	Yes	No	Yes	Yes	13	Year 7 mainstream school with ASD unit	Female (16)	\$40000
Family 5	Yes	Yes	Yes	Yes	15	Year 9 mainstream school with ASD unit	Female (17)	\$60000
Family 6	Yes	Yes	Yes	No	12	Year 7 mainstream school	Male (19)	\$90000
Family 7	Yes	Yes	Yes	No	15	Year 9 mainstream school	Female (16)	\$50000
Family 8	Yes	Yes	No	No	14	Year 8 mainstream school	Male (12)	\$70000

Procedure

Ethical approval was granted by the University's Human Research Ethics Committee (see Appendix L) prior to commencing the participant recruitment process. Research aims were explained by a participant information sheet (see Appendix M) and an introductory meeting with the first author. Following ethical standards for research with children, written consent was obtained from the participants and parents (see Appendix N).

An interview guide was developed based on a review of relevant interview guides (Benderix & Sivberg, 2007; Carrington & Graham, 2001; Mascha & Boucher, 2006; Vliem, 2009) and through multiple discussions amongst the research team. Based on research recommendations (Cridland, Jones, Caputi, & Magee, 2014b), the interview guide was pilot tested on one family with an adolescent family member with ASD. Minor wording changes to questions resulted from pilot testing.

Interview questions were generally related to experiences of being an adolescent/having a family member with ASD. There was scope for flexibility in topics discussed as well as follow-up questions to encourage elaboration. A copy of the interview guide is available from the corresponding author (see Appendix O).

Interviews were conducted based on recommendations outlined in Cridland et al (2014b) (see Appendix A), including conducting interviews with individual participants in a private space within the family home (e.g., study or quiet living area); conducting interviews at a preferred time for participants; and conducting interviews at an appropriate pace to facilitate accurate interpretation of interview questions. Interviews lasted for an average of approximately 60 minutes (range 40-150 minutes). Interviews were audio recorded for transcription.

Data Analysis

NVivo10 (QSR International, 2012), a qualitative data management program, was used to manage and analyse the data. Data were initially coded based on the themes discussed in Cridland et al (2013a), with additional themes generated from remaining data⁸. A formal measure of inter-rater agreement was not employed. Rather the process involved one of the co-authors and one independent checker reading all transcripts with the potential themes identified by the first author. No major changes to the themes identified by the first author were identified as being necessary by either check. Following the analysis procedure outlined by Braun and Clarke (2006), a final consultation with the authors followed to discuss specific theme descriptions and selection of most relevant quotes.

4.5 Results

Table 4.2 presents the themes and subthemes presented in the current investigation. Specifically, the first four themes are based on themes presented in Cridland et al (2013a), with one additional theme, describing the challenges of puberty, emerging from remaining data.

Direct quotations are presented in indented paragraphs, in which square brackets ([]) indicate information added by the authors for clarity and ellipses (...) indicate material omitted for conciseness. All names have been changed for anonymity.

⁸ Additional information outlining data analysis procedures including thematic coding procedures and data integrity and credibility strategies employed are elaborated in Appendix V, Section 2.

Table 4.2: *Thematic codes*

Themes presented in Cridland et al (2013a)	Themes and subthemes presented in the current investigation
Increasing complexity of the social realm	Increasing complexity of the adolescent social realm <ul style="list-style-type: none"> - Developing and maintaining friendships - Interacting with girls - Experiences of bullying - Limited social opportunities with peers
Sense-making in complex social situations	Sense-making in complex social situations <ul style="list-style-type: none"> - Processing and functioning within multifaceted situations - Unique perception of the world
Identity development	Identity development <ul style="list-style-type: none"> - Self description - Impact of ASD on identity
Developing flexible processing styles	Developing flexible processing styles <p>Challenges of puberty</p> <ul style="list-style-type: none"> - Understanding and managing physical changes - Understanding and managing emotions

Increasing complexity of the adolescent social realm.

Developing and maintaining friendships. All participants ($n=26/26$ described difficulties that they/their family member experienced developing and maintaining friendships during adolescence. Reasons for these difficulties included trouble understanding perspectives of others, difficulty conversing effectively, and challenges understanding the more subtle and complex functioning of adolescent relationships.

“Their [people with ASD] brain is different so they have to learn how to read other peoples’ emotions... I can’t read other people...”
(Adolescent, Family 1)

“...he finds it hard to mix with kids who don’t have ASD... And now that he’s a teenager he has less friends than in primary. He still has a few friends but not many close friendships... I think the friendships just become more complicated.” (Mother, Family 3)

“I know that he has trouble making friends... like making conversation... I think he likes talking but... when he is around people, especially when he gets excited, weird things blurt out...” (Brother, Family 2)

Difficulty discerning between acquaintances and close friendships was another challenge for the adolescents. More specifically, whilst the majority of adolescents ($n=6/7$) described having close friends and/or being part of a friendship group, the majority of family members ($n=15/19$) considered these relationships to be acquaintances rather than close friendships. Interviews indicated that the adolescents’ awareness about these relationship differences ranged from ignorance to a desire to form closer connections with their peers.

“At school I generally hang around with my mates... We always joke around... [we] play soccer on the field and sometimes talk...” (Adolescent, Family 2)

“...he thinks he has got kids at school that he can hang around with and they are ‘friends’ [but] they are people he hangs around with and they are not actually there to care about him... I think in general he is pretty well liked but the other kids don’t really interact with him.” (Father, Family 2)

“...if you ask him if he has friends he will say yes but... he doesn’t actually interact with them he just watches them from the side lines... he thinks that is friendship.” (Mother, Family 7)

Interacting with girls. Some participants discussed the challenges faced by the adolescents regarding interacting with adolescent girls. Such issues included feeling uncomfortable talking with girls, and uncertainty regarding the concept of a ‘girlfriend’.

“He doesn’t mix with girls, like when he’s around girls he kind of just gets a bit bashful and steps back a bit. Like he doesn’t have that kind of confidence with talking to girls... I think he’s interested... But only with the girls that are like him, not the other girls in his grade.” (Sister, Family 5)

“He struggles with this idea about having a girlfriend. We have been very lucky because [his brother] has described him some boundaries [such as] that you probably don’t want a girlfriend before you are 16, when you chose a girlfriend this is the type of person you look for, this is how you behave around a girlfriend... But I haven’t quite gotten to the part about the other person needing to choose you too!” (Mother, Family 2)

Experiences of bullying. At least one participant from each family described experiences where their family member with ASD had been bullied as an adolescent. Various reasons for the bullying were discussed, including the adolescent’s limited understanding of NTD adolescent behaviour, naivety, and/or social awkwardness.

“He has been bullied a lot... Little things like [someone] tapping a pen in the class would drive him mad and... of course kids being kids they would do it more just to annoy him so that would make him snap... then of course the teacher would send him out.” (Mother, Family 8)

“...he was getting bullied by this one guy... [who] was saying to him, ‘Give me \$10 and I’ll give you an i-phone’ and my brother would believe it and would give him the money and wouldn’t get anything from it... he just doesn’t understand that they are lying... I think it makes him feel vulnerable.” (Sister, Family 4)

Limited social opportunities with peers. The majority of participants ($n=17/26$) made reference to the adolescents’ limited involvement in social outings. These comments were generally made in comparison to the siblings’ social patterns. Reasons for the limited social outings included minimal invitations from peers, social anxieties, and difficulties managing social events.

“[NTD teenagers] get out more and do stuff... [I don’t go out much but] it’s not that I don’t want to do it; it’s that they don’t want me to... [Also] I don’t like getting out that much but I want to.” (Adolescent, Family 4)

“I can’t remember the last time he went to a birthday and that was the sort of thing I was doing at his age...” (Brother, Family 2)

“A lot of kids don’t want to play with him and they don’t invite him to birthday parties and they don’t invite him over to their place because with the behavioural issues it just turns them off.” (Father, Family 6)

Sense-making in complex social situations.

Processing and functioning within multifaceted situations. Family members discussed various challenges the adolescents faced when processing and functioning within multifaceted situations. Some of these challenges included processing multiple instructions, planning steps necessary to complete an activity, and simultaneous processing of sensory information and body movements to engage in daily activities such as sports or cooking.

“You can’t give him directions; if you give him more than two things in an instruction to do, he gets confused... [Also] he really struggles with school, it’s all too much of a sensory onslaught for him; ...the bells go and kids are running everywhere... [or when the teacher is] standing in front of the classroom talking, he just gets information overload and he just can’t absorb it... [Also] he can’t play sport... everyone gets angry at him because he can’t kick the ball and they get frustrated at him...” (Mother, Family 7)

“His learning style is very sequential and the pace of learning is a lot slower... He has a lot of difficulty in seeing clear steps that you take and manually being able to carry it out and having the dexterity to carry it out, he gets frustrated with himself because he can’t get things to work but he doesn’t seem to see the easy way to get it to work...” (Mother, Family 2)

Ability to focus. Many family members ($n=14/19$) discussed the adolescents’ ability to intensely focus on topics of interest. The ability to focus on topics of interest was contrasted with general focusing ability, which was considered to be comparatively poor.

“When he gets into something, he really gets into it. Like if we’re talking about a book that we have both read he will remember it in immense detail... I admire that, I really like it. [But it’s] so funny because he never remembers where his lunch box is or his socks!” (Mother, Family 1)

“Some people [with ASD] are focused on one thing... I like to play computer games and board games. They are my main hobbies and favourite things to do.” (Adolescent, Family 1)

“He’s incredibly focused on things, whether it is a good thing to be focused on or not! Like he was incredibly focused on guns and stuff, which Mum didn’t like so much, but he knew every gun!” (Brother, Family 2)

The ability to focus intensely also resulted in strong memory skills for topics of interest. In particular, some family members ($n=12/19$) commented on the adolescents’ ability to remember detailed information.

“I like the way he can read a book and remember lots of information out of it without even really thinking about it... he might not be able to concentrate on his school work but when he is doing different things like that, like even watching the History Channel he can concentrate fully and take it all in.” (Father, Family 7)

“He’s got a good memory, like he can remember things from years ago that you don’t even know about and even though he is not looking at you or even in the room he is still listening to what is being around the surrounding environment and what is going on. He’s a cluey kid.” (Father, Family 6)

Unique perception of the world. The adolescents’ way of making sense of complex situations often resulted in a unique way of perceiving the world. In particular, some family members ($n=9/19$) discussed their adolescent’s ability to observe the world in its simplicity.

“His understanding of the world is brilliant... He has this ability to boil it down to the essence... he will say something really, really profound and it changes the way you see the world. He is just amazing.” (Mother, Family 2)

“...just the way he just sees things... He just sees things in their simplicity really. Nothing is too complicated...” (Father, Family 7)

Identity Development.

Self-description. In order to investigate personality development, the adolescents

were asked to describe themselves. The majority of adolescents ($n=6/7$) were able to provide self-descriptors to varying extents, despite the fact that some were only able to provide minimal elaboration and/or focused on activities they liked rather than personality characteristics. Some self-descriptions described core characteristics of ASD, such as difficulty connecting with people.

“I can be dogged... [and] it takes me a while to connect with people and I read books a lot.” (Adolescent, Family 1)

“I don’t even know if I even have a personality... I’m not very describable...” (Adolescent, Family 3)

“I don’t really know if I can describe myself because... That is difficult... [I am] a smart person and quiet person... those are actually two traits of my personality... [Another] would be the things I do like most of the time I’m typing away on my lap top...” (Adolescent, Family 5)

Difficulties describing identity/personality characteristics were echoed by some family members ($n=3/19$).

“I imagine he might have trouble describing himself. He loves gaming and stuff so whether he would take that as part of [his identity]? He might say that he is friendly in his own little way... I don’t really know.” (Mother, Family 7)

When family members were asked to describe their adolescent’s identity/personality, various participants described ways in which it had developed over time. The predominant personality characteristics developing during adolescence included self-confidence, social skills, affectionate nature, and sense-of-humour.

“He’s just lovely... he’s a bit of a joker, which came with age. He hated dressing up and pretend-play, he hated that as a little boy but he sort of grew into jokes and stuff.” (Mother, Family 5)

“He is really affectionate and has remained more affectionate at an older age than Rick [my NTD son] did.” (Mother, Family 2)

Impact of ASD on identity. The majority of adolescents ($n=4/7$) conveyed uncertainty around the ways ASD impacted their identity and/or stated that ASD had no impact on their sense of self.

“It’s okay that I have AS, otherwise I wouldn’t be who I am, so it’s ok but it’s not good but it’s also not bad...It doesn’t really matter that I have AS... It doesn’t really affect me... You are born with AS so I have always had it and have never had a problem with it... I mean it’s a brain thing so that is going to make you different, but I don’t know what ways.” (Adolescent, Family 1)

“I don’t really know what AS does [to me] ... It’s not a good thing or a bad thing, it’s just a thing!... Some people say that I don’t look people in the eyes when I talk or that I don’t talk really at all, so that might be something?” (Adolescent, Family 7)

The other adolescents ($n=3/7$) reflected that having ASD influenced them in both positive and negative ways. The main positive aspect of having ASD they identified was feeling special or unique. Negative aspects of having ASD included feeling different and/or misunderstood, and having social difficulties.

“I actually really like having this disability because it actually makes me feel a bit special... [but] everyone with AS feels frustrated when people do not understand them....” (Adolescent, Family 5)

“Sometimes it’s like I’m an alien.... [but] at least I’ve got something in my life that happens, like at least I’ve got something positive in my life that will stick with me forever.” (Adolescent, Family 4)

“I don’t mind [having ASD] but I just wish I was more social... [It would feel] nice for someone to at least comprehend the problems I go through every day.” (Adolescent, Family 2)

Developing flexible processing styles.

The majority of family members ($n=15/19$) discussed the adolescents tendency to have rigid thought processing styles rather than developing flexible processing. Common areas of rigidity included retaining an opinion despite conflicting evidence, following rules without exception, difficulty accommodating change, and perfectionism.

“He gets very fixed on an idea. It can be very frustrating at times but it can be good at other times... If he has an idea on something... he will stick to that even if you tell him it is wrong...” (Brother, Family 2)

“[He] thinks he is right all of the time and that is his downfall...He sort of contradicts everything you say. He’s a real challenger; he will challenge you on everything.” (Father, Family 6)

Challenges of puberty.

Understanding and managing physical changes. Family members described various attitudes exhibited by their family member with ASD regarding the physical changes they were experiencing associated with adolescence. These attitudes ranged from disgust to confusion to a logical and mature outlook.

“[He didn’t like] being at school for sex education and personal development and things like that. He was horrified... he was just like, ‘Oh my God! This is gross’.” (Mother, Family 8)

“Curtis didn’t have many questions [about puberty]... he knows all the factual stuff but I don’t know if he knows the romantic side of it all. They all are mature like that... it’s all just a body thing... He didn’t particularly get embarrassed.” (Mother, Family 3)

Difficulty managing the bodily changes associated with puberty was discussed by the majority of family members ($n=14/19$). Areas of difficulty included adjusting to the heightened hygiene routines of adolescence, and understanding appropriate versus inappropriate public behaviours.

“He also doesn’t always realise when his feet and armpits smell. He doesn’t pick up on the social things with that.” (Mother, Family 1)

“He’ll just strip off wherever! ...And now that he has hit puberty it has gotten worse... I just constantly tell him that he is developing now and he can’t do it anymore because he is not a little kid. But he keeps doing it! It’s scary sometimes.” (Mother, Family 8)

Understanding and managing emotions. All but one family member ($n=18/19$) discussed the challenges experienced by adolescents regarding understanding emotions. In

particular, participants described their adolescent's difficulty understanding degrees of negative emotion expressed by others.

"You've got to try and not get cranky with him because when you get cranky with him he actually gets quite upset and really takes it to heart... he just doesn't understand the extent of how cranky you are. Even if you yell because he's downstairs, so you yell out, 'Where's your clothes?' He thinks that's really cranky and upset... he doesn't see you as being a little but upset." (Father, Family 7)

"He gets very moody and thinks I'm cranky at him whenever I say 'No'... He just doesn't understand that sometimes I have to say no and I'm not doing it to be angry or mean, but it's for a reason." (Mother, Family 4)

Management of emotions was considered a challenge for adolescents by all family members who discussed this issue. These participants indicated the most challenging emotion to be managed was anger. More specifically, it was identified that the adolescents struggled with controlling their emotions, and sometimes expressed their emotions in a socially inappropriate way.

"I get angry easy... A lot of things [make me angry], probably people saying stuff about me... like, 'Aw look at that retarded kid'... I usually just swear at them and sometimes hit them... I know it's bad." (Adolescent, Family 6)

"His anger is a big part of his challenges... He waits until he gets home, like into a safe environment where he knows he can 'go-off'... [He has] trouble controlling his emotions and what's going on for him inside"... He'll get violent if any of us is in his way or trying to help and he doesn't want it..." (Sister, Family 4)

4.6 Discussion

This study applied PCT for understanding the experiences of adolescents with ASD. Analysis of interview data was structured according to themes presented in previous theoretical application of PCT for understanding adolescents with ASD (Cridland et al,

2013a). Further consideration of the themes based on a PCT perspective and general research literature is considered below.

Increasing complexity of the adolescent social realm

Family member interviews indicated that all adolescents had experienced significant difficulties developing and maintaining friendships with their NTD peers. Such difficulties included confusion differentiating between friends and acquaintances, difficulties interacting with girls, experiences of bullying, and having limited social outings with peers. Many of these difficulties were related to the core social deficits inherent to ASD, such as difficulties with perspective taking and conversing with others, and/or were compounded by the increasing complexity of adolescent relationships. Importantly, some of the perceptions expressed by the adolescents differed from those of their family members. For example, the majority of adolescents reported having close friends and/or being part of a friendship group, whilst the majority of family members disagreed. This disparity may reflect an underestimation of friendship quality by family members or may reflect the adolescents' misunderstanding of social interactions.

These findings that adolescents had difficulties interacting with NTD peers is in line with research which indicates that many adolescents with ASD experience social difficulties given the increasing complexity of adolescent relationships coupled with the heightened societal expectations of functioning that occur during adolescence (Adreon & Stella, 2001; Howard, Cohn, & Orsmond, 2006; Templeton, Papinczak, & Carrington, 2003; White & Roberson-Nay, 2009). These findings also support a PCT perspective, in which adolescents with ASD find complex social situations challenging, and thus anxiety provoking, if they do not have well developed constructs about the social situation (Cridland et al, 2013a; Kelly, 1955; McCoy, 1977). A PCT perspective also posits that

adolescents' with ASD have difficulty understanding that other people's constructs about the world may differ from their own (i.e., Theory of Mind deficit), which can compound their social difficulties (Cridland et al, 2013a).

The social isolation reported by the majority of adolescents, resulting from difficulty developing and maintaining friendships, has also been echoed in the literature. For example, Müller (2008) found adults with ASD reported that intense and chronic isolation was a defining feature of their experience of ASD, despite their longing for social connectedness. Similarly, a diary study tracking how adolescents with ASD spent their free time indicated these individuals spend relatively more time engaged in solitary activities compared to their NTD peers due to the unavailability of others' company rather than choice (Orsmond & Kuo, 2011). The present findings, along with existing research, indicate that adolescents with ASD have a strong desire for meaningful peer relationships and enjoy positive social interactions with peers, but often have difficulty successfully achieving this (Bauminger, Shulman, & Agam, 2003; Howard et al., 2006; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; McGuire, 2009; Müller et al., 2008; Orsmond & Kuo, 2011). This suggests it would be important for families and clinicians to facilitate organisation of social activities for adolescents with ASD.

Peer relationships are of increased importance during adolescence and protective against mental health issues such as depression and anxiety (Pinkerton & Dolan, 2007; Schuntermann, 2007). Conversely, difficulties experienced with peer relationships, and the social isolation often associated with this, can contribute to and/or exacerbate mental health problems (Barnhill & Myles, 2001; Koning & Magill-Evans, 2001; Müller et al., 2008). Given the difficulties adolescents with ASD have in developing and maintaining friendships, they are particularly vulnerable for experiencing emotional problems. For example, research indicates that levels of co-morbid mental health issues in adolescents

with ASD may be as high as 81% (Barnhill & Myles, 2001; Lasgaard et al., 2010; Levy & Perry, 2011; White & Roberson-Nay, 2009).

Sense making in complex situations

The adolescents in this study experienced various challenges processing and functioning within multifaceted situations. Such challenges included difficulties processing instructions and planning steps needed to enable them to undertake daily tasks, and difficulty co-ordinating bodily movements with sensory input needed for daily tasks typically expected of adolescents. Importantly, the reporting of these difficulties was from family members, rather than the adolescents themselves. This may indicate the adolescents did not perceive they had difficulty interpreting complex situations. Alternatively, the adolescents may have had difficulty expressing these difficulties and therefore chose not to discuss these issues. Another reason why they may not have discussed difficulties making sense of complex social situations is that they were not explicitly asked about such issues.

Utilising a personal constructivist position, these difficulties can be attributed to the processing style of adolescents with ASD. That is, adolescents with ASD may underutilise hierarchically organised construct systems leading to construct systems dominated by isolated, subordinate constructs that require ‘manual’ interpretation of the numerous ‘separate’ components of the situation (Cridland et al, 2013a). The drawback of such processing is that the ‘big picture’ of a situation may not be realised; increasing opportunity for misinterpretation and placing greater cognitive demand on the individual. This processing style, coupled with underdeveloped abstract thinking skills, accounts for the difficulties adolescents with ASD experience making sense of complex situations.

Discussion of the adolescents’ ability to focus and remember immense detail about topics of interest, and comparatively poor ability to focus on other everyday tasks, can be

taken as evidence for their underutilisation of hierarchically organised constructs. Additionally, discussion about the adolescents' unique way of perceiving the world, especially in regards to their ability to 'boil a situation down to its essence', may be considered evidence of a 'subordinate processing' style. Whilst some participants recognised positive aspects of this style of processing (e.g., ability to focus, memory for detail, unique perception of the world), drawbacks were also acknowledged (i.e., difficulty processing complex situations, poor general memory, and difficulty focusing on meaningful aspects of a situation).

Identity development

Identity development, or forming a sense of self, is a central component of adolescence (Artar, 2007). According to PCT, a person forms a sense of identity with the development of highly complex constructs, referred to as core constructs (Butler, 2006; Kelly, 1955). Given the reliance of individuals with ASD on subordinate constructs, it has been theorised that adolescents with ASD may experience a poorly developed sense of identity (Cottenceau et al., 2012; Cridland et al, 2013a; Procter, 2001).

Additionally, identity development is considered a largely social process as it involves interpretation of implicit and explicit feedback from others (Artar, 2007; Butler, 2006; Rowe, 2003; Walker, 1996; Willey, 2003; Ybrant, 2008), which adolescents with ASD typically find difficult. Together, these factors have resulted in the prediction that adolescents with ASD will have difficulty developing a sense of identity (Cottenceau et al., 2012; Cridland et al, 2013a; Procter, 2001).

The results of the current investigation both substantiate and contradict the hypothesis that adolescents with ASD have a poorly developed sense of identity. First, the majority of adolescents showed evidence of a developing sense of self, as they were able to provide self-

descriptions. However, some adolescents provided basic self-descriptions and/or described their hobbies or interests rather than their identity. Further, several family members predicted that the adolescents would have difficulty describing themselves. Together, these findings suggest some of the adolescents may experience difficulty developing a sense of identity.

Regarding the social process of identity development, some comments from the adolescents indicated reflection on feedback from others (e.g., ‘Some people say I don’t look people in the eyes when I talk...’). However, it remains unclear the extent to which this feedback impacted on their sense of self. The nature of identity development in adolescents with ASD needs to be further investigated (Cridland et al, 2013a; Pakenham, Sofronoff, & Samios, 2004).

The adolescents were also asked to discuss the impact of ASD on their identity. The majority of adolescents were unaware or unsure of the influence of ASD on their sense of self. However, some described core characteristics of ASD in their self-descriptions (e.g., difficulty connecting with people), as did various family members (e.g., genuine and affectionate nature, and resistant to change). Denial that ASD had any impact on their identity may also be associated with uncertainty about the nature of ASD itself.

Among those adolescents who did acknowledge an impact of ASD, both positive and negative impacts were discussed. This finding is consistent with previous research which found adolescents with ASD described both positive and negative aspects of their condition, with many expressing both views (Poon et al., 2012). Common to both the positive and negative influences of ASD was a sense of feeling different; with some adolescents construing this as being unique or special, and others construing this as feeling isolated and misunderstood. The adolescents’ sense of feeling ‘different’ is echoed in the literature, as research indicates that adolescents with ASD can become increasingly aware of their social difficulties, their trouble ‘fitting in’, and their general distinction from peers (Fullerton &

Coyne, 1999; Stoddart, 1999). Such awareness has been associated with mental health issues, including depression and anxiety, and externalising behaviour, including aggression (Barnhill & Myles, 2001; Levesque, 2011; Myles & Simpson, 2003).

Developing flexible processing styles

The current findings indicated the majority of adolescents utilised rigid thought processing styles rather than more flexible processing. Common areas of rigidity included retaining an opinion despite conflicting evidence, following rules without exception, difficulty accommodating change, and perfectionism. As with sense making of complex situations, the difficulties experienced by the adolescents were reported by family members rather than the adolescents themselves. Reasons for this lack of discussion may include minimal awareness of their rigid processing styles, difficulty expressing their challenges with flexible processing, and/or may be reflective of the interview guide which did not ask directly about processing styles.

From a PCT perspective, rigid thought processing styles inhibit reflection, revision, and elaboration of personal constructs (Kelly, 1955). During adolescence, inflexible processing may be particularly ineffective given the increased variety of new and complex situations individuals are exposed to, such as high school, and the physical and emotional changes associated with puberty (Cridland et al, 2013a). Along with increasingly complex social interactions and expectations for functioning, adolescents with ASD are vulnerable to finding everyday situations challenging. This was evident throughout the interviews. Understanding the reasons why adolescents with ASD have rigid processing styles, within a PCT framework, may foster more empathetic and understanding attitudes.

Co-morbid mental health issues can also influence the cognitive functioning of adolescents with ASD. Research indicates areas of particular vulnerability include cognitive

flexibility, perspective taking, and abstract thinking (Barnhill & Myles, 2001). Given the susceptibility of adolescents with ASD to mental health issues, and their cognitive processing styles, their experience of adolescence as challenging comes as no surprise.

Challenges of puberty

Participants described a range of physical and emotional changes experienced by the adolescents. Whilst these changes may be considered common to all adolescents (e.g., growth spurts, sexual development, need for increased hygiene routines, emotional sensitivity, management of strong emotions) (Levesque, 2011), of particular interest here was the adolescents' understanding and management of the changes. The adolescents' perceptions about puberty varied from confusion to disgust to a mature level of understanding. Regarding management of pubescent changes, responses ranged from ignorance to curiosity to feeling overwhelmed.

From a PCT perspective, the varying perceptions about puberty may be reflective of the individuals' different construct systems; with negative perceptions reflective of negative constructions about pubertal changes. Alternatively, the differing perception may be understood as a reflection of differing degrees of construct elaboration. That is, individuals with well-developed constructs about pubertal changes may be more likely to have a mature response to adolescent development as opposed to those with poorly developed constructs about puberty. For parents and clinicians, this means adolescents with ASD may adjust more easily to developmental changes with greater knowledge about puberty.

Many family members discussed their adolescent family members' difficulties in recognising degrees of emotion, especially anger, expressed by others as a key challenge during this period. Interestingly, none of the adolescents discussed this reported difficulty as a challenge for them, which may indicate their minimal awareness of their troubles

identifying negative emotions. Research in this area supports these findings, as it indicates individuals with ASD process negative facial expressions differently, and less efficiently, than NTD controls (Farran, Branson, & King, 2011; Isomura, Ogawa, Yamada, Shibasaki, & Masataka, 2014; Pelphrey, Sasson, Reznick, Paul, Goldman, & Piven, 2002). Such processing differences have been understood to reflect the deficits in facial affect recognition, particularly of negative expressions, evident in some individuals with ASD (Farren et al., 2011; Pelphrey et al., 2002). According to a personal constructivist interpretation, the differing processing styles of NTD individuals and individuals with HFA can be attributed to the organisation of personal constructs, as discussed previously.

In addition to difficulties identifying and understanding emotions expressed by others, participants discussed the adolescents' difficulties managing their experiences of anger. Although not inherent to the condition, anger is a clinically significant issue for many individuals with ASD and their families, with research indicating it is particularly problematic for adolescent males with ASD (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Kane & Mazurek, 2011; Mazurek, Kanne, & Woodka, 2013). For example, two large-scale studies investigating the experiences of anger in children and adolescents with ASD have found over half display significant physical aggression (Kane & Mazurek, 2011; Mazurek et al., 2013). Whilst the predictors of anger in individuals with ASD are not well understood, it has been suggested it may stem from the frustration of feeling different and isolated from their peers (Barnhill & Myles, 2001; Levesque, 2011; Nasir & Tahir, 2012), their difficulties with communication (Simpson & Myles, 1998), and from coping with a range of often co-occurring challenges such as sleep problems and sensory abnormalities (Mazurek et al., 2013). Aggressive behavior can also limit access to treatment, and impede social opportunities and involvement in everyday activities for both the individual and their family (Hodgetts et al., 2013). Additionally, the implications for family members of adolescents with

ASD who display physical aggression are serious given the size and strength of these individuals (Mazurek et al., 2013)

4.7 Strengths and Limitations

A primary strength of this study was utilisation of a PCT framework. The PCT perspective offered a detailed and helpful view for understanding a range of issues experienced by the adolescents with ASD and their families. The use of a qualitative methodology is also a strength of this study, as there is currently a dearth of literature incorporating the direct perspectives of individuals with ASD and their families (Carrington, Templeton, & Papinczak, 2003; Cridland et al., 2013b; Fong, Wilgosh, & Sobsey, 1993; Vliem, 2009).

However, it is necessary to interpret the findings with caution due to the relatively small and specific sample, as the findings may not be representative of all adolescents with ASD. The results nevertheless may be reflective of other adolescents' experiences, especially as the issues discussed were largely consistent with available literature. Further, these preliminary findings may be useful for informing further research and clinical interventions. For example, the nature of identity development in adolescents with ASD, and the most suitable method of investigating this issue, remains unclear. Further research is recommended to investigate these, and other, issues raised in this study.

4.8 Clinical recommendations

This investigation raises the need to address a range of social, emotional, cognitive, and physical issues faced by adolescents with ASD. The following points outline recommendations for parents, clinicians, and teachers.

1. Interviews indicated that many of the adolescents would benefit from more information about ASD. Information may have been provided to these individuals as children; however, given the range of new issues faced by adolescents, it is necessary to provide them with age specific information. There are a range of resources targeted at this age group (e.g., books, DVDs, websites, chat-rooms, and blogs) that adolescents with ASD and their families may benefit from.
2. Providing adolescents with developmentally appropriate information about puberty is recommended (Chan & John, 2012; Sullivan & Caterino, 2008). The most efficacious strategies are likely to be those provided collaboratively between parents, clinicians, and teachers (Klett & Turan, 2012; Nichols & Blakeley-Smith, 2010; Travers & Tincani, 2010). Critical information about puberty includes age specific physical and emotional changes, healthy strategies for expressing emotions and sexuality, and socially appropriate versus inappropriate behaviour (as well as the rationale underlying these social ‘rules’) (Klett & Turan, 2012; Tarnai & Wolfe, 2008). The context for puberty education should also be considered, as some of the adolescents conveyed embarrassment about having puberty lessons within a general class environment.
3. Clinical support is generally recommended for all individuals with ASD; however it may be especially important for adolescents and their families, given the range of challenges inherent to this period (Carrington et al., 2003; McGorry, 2007; Stoddart, 1999). Crucial elements of clinical support include understanding the adolescent’s worldview, facilitating awareness of the impact of oneself on others, issues of identity development, and managing day-to-day challenges (Cottenceau et al., 2012; McGorry, 2007; Stoddart, 1999).

Monitoring, and where necessary intervention, for mental health issues is also imperative for adolescents with ASD (Kim, Szatmari, Bryson, Streiner, & Wilson,

2000). Early warning signs for anxious or depressive symptomology in adolescents with ASD may include disorganization, inattentiveness, decreased stress threshold, fatigue, and disinterest in hobbies and pleasurable activities (Carrington & Graham, 2001).

4. The influence of the school environment on the wellbeing of adolescents with ASD must not be underestimated. Strategies to promote a positive high school experience for adolescents with ASD may include the following:
 - Staged transition from primary to high school with multiple orientation events and activities (Adreon & Stella, 2001).
 - Ongoing meetings between teachers and the family to ensure a collaborative approach to learning (Brewin, Renwick, & Fudge Schormans, 2008).
 - Teachers who have a general understanding of ASD and how it affects learning, as well as a detailed understanding about individual students with ASD and their unique sensitivities and interests.
 - Suitable classroom support such as preferential seating arrangements, individualised learning plans, and assistance for assignments and exams (Adreon & Stella, 2001).
 - Peer education and coaching programs for increasing peer acceptance and understanding about ASD (Chan et al., 2009; Cridland et al., 2014a; Humphrey, 2008; Humphrey & Symes, 2010).
5. The present findings indicate that the adolescents' minimal involvement in social activities with peers did not equate to a lack of interest. Families would benefit from facilitating social interactions with both NTD and ASD peers, as both groups satisfy different social needs; including exposure to normative social interactions and the need to feel belonging (Bauminger et al., 2003). Interaction with peers is also

important for identity development (Bauminger, Shulman, & Agam, 2004).

Additionally, families, clinicians, and teachers should be wary of focusing discussions with adolescents on the difficulties they may have in making friends, as the adolescents may internalise such statements and limit their attempts to develop friendships (Lasgaard et al., 2010).

4.9 Conclusion

The present study provides preliminary support for the application of PCT for understanding adolescents with ASD. More specifically, findings indicated that PCT can provide an eloquent and empathetic approach for understanding a range of issues for adolescents with ASD, including interacting in the complex adolescent social realm, sense-making of multifaceted situations, identity development, development of flexible processing styles, and understanding and managing physical and emotional changes associated with puberty. Further research investigating the application of PCT for understanding adolescents with ASD is warranted in order to increase our understanding of ASD in general and provide these individuals, and their families, with appropriate support.

4.10 References

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CHAPTER 5: BEING A GIRL IN A BOYS' WORLD: INVESTIGATING THE EXPERIENCES OF GIRLS WITH AUTISM SPECTRUM DISORDERS DURING ADOLESCENCE

Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders*, 44, 1261-1274. DOI 10.1007/s10803-013-1985-6.

5.1 Abstract

This study investigates the experiences of adolescent girls with autism spectrum disorders (ASD) during adolescence. Semi-structured interviews were conducted with three mother–daughter dyads and two additional mothers. A range of issues were highlighted covering physical, emotional, social and sexual domains. Some of these issues were similar to those experienced by boys with ASD during adolescence, such as negative implications of late diagnosis, challenges of transitioning to and coping with high school, ‘hands-on’ role of parents into adolescence, difficulties adjusting to the increased demands of adolescent hygiene routines, and the importance of learning personal boundaries in interactions with others. Other issues discussed were of particular relevance to adolescent girls with ASD, such as difficulties socialising with neurotypically developing girls, sex-specific puberty issues, and sexual vulnerabilities. This study highlights an important research area and is a preliminary step towards understanding the experiences of adolescent girls with ASD and their families.

Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence

5.2 Introduction

The aim of this paper is to investigate the experiences of adolescent girls with an Autism Spectrum Disorder (ASD). Studies investigating the experiences of adolescents with ASD have largely focused on males (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007) and those studies that have included females have involved mixed sex samples, preventing detailed exploration of female specific issues (Nichols & Blakeley-Smith, 2010; Stokes, & Kaur, 2005). Consequently, this research area has been highlighted as a significant gap in the literature (Hsiao, Tseng, Huang, & Gau, 2013; Nichols, Moravcik, Tetenbaum, & Ebrary, 2009; Stokes & Kaur, 2005).

The focus on males with ASD in research to date is attributed to the consistent predominance of males diagnosed with ASD (Holtmann, Bölte, & Poustka, 2007; Krahn & Fenton, 2012). The most commonly reported male:female ratio of ASD diagnoses is 4:1; but there is some disparity, with other estimates as high as 16:1 (Fombonne, 2002, 2003). A wide range of hypotheses regarding the aetiology of the sex differences have been proposed including genetics, lateralisation of brain function, imprinting, and low validity of current assessment tools in detecting the disorder in girls (for a review see Rivet & Matson, 2011b).

Difficulty detecting ASD in girls has been attributed to various factors. Firstly, some research indicates a larger proportion of girls with ASD have lower IQ ranges (Nichols et al., 2009; Rivet & Matson, 2011a, 2011b; Volkmar, Szatmari, & Sparrow, 1993). This can result in females being diagnosed with Learning Disorders (Rivet & Matson, 2011b; Volkmar et al., 1993) or vague diagnoses such as Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) (American Psychiatric Association [APA], 2000; Attwood, 2012,

2013). However, other research reports more even sex-ratios for individuals with ASD with IQ levels in the normal or subnormal range (Mattila et al., 2007)

A second factor contributing to difficulties detecting ASD in girls is their relatively ‘strong’ social skills, including pretend play (Attwood, 2012, 2013; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012), communication (Nichols et al., 2009), social imitation (Baron-Cohen et al., 2011; Hsiao et al., 2013; Rivet & Matson, 2011b), and ability to focus (Nichols et al., 2009). Additionally, girls with ASD generally have fewer behavioural problems compared to their male counterparts (William et al., 2012).

These ‘strengths’ can mask underlying social impairments and contribute to delayed diagnosis (Attwood, 2012, 2013; Baron-Cohen et al., 2011; Nichols et al., 2009; Solomon et al., 2012). Consequently, many girls with ASD are not diagnosed until they have entered adolescence (Begeer et al., 2013; Bolick, 2001; Willey, 2003). For example, the imitation of social interactions is often adequate to maintain friendships during childhood, but it is not sufficient during adolescence as the complexity of social relationships increase (Bauminger et al., 2008; Carrington, Templeton, & Papinczak, 2003), and it is at this time that their significant social impairments become more evident.

The complexities of adolescent relationships are particularly apparent in adolescent female relationships as they rely primarily on intimate social communication (McLennan, Lord, & Schopler, 1993; Nichols et al., 2009; Solomon et al., 2012). That is, adolescent female relationships require more complex skills such as reciprocal sharing, emotional support, and social problem-solving. In contrast, adolescent male relationships tend to be based on ‘doing’ rather than ‘talking’ (Nichols et al., 2009). Generally, adolescent girls with ASD also need extended time to process and then respond to information (Nichols et al., 2009), which adds to their difficulties following and contributing to fast-paced conversations with their peers. These issues highlight the ways adolescent girls with ASD are more

disadvantaged in relation to the development and maintenance of friendships compared to their male counterparts (Hsiao et al., 2013; McLennan et al., 1993; Nichols et al., 2009; Rivet & Matson, 2011b).

Additionally, research focusing on neurotypically developing (NTD) adolescent relationships has indicated that males and females differ in relation to conflict management (Card, Stucky, Sawalani, & Little, 2008). Whilst boys tend to display overt aggression, girls display anger in more subtle and indirect ways such as spreading rumours, gossiping, exclusion, ignoring, and other non-verbal behaviours like giggling and eye-rolling (Card et al., 2008; Nichols et al., 2009). These latter behaviours have been termed ‘relational aggression’ as they typically involve a third-party in order to be hurtful to another individual (Nichols et al., 2009). This style of aggression is more socially complex, meaning girls with ASD are likely to have difficulty acknowledging and understanding this behaviour.

These differences in relationship styles may be a primary factor contributing to the higher rates of social isolation (Solomon et al., 2012; Sullivan & Caterino, 2008) and mental health problems (such as depression, anxiety, eating disorders and poor self-image) (Cottenceau et al., 2012; Rivet & Matson, 2011b; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Solomon et al., 2012; William et al., 2012) identified in adolescent girls with ASD, compared both to adolescent boys with ASD and to NTD adolescent girls. Together, the literature in this area highlights that adolescence is a critical period for girls with ASD.

5.3 Study Aims

There is a need for research focusing on the experiences of adolescent girls with ASD and their families. This point is highlighted both in the research literature and by families themselves. Consequently, this study investigates the experiences of girls with ASD during adolescence, from the perspectives of the individuals themselves and their mothers. By

interviewing the individuals with ASD and their mothers, we aimed to gain a multifaceted understanding of their experiences. We chose to focus solely on mothers, rather than all family members, as this is a preliminary investigation. Additionally, by focusing specifically on mother-daughter dyads we were able to conduct an in-depth investigation of the nature of these relationships during adolescence.

5.4 Method

Methodological approach

Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith, Jarman, & Osborn, 1999) was used as a guiding approach for data collection and analysis. The aim of IPA is to explore participants' views and personal meanings of an issue, rather than provide objective accounts or explanations (Oliver, 1992). In doing so, the researcher aims to get close to each participant's psychological world, while recognising one can at best do this indirectly (Smith et al., 1999). The benefits of this approach include acknowledgement of each participant being the expert of their personal experiences, recognition of both the commonalities and diversities of participants' experiences, and awareness of the investigators' influence during interpretation of interview data. Further, IPA is suitable for clinical psychological research and has been used to inform similar research in this field (Carrington, & Graham, 2001; Petalas, Hastings, Nash, Dowey, & Reilly, 2009a; Petalas, Hastings, Nash, Reilly, & Dowey, 2012).

Sample

A multiple-case study approach was employed to collect data from three mother-daughter dyads and two additional mothers⁹. This sample is consistent with IPA methodology

⁹ The daughters were not able to be interviewed as one did not have knowledge of her ASD diagnosis and parental consent was not provided for the other.

which typically involves small and homogenous samples, allowing for in-depth investigation of a specific issue (Smith, 1996; Smith et al., 1999). The participants with ASD were all female, adolescent (age range 12-17 years), and had a formal diagnosis of ASD based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) 4th edition (American Psychiatric Association [APA], 2000) (which includes conditions within the Autism spectrum such as Pervasive Developmental Disability- Not Otherwise Specified (PDD-NOS), Autistic Disorder, and Asperger's Syndrome [AS]). The annual household income of participants ranged from AUD\$20,000 to AUD\$200,000 ($M = \text{AUD\$84,000}$). Participants with ASD and their biological parents were all born in Australia. More detailed demographic information is presented in Table 5.1

Table 5.1: *Demographic information*

Daughter with ASD ^a pseudonym (age)	ASD Diagnosis	Additional Diagnoses	Age at ASD Diagnosis	Diagnostic pathway	Current education or employment	Mother's pseudonym (age)	Family dynamics (age)
Kasey (16)	Autistic Disorder	-Epilepsy (treated with left temporal lobectomy) -Scoliosis -GORD ^c	12	Clinical psychologist	Year 9, mainstream school with ASD support unit	Tina (47)	-Father (53) -Brother (23), not living at home -Sisters (12 and 9)
Erin ^b (12)	Asperger's Syndrome	Nil	6	Paediatrician and clinical psychologist	Year 6 equivalent, specialised ASD unit	Sharon (50)	-Father (50) -No siblings
Bec (16)	PDD-NOS ^d	Learning Disorder (estimated at Year 6 equivalent)	12	Paediatric psychiatrist	Year 11, mainstream school with ASD support unit	Valerie (50)	-Father not present -Sisters (19 and 20)
Hannah (17)	Asperger's Syndrome	Epilepsy	14	Paediatrician and school counsellor	Supported Employment Program	Dianne (51)	-Stepfather -Brother (35), not living at home -Sister (23)
Sally ^b (14)	Asperger's Syndrome	Nil	9	Psychiatrist	Year 9, mainstream school	Lisa (54)	-Father not present -Brother (12), diagnosed with ASD

^aAutism Spectrum Disorder^bIndividual with ASD not interviewed^cGastro-Oesophageal Reflux Disease^dPervasive Developmental Disorder- Not Otherwise Specified

Procedure

Ethical approval was granted by the University's Human Research Ethics Committee (Appendix L) prior to commencing the participant recruitment process. Participants were recruited through local schools and community groups via personal communications from staff at these sites who were informed about the study. Interested participants were then provided contact details of the research team.

Research aims and potential discussion topics were outlined with participants as part of the informed consent process (Appendix M). Following ethical standards for research with children, written consent was obtained from the participants and their parents (Appendix N) before commencement of the interviews. The interviews were conducted face-to-face in the participants' homes to promote familiarity and comfort as well as avoid connotations of a clinical interview or school related assessment (Mascha, & Boucher, 2006). On average, interviews lasted for 60 minutes (range 20-120 minutes¹⁰). Interviews were recorded for later transcription.

The interviews followed an in-depth, semi-structured format. Interviews began with an open-ended statement ('What have been your experiences of being an adolescent girl with ASD/having an adolescent daughter with ASD?'), allowing participants to lead the discussion. General facilitation was provided to all participants by suggesting topics of discussion (e.g., school, friendships, family, and developmental changes), and asking clarifying questions. This format allowed participants to speak freely and at length about their experiences, minimized researcher control over the discussion, and facilitated rapport building (Barbour, 2000). Such interview approaches are consistent with IPA because the researcher is trying to enter the psychological and

¹⁰ The shortest interview was with a participant with ASD and was cut short because the participant was feeling sick and an alternate time to complete the interview was not available. The interview was included in data analysis because useful information was obtained.

social world of the participant as she is seen as the expert (Smith, 1996; Smith, et al., 1999).

Data Analysis

NVivo10 (QSR International, 2012), a qualitative data management program, was used to manage and analyse the data. Data analysis followed the inductive coding process outlined by Braun and Clarke (2006), which involves familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final definition of themes (Braun & Clarke, 2006)¹¹. Credibility of data analysis was facilitated by a systematic record of how data were collected, maintained, and prepared for analysis. Credibility checks involved the research team reviewing all transcripts together with the potential themes identified by the first author. Consultation amongst the research team followed and refinement of themes was undertaken. This consultation process is recognised as an important process in IPA, given that the analysis of the interview material is inevitably influenced by the researchers' characteristics. The research team consisted of four researchers with various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences.

5.5 Results

Seven key themes emerged from data analysis. The themes are reflected in bold subheadings. Direct quotations are presented in indented paragraphs, in which square

¹¹ Additional information outlining data analysis procedures including thematic coding procedures and data integrity and credibility strategies employed are elaborated in Appendix V, Section 3.

brackets ([]) indicate information added for clarity and ellipses (...) indicate material omitted for conciseness. For purposes of anonymity, all names have been changed.

Diagnostic Issues

All mothers described the process of obtaining an ASD diagnosis as challenging. Reasons for this included presentation of symptoms, imitation of social behaviour, higher incidence of ASD in boys, misdiagnosis, and reluctance from health professionals (e.g., paediatricians, psychologists, psychiatrists, etc) to provide a formal diagnosis. Four of the five mothers considered the diagnostic process to be more difficult for girls, when comparing their personal experiences with those of friends who have boys on the spectrum:

“A lot of the parents in our group have boys on the spectrum and they got their diagnosis quite early, as early as two years old. We knew there was problems around that age but we didn’t know enough about Autism to pursue it... I think Autism is a male thing, I mean more boys get diagnosed but I think also that a lot of girls with Autism sort of slip through the cracks because their behaviour gets put down to something else... I think there is a lot of wrong diagnoses.” (Tina, mother)

“We took her to a psychologist and he said she was showing some features but he didn’t want to give her a firm diagnosis... she was ‘ghosting of AS’... Basically it was hard at the beginning because she had some atypical symptoms.... she wasn’t suffering any anxieties, she wasn’t acting up, she wasn’t deficient in anything other than social interaction, she hadn’t chosen an obsessive subject (she still hasn’t, she has multiple) and those things are normally present in boys.” (Sharon, mother)

“I didn’t really realise there was an issue with her until probably about Year 4... I think because people look for it more in boys and often it stands out more. They say that sometimes the girls copy behaviour and that they can hide it. And Hannah did maintain friendships... That’s why I get annoyed when people say to me, ‘How did you not know?’.” (Dianne, mother)

“I always knew there was a problem but nobody wanted to put a diagnosis on it... no one was willing to put their name down and say that she had it. It was only when I really started pushing that there was a problem... that we got the diagnosis.” (Valerie, mother)

The mothers discussed a range of negative implications related to obtaining a delayed diagnosis. These implications included inability to access early intervention and support services, and negative judgement from others:

“I find the late intervention is a huge problem, whereas if we had had things earlier we could have taught her a lot more things. Like, I still need to teach her about facial expressions because she still doesn’t know how to read people at all.” (Dianne, mother)

“Before we had the diagnosis our life was hell... we knew that there was problems but we didn’t have a diagnosis and that was really hard to work with the teachers. We changed her schools because they just seemed to think that she was a bad kid... We were so isolated from the whole community because people just looked at us as bad people and looked at her as a bad child.” (Tina, mother)

Contributing to the challenges of obtaining and coping with a diagnosis was the limited follow-up support received from health practitioners:

“It was like, ‘Well there’s your diagnosis, see ya later.’ We were left on our own to work through all this information and because you’re going through that grieving process you can’t think clearly. You don’t know where to start. You actually need someone to come in and go through it with you and say, ‘Well what do you think about this? Maybe we can try that?’ You can’t process it on your own because your brain is so scrambled with dealing with what you have just been diagnosed... it was overwhelming.” (Tina, mother)

“...it was hard to link in with services. Nobody made us aware of what services were available so I have had to do that... [Health practitioners] don’t link you in with services they just give you a label and leave you in the dark.” (Valerie, mother)

Being Surrounded by Boys

Participants discussed the experience of living with a disorder primarily associated with boys. Discussion from the girls and their mothers indicated mixed opinions. The following quote illustrates the feeling of ‘being different’ that many of the girls and their mothers described:

“It’s also hard because she’s different from the students in mainstream but being a girl makes her different from the kids in the Autism Unit too, she doesn’t fit in anywhere.” (Valerie, mother)

The difficulties of fitting in were felt most by the girls who did not have interest in traditionally ‘boys’ activities such as sports. For example:

“Many of the services aren’t catered for the girls, so it can be hard to get support. Many of the times boys get preference for using the service and sometimes the activities are geared towards the boys. It makes it hard because Bec doesn’t like to do sports and I have to force her to do it.” (Valerie, mother)

Despite the drawbacks, many of the participants discussed positive aspects of ‘being surrounded by boys’. These positive aspects included the perception that adolescent boys were easier to get along with than adolescent girls and that gender may not be important for the girls with ASD as their relationships were primarily built on common interests. For example:

“It’s good. I get along better with boys than the girls because I’m like more of a tom-boy, like I’m into boys stuff like soccer and skateboarding so me and all the boys have lots in common so I have gotten along well with them. I’ve got a group of friends with them.” (Kasey)

“I was the only girl in the [electronics] class... at first it was really weird but then I got used to it and I got to know them... I have noticed that I get along with boys better than girls... I’m not sure [why].” (Hannah)

“When I saw the Autism Unit was all boys I thought it was going to be really hard for her... but I must say that she has fitted in and I think it’s because they are boys because girls are bitchy and they get jealous and they try to bring you down whereas boys aren’t like that and like they’ll go play soccer and she’ll join in... I think the fact that there are not a lot of girls there makes her feel a bit more secure because when she has been around girls they have really bullied her.” (Tina, mother)

“She knows everyone in her class so I don’t think she’s worried about being the only girl in the class. I think it’s not a problem because she’s more likely to like some of the subjects they like, they all like space and animals and the detail of things. She’s more like a boy in that sense. I don’t think it worries her that you’re a boy and I’m a girl.” (Karen, mother)

Experiences of High School

Experiences at high school were discussed by all participants. Mixed experiences and opinions were discussed both by girls with ASD and by the mothers. Positive aspects of high school included being exposed to a broader range of subjects and students, and the more structured environment:

“It was ok changing classes and having lots of teachers was different but it was ok. It didn’t bother me having to pack up my bag and move classes...” (Bec)

“I think she’s coping with [high school] ok, I didn’t think she would but she organises herself well with her diary. And I’ve seen her write little notes on her school bag going, ‘remember to take sports uniform’. So she’s actually quite organised... The thing with high school is that even though they are going to different classes with different teachers, I think because they get a diary and a timetable they’re ok because it’s probably structured more than what primary school is.” (Tina, mother)

“I think the high school environment is more academic and there is a bigger range of people, she’s not with the same 25 kids day in, day out. She will be changing subjects, so she has a chance to meet people with her interests and they also have social clubs and groups so she can join one that suits her interests. So I think that is a friendlier environment than primary school which can be really nasty if you don’t fit in.” (Sharon, mother)

Negative aspects of high school raised by girls with ASD included finding the class work difficult and/or uninteresting, challenges making friends, and managing the larger school environment:

“[High school is] boring... It’s not interesting, it’s boring [and it’s hard] trying to keep up with the work... both [class work and homework], it’s too hard.” (Bec)

“High school was harder because I had friends in primary... [Going to a larger school] was hard sometimes. It was different.” (Hannah)

Negative aspects raised by mothers involved mainstream teachers’ limited knowledge of ASD symptomology in girls:

“School has been one of the biggest struggles that we have had... the teachers just didn’t have an understanding about Autism and they were sending her home from school for doing things that were clearly autistic... We got the spot at [School X, a high school with an Autism unit and]... she absolutely loves it and they totally get her. Her behaviours have settled down, her marks are improving. It is just sad because it took so long because you’re dealing with people that don’t understand the disability...” (Tina, mother)

“The problem I found with the schooling system when she was in mainstream was that the teachers didn’t always understand the problem. They didn’t always acknowledge that there was a problem there at all and if they did they didn’t always know how to deal with it. The ones that knew about Autism knew more about what it was like in boys like the stereotype things like hitting their head against the wall. And the issue was that a lot of those ‘bad’ behaviours she doesn’t display.” (Valerie, mother)

The transition from primary to high school was discussed by all mothers, with the general consensus that this transition was a difficult period. The main challenges involved adjusting to new routines such as having multiple teachers:

“[The transition from primary to high school] was a nightmare... She struggled with all the different classes, the physical stuff of having to carry a bag... she didn’t like most of her teachers, she didn’t like the different buses... The first two years of high school she didn’t use her diary and she was carrying the wrong books every day... This year when I ask her how it is going she says, ‘Aw good’.” (Lisa, mother)

“The transition from primary to high school was difficult, even the change from one teacher to another at the beginning of the year at primary was always difficult for her so going from primary to high school was extremely difficult for her. I was constantly up at the school talking to her year advisor and discussing issues with teachers... She didn’t cope at all, then when she finally got into the Autism Unit in year 8 it made it a lot easier.” (Valerie, mother)

Complexity of Adolescent Female Relationships

A participant with ASD eloquently described her negative experiences of trying to develop friendships with her NTD peers:

“Because I have a disability, they ignore me or pick on me and bully me just because of that. It’s hard, especially with like the really popular girls, they won’t even listen to me; as soon as they hear that I have a disability they just won’t even listen to me and what I have to say.” (Kasey)

Similarly, all five mothers described the difficulties their daughters experienced developing and maintaining friendships with NTD adolescent girls. Topics discussed included; the increasing complexity of adolescent female friendships, experiences of relational aggression, and, for some, an apparent disinterest in relationships:

“She had friendships but then they all just fell apart... [When she was younger] she could play with others, I don’t know if she learnt it from watching others, like she would do the ‘Barbie thing’ with the other girls and she had sleepovers and all that.... but between Year 4 and Year 6 they just went downhill dramatically, she could not read what people expected of her, she didn’t know how to do the conversation thing of I talk then you talk....” (Dianne, mother)

“As far as friends-wise she has to rely on the mainstream kids to become friends with [but] I’ve noticed that other teenage girls are a lot more social than she is. She tends to be more of a loner, so that whole thing of being a teenager and being off with your friends all the time hasn’t happened yet.” (Valerie, mother)

“...[adolescent girls with ASD] get shunned by the others and they get left on their own and they get picked on because adolescence is so much about fitting in for girls.” (Tina, mother)

“Girls are so nasty. I took her to the movies a couple of months ago and... these girls just stood there laughing at her and Hannah didn’t realise what was going on but I certainly did... I think girls have such high expectations within their own little social groups... Like, you know how they all kiss and cuddle and that? Hannah can’t do those things, like she would know when she is supposed to... So if you don’t know the rules, how are you going to survive in a little pod like that?” (Diane, mother)

Three of the five mothers felt that the difficulties experienced by their daughters in connecting with their NTD peers were greater than those experienced by boys they knew with ASD. The main reason proposed was the tendency for male relationships to be based on hobbies:

“... [Boys with ASD] sort of fit in so they don’t have the problems at school like the girls have... like if you’re a bit of a geek these days it doesn’t matter, it can even be a cool thing! But it’s not cool for a girl... I can see the difference in the boys who can just slide under the radar but the girls stick out like a sore thumb... I think the girls do want it more whereas I think the boys don’t care. And if they’re into their video games well that is normal for a boy!” (Tina, mother)

“The Autism boys tend to like sports and that makes them more socially acceptable... [the ones] who don’t fit in aren’t terribly sporty and they like more intellectual things.” (Sharon, mother)

All mothers discussed their daughters’ limited interest in fashion in comparison to NTD adolescent girls in a Western culture. Reasons for this disinterest included preference for practical clothes and difficulty understanding of the social aspects of fashion, such as ‘dressing-up’ for certain occasions, and dressing to impress others or portray femininity:

“Hannah has always liked pretty plain, more like boys, clothes. I think it’s because they are easy and practical. And she’s never really understood the thing of clothes for going out and clothes for just day time stuff. Like I might say, ‘Go and put something nice on because we are going out’ and she’d say, ‘But I don’t know what you mean! What do you mean?’” (Dianne, mother)

“If I tell her that something is the sort of thing you wear to a party then she will wear it and look the part but she’s not a ‘girly’ girl... I don’t know how many ‘girly’ girls there are on the spectrum. I have never met one... Their Mums’ might be teaching them how to look nice but I don’t think it’s innately in them....” (Sharon, mother)

The mothers described the ways their daughters’ disinterest in fashion had impacted negatively on their opportunity to fit in with NTD peers:

“I think being a girl and having to go through all those girly stages like having the nice hair and the trendy clothes [must be hard]. And I think sometimes the girls [with ASD] will wear something that is just not right and they think it looks great but it’s so hard to actually say, ‘Look don’t wear that because you’ll get bullied.’” (Tina, mother)

Puberty and its related issues

Puberty was a major issue of discussion in all interviews with the mothers. Onset of menstruation was by far the greatest puberty-related concern for the mothers. However, of those whose daughters had begun their periods (4/5), all described surprise at how well their daughters had managed. Factors contributing to this positive coping

included the logical and factual attitude their daughters showed towards periods, and their daughters' willingness to discuss issues:

"I was dreading her getting her periods because I didn't know how she was going to cope but I think she might be better than my NTD children! ... she's always prepared and if there's any problems she will come and talk to me about it. So she's open about it, she doesn't try to hide it, she's not embarrassed... I find that quite refreshing actually; I like that she is open and feels she can talk to me about things." (Tina, mother)

"When I talked to Erin [about puberty]... she was very factual about it... for her this was a whole bunch of facts about her body and it wasn't emotional... for the girl on the spectrum... it is pretty black and white. So it is easy to tell them facts." (Sharon, mother)

The mothers also highlighted various challenges associated with the logical attitude towards puberty described previously in this section. The main challenge was their daughters' having little discretion about usually private matters:

"...the concept I had to get my head around was how she does everything literally, like I would say, 'Ok, when you're finished with your pads you need to put them in the bin' so Hannah would walk through the house with them in her hand. My son was like, 'Argh!' because they weren't wrapped up or anything. So then you have to go, 'Ok, I need to think how Hannah needs to hear this.' ...Even now she will put it in the bin... [but] she wouldn't think that she should hide it or anything..." (Dianne, mother)

"When she's got her periods we all know about it! Whereas a NTD child would probably be a bit shy and quiet and not say anything about it.... she's not discrete and I guess that's part of the Autism." (Tina, mother)

Hygiene routines was another issue discussed by all mothers, with four of the five saying they continued, from childhood, to be involved in a 'hands-on' role with their adolescent daughters. The main issues discussed involved their daughters' difficulties adjusting to the increased demands of hygiene practices (e.g., use of deodorant and need for daily showering), and the impact these hygiene practices had on themselves as mothers of an adolescent girl with ASD:

"I have to remind her to have a shower every day... And she'll get in the shower and she'll stand there and play with the water if I don't remind her"

to put her shampoo in her hair and rinse it... She'll be in the shower for half an hour and do nothing! After years of having showers and baths she's not bothering to learn and yet she can learn really complicated things. It's typical of AS girls that that sort of thing isn't important to them. So yeah I would like to stop doing that... And I do see my friends and their [NTD] girls seem to take all that responsibility onto themselves and it would be nice not to have to do it but it's the way it is." (Sharon, mother)

"I have to take more responsibility for her in terms of hygiene and making sure she has a shower everyday [and] getting her to use deodorant and basic hygiene stuff." (Valerie, mother)

Sexual relationships and concerns

Increasing exposure to sexual issues and romantic relationships was another issue discussed by the mothers. Three of the five mothers felt that their daughters were less involved in these issues than their NTD peers. Reasons for this included showing little interest romantically in boys, knowing personal boundaries and rules, and willingness to talk to parents about issues:

"She's not interested in the whole boy issue or the sexuality stuff. In that sense I'm kind of happy because I was always worried about what my other [NTD] girls were getting up to!" (Valerie, mother)

"[Regarding sex] I think she understands it and knows about it but I think she is not interested at this stage... she actually has a boyfriend... but because they are all on the spectrum they sort of know their boundaries, like they know that there are things they shouldn't do before they get married... I have to kind of trust her. And because she will come and talk to me about anything I think that if anything happens she will come and talk to me more than my other kids might!" (Tina, mother)

One mother also discussed how she thinks puberty is different for adolescent boys with ASD compared to girls because she speculated that the boys may have more sexual urges that need to be managed:

"...I think as the boys [with ASD] mature it may be harder for them to deal with those urges then what it might be for a girl... so I think the boys are probably more involved in the sex stuff than the girls." (Tina, mother)

All mothers agreed that their daughters faced unique challenges related to sexuality and romantic relationships due to their ASD. Such challenges included their propensity to become fixated on particular issues, possible confusion about personal boundaries, and misunderstandings over typical adolescent behaviour such as flirting:

“Sometimes I have thought she is gay... or that she’s asexual. It’s nearly like she doesn’t want anyone to touch her because she never gets that close to anybody. But then if the physical gratification makes her feel that somebody likes her then she might become really into sex. I think it could go either way, either totally into sex or totally not.” (Lisa, mother)

“[Romantic relationships are] not as factual and not as scientific. It’s so much more judgemental- ‘How do I know that when he’s touching me, he’s just touching me in an ok way?’ How exact can you be? It’s so grey.” (Sharon, mother)

“She doesn’t understand it, like my niece is 15 tomorrow and she’s all over boys and Hannah just says, ‘What is she doing Mum? Why does she act like that? Why does she wear those short shorts?’ She doesn’t understand any of it. She doesn’t understand how other girls are wearing revealing clothes to attract men or boys or whatever, she doesn’t understand it... and the whole sex thing- she gets all that, but her difficulty is that she doesn’t understand why, she’s always like, ‘Yeah, but why?’.” (Dianne, mother)

Related to this issue was concern that their daughters with ASD may be vulnerable to being exploited by others. The primary concern related to this issue was that their daughters can be overly trusting of others:

“One of the parents I know, who also has AS, has told me that when she was young she slept with lots of boys because they told her that they loved her. So I do worry that she doesn’t have a deep understanding of these issues and I don’t worry that Hannah would do something, it’s the case of somebody taking advantage of her.” (Dianne, mother)

“...it is a worry that she may meet someone who is NTD and knows that she is not NTD and takes advantage of her, so there is always that worry. And the fact that she is very trustworthy, like if somebody says something she believes that to be true... But that worry will become bigger when she gets older and leaves school and starts working and starts going out of a night... because there are people out there that would take advantage of her and to fit in she would probably do things to fit in.” (Tina, mother)

“...it’s coming to that point where I am going to have to have very specific conversations with her... to make sure we have the same understanding

around who can do what and who can touch what... I know she won't like it because she will think she knows the answers. But I will have to because a couple of boys are paying attention to her... you do worry what would happen if they were in a room alone together, like whether he would take advantage of her." (Sharon, mother)

Impact of having an adolescent daughter with ASD

Throughout the interviews mothers discussed various ways having an adolescent daughter with ASD impacted them. The predominant theme was that they remained very involved in their daughters' lives compared to mothers they knew who have NTD adolescent girls. Such 'involvement' included being connected with the school and other activities, helping with homework, facilitating hygiene routines, and undertaking high levels of planning for activities:

"I was constantly up at the school talking to her year advisor and discussing issues with teachers. I've always been very active and involved with her... For other parents adolescence is a time of stepping back, like still being there for them and giving them advice or whatever, but I have to constantly push her along... I see other parents with teenagers and it's like they are getting their lives back but for me it is ongoing." (Valerie, mother)

"We are thinking about her all the time... virtually our whole lives have revolved around her... Even planning a day out to a beach takes lots of planning and things you have to think about. You can't just on the spur of the moment go and jump in the car and go somewhere... all of that constant thinking is really draining... I guess because she has Autism we are a little but more protective of her than what we are of the others. We virtually know where she is all the time, there hasn't been a situation where we haven't known exactly where she was and who she was with... I feel like I am a hands-on parent until the day I die and I will be." (Tina, mother)

The mothers also discussed the impact of having a daughter with ASD in comparison to how they perceived the impact of having a son with ASD would be. Issues discussed primarily involved remembering the importance of being accepted by other teenage girls and a desire for their daughters to experience acceptance:

“I think it’s heart breaking for the Mums, and it probably is for the Mums of boys [with ASD] as well, but I think for the girls it’s different because you’re a girl and you know what it is like going through school and how it was to be popular and look nice and be accepted and to be involved in things and to be invited to things. I think when they are not invited to parties and outings with kids their own age, I think it hurts you more than it hurts them. I think they deal with it in their own way but I think the parents take it on board themselves and it is just heart-breaking to see...” (Tina, mother)

“At her formal when she left primary school she wore black pants and a black and white check shirt with a black leather hat.... The comments from the Mums... hurt because she wasn’t in a dress, massive heels and all glammed up like the other girls....” (Lisa, mother)

Throughout the interviews the mothers indicated various attitudes towards having an adolescent daughter with ASD. These attitudes ranged from a focus on the challenging aspects (such as reduced career and social opportunities) to acceptance, positive meaning making, and even personal growth:

“For me, because I had kids so early, I always felt like at some point I would get my life back... Then I realised that that wasn’t going to happen... It is like a loss... And now that she’s becoming more clingy it makes it really hard.” (Dianne, mother)

“It’s such hard yakka just keeping things going so I’ve had to step back. I can’t put any more time into her, I have done 150% but if I did 300% it still wouldn’t be enough for her. Also, I have felt she doesn’t want that attention. I remember helping her with homework and she was like, ‘Oh you don’t do it that way!’ And it was just this horrible battle where she would turn on me but I was just trying to help... It used to hurt. I am disappointed about it because I think, ‘I’m her Mum but she won’t hug her Mum.’ It used to bother me more but I am sort of over it... I’m totally exhausted and totally burnt out.” (Lisa, mother)

“I feel that having Bec has isolated me due to the sheer time she demands... I need help with getting her more independent because the more independent she becomes the more independent I can be... [As she gets older] I have a better understanding of her and understand the ways she is different from an ordinary teenager.” (Valerie, mother)

“I think it has been like a roller-coaster, in the beginning we didn’t know a lot about it [ASD]. When you get the diagnosis I think you go through a sense of grieving... now that we are getting more connected with the services and we are not feeling so isolated like it is just us, I’m a lot more confident and the positives are coming out a lot more... it’s like we’ve

come through the fog and are coming out through the other end... I can see how far she has come and she has come that far because we are learning as well as her...” (Tina, mother)

The mothers discussed a range of practical strategies they used to cope with these challenges. The main strategies included taking ‘time-out’, and social involvement with mothers of both NTD children and those with ASD:

“I make time to myself and I sit down and read a book... I also talk to other parents of kids on the spectrum; I make time to do it... You need people that you can trust with your information. I think I’m lucky that I have people like that both on the spectrum and off the spectrum...” (Sharon, mother)

“The parents get a lot out of it [social group] too... its always like, ‘Gee, this is what has happened with my son or daughter this week, has that ever happened to you?’ and others will be like, ‘Oh yeah, exactly the same!’ And I think just hearing it come out of other parents mouths- that their kids are doing the same as your kids, you sort of get that feeling that you’re not the only ones and that you’re not that different. We may not belong in the NTD society but we can form our own little group. It makes you feel like your socialising again and you’re not isolated...” (Tina, mother)

5.6 Discussion

To our knowledge, this is the first study to investigate the experiences of adolescent girls with ASD from the perspectives of the individuals themselves and their mothers. The main themes included: diagnostic challenges; the impact of ‘being surrounded’ by boys; experiences of high school; the complexity of adolescent female relationships; puberty and sexual issues; and positive and negative impacts of having an adolescent daughter with ASD.

Some of these issues may be similar to the experiences of adolescent boys with ASD, such as negative impact of late diagnosis (Kabot, Masi, & Segal, 2003); challenges of transitioning to and coping with high school (Adreon & Stella, 2001); ‘hands-on’ role of parents into adolescence (Brewin, Renwick, & Fudge Schormans, 2008); difficulties adjusting to the increased demands of adolescent hygiene routines

(Bolick, 2001; Chan & John, 2012); and the importance of learning personal boundaries in interactions with others (Nichols & Blakeley-Smith, 2010). Other issues seem to be unique to the experiences of adolescent girls with ASD and their families, such as some of the difficulties developing and maintaining friendships with NTD peers; the implications of having a condition with a skewed sex differentiation; sex-specific puberty issues; and sexual vulnerability. These issues will be discussed in more detail in the next section.

Challenges developing and maintaining friendships

All participants with ASD reported experiencing difficulty developing and maintaining friendships with NTD adolescent peers. Contributing factors discussed by participants were in line with the literature, and included reliance on imitation skills during childhood to mask underlying social deficits; difficulty following conversations due to the length of time needed to process information; and difficulty fitting in due to disinterest and minimal understanding of fashion (Nichols et al., 2009; Solomon et al., 2012).

Another factor which may have contributed to the girls' difficulties developing and maintaining friendships with their NTD peers is their history of socialising predominantly with males who have ASD (McLennan et al., 1993; Nichols et al., 2009). Greater socialisation with males with ASD (in school classes and social groups) is natural given the preponderance of males diagnosed with the disorder. The implications of socialising predominately with males with ASD may be that the girls develop friendships that are more in line with 'male' friendships (Knickmeyer, Wheelwright, & Baron-Cohen, 2008). Characteristics of adolescent ASD male friendships include: more numerous, casual friendships (Card et al., 2008); companionship based on activities

(Bauminger, Shulman, & Agam, 2004; Carrington et al., 2003); and less socially complex interactions (Bauminger, Shulman, & Agam, 2003; Bauminger et al., 2008; Koning, & Magill-Evans, 2001). These characteristics were reflected in the interviews, with participants indicating that males with ASD were easier to get along with than NTD girls, especially when they shared similar interests.

Puberty-related challenges and concerns

This study also highlighted the range of changes and challenges related to puberty that adolescent girls with ASD, and consequently their mothers, experience.

Apprehension regarding the onset and ongoing management of menstrual care was the most salient puberty-related concern reported by the mothers. Maternal concern about the onset and management of menstruation for daughters with ASD is echoed in the broader literature (Klett & Turan, 2012; Koller, 2000; Nichols et al., 2009). Specific concerns highlighted in this study, and by the literature, include explaining menstruation in a developmentally appropriate way; management of the practical aspects of menstruation; and importance of hygiene practices (Nichols et al., 2009). Despite these concerns, our findings and other research indicate that girls with ASD generally cope well with this aspect of puberty (Koller, 2000). However, it should be noted that interviews did not capture the girls' perspectives about menstruation. We suspect this was a result of the open nature of the interviews, in which participants were asked generally about 'developmental changes' but not asked specifically about menstruation.

Another puberty-related concern expressed by mothers was the potential sexual vulnerability of their adolescent daughter with ASD. Specific concerns highlighted by this study, and echoed in the literature, include fears of sexual exploitation, the need to play a protective role for their child, and concern their child may misinterpret the

intentions and behaviours of others due to their intrinsic social and communicative impairments (Murphy & Elias, 2006; Nichols & Blakeley-Smith, 2010; Stokes & Kaur, 2005; Sullivan & Caterino, 2008). It should be noted that the prominence of sexual concerns may be inflated in this sample as the majority were older adolescents. Despite this, sexual concerns appear warranted with estimates that 16-25% of individuals with ASD have been sexually abused (Chan & John, 2012; Chan et al., 2008). Additionally, the literature indicates sexual vulnerability concerns are shared by both parents of girls and boys with ASD (Ruble & Dalrymple, 1993).

Experience of being a mother of an adolescent girl with ASD

Throughout the interviews mothers reflected on the impact of having an adolescent daughter with ASD. Some mothers discussed the challenges associated with ASD during adolescence, including the need for high involvement in daily activities with their adolescent daughters, and experiencing a sense of isolation associated with this. Positive aspects of parenting a child with ASD were also evident. These positive aspects included close relationships with their daughters, increased understanding of ASD over time, witnessing improvements in their daughters' functioning, and connecting with other families living with ASD. Importantly, interviews also reflected multifaceted attitudes that included both positive and negative elements. Such attitudes included positive meaning making of challenges, altered expectations for their daughters, and acceptance of their role as a parent of a child with ASD. These mixed attitudes highlight the complex impact of ASD on families. The theoretical concepts of 'Ambiguous Loss' (Boss, 1999, 2004; O'Brien, 2007) and 'Traumatic Growth' (Heiman & Berger, 2007) account for such impact by recognising that distress and psychological growth often co-exist. Cridland et al. (2013) discuss the importance of acknowledging

the complex impact ASD has on families by investigating both positive and negative implications of living with ASD.

5.7 Limitations and Recommended Future Research

The following points highlight some limitations of the current study and how these issues may be addressed in future research.

1. Findings highlight various issues which may be unique to the experiences of adolescent girls with ASD and their families (e.g., implications of having a condition with a skewed sex differentiation; sex-specific puberty issues; and sexual vulnerability). Whilst replication of these findings is needed, they acknowledge the need to investigate the experiences of adolescent boys and girls with ASD, and their families, separately.
2. This study utilised the perspectives of adolescent girls with ASD as well as their mothers. However the perspectives of other family members are also needed. Future research may benefit from including perspectives of various family members (e.g., fathers, siblings) and other significant individuals (e.g., teachers, extended family).
3. Whilst this sample may be considered homogeneous relative to other studies, there remain areas to be improved. For example, future studies could aim for greater diagnostic homogeneity within the autism spectrum (i.e., level of social and/or cognitive functioning); more specific age of participants (young, middle, and late adolescence); and greater attention to the influence of family dynamics (e.g., sibling age, birth order, and gender).
4. This study utilised an open-ended interview format, in which participants were merely provided with a suggestion of topics related to their experience of being an

adolescent girl with ASD/having an adolescent daughter with ASD. Whilst this approach allows participants to speak freely about issues which are most salient to them, future research may benefit from utilising a more structured approach with specific questions related to adolescent issues (e.g., regarding adolescent girls' with ASD experience of menstruation).

5.8 Clinical Recommendations

The following clinical recommendations are based on the issues raised in this study, and may be useful for health practitioners, clinicians, teachers, and families living with ASD.

1. Clinicians need to become more aware of the presentation of ASD in females and the ways this may differ from typical male presentations (Attwood, 2012, 2013). Greater awareness of ASD by clinicians is likely to facilitate less challenging diagnostic pathways and earlier access to support services.
2. The difficulties experienced with peer relationships (and the social isolation that can often occur as a result) are a key factor contributing to mental health problems, such as depression and anxiety, during adolescence (Müller, Schuler, & Yates, 2008). Clinician support may include in-depth measurement of mood symptoms (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000), communication and social skills training, strategies to increase self-esteem, and exploration of identity (Cottenceau et al., 2012; Nichols et al., 2009). Peer education and coaching programs at schools may also be important for increasing peer acceptance and understanding about ASD (Chan, 2009; Humphrey, 2008; Humphrey & Symes, 2010). Families should endeavour to provide accepting

home environments and involve their adolescent with ASD in support services with a social component to facilitate friendship opportunities.

3. The sexual vulnerability of adolescent girls with ASD was highlighted in this study. Sexual education and support should begin during childhood (Chan & John, 2012) and needs to be individualised and developmentally appropriate (Sullivan & Caterino, 2008). Appropriate topics to cover include physical changes associated with puberty, personal boundaries, and healthy strategies for expressing sexuality (Klett & Turan, 2012; Tarnai & Wolfe, 2008). The most efficacious sexual education and support will be provided collaboratively between parents, clinicians, and teachers (Klett & Turan, 2012; Nichols & Blakeley-Smith, 2010; Travers & Tincani, 2010).
4. Involvement in social support services is recommended for all adolescents with ASD and their families (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Pinkerton & Dolan, 2007). Further, gender specific groups may be helpful for adolescent girls with ASD, and their parents, given the unique issues they face (Holliday-Willey, 1999; Nichols et al., 2009).

5.9 Conclusion

We conducted this qualitative study with no intent of generalizing the results to all adolescent girls with ASD and their mothers. Nonetheless, the experiences discussed by the participants may well be shared by other adolescent girls with ASD and their families. The themes highlight a range of issues covering physical, emotional, social and sexual domains. Some of these issues were similar to those experienced by boys with ASD during adolescence; such as negative implications of late diagnosis, challenges of transitioning to and coping with high school, ‘hands-on’ role of parents

into adolescence, difficulties adjusting to the increased demands of adolescent hygiene routines, and the importance of learning personal boundaries in interactions with others. Other issues discussed were of particular relevance to adolescent girls with ASD; such as difficulties socialising with NTD girls, sex-specific puberty issues, and sexual vulnerabilities. It is important that we, as researchers, clinicians, and family members, attempt to understand these issues in order to provide these individuals with appropriate support.

5.10 References

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CHAPTER 6: EXPERIENCES OF PARENTS OF ADOLESCENTS WITH AND WITHOUT AUTISM SPECTRUM DISORDER: ROLES, RESPONSIBILITIES, CHALLENGES, AND COPING STRATEGIES.

Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (under review). Experiences of parents of adolescents with and without autism spectrum disorder: Roles, responsibilities, challenges, and coping strategies. *Focus on Autism and Other Developmental Disabilities*.

6.1 Abstract

This study investigates the parenting experiences of mothers and fathers with both a neurotypically developing (NTD) adolescent and an adolescent son with Autism Spectrum Disorder (ASD). More specifically, the study explores the roles and responsibilities undertaken by parents for their adolescent son with ASD, compared to their NTD adolescent child. Qualitative interviews were conducted with 26 participants from eight families, including mothers, fathers, adolescents with ASD, and NTD adolescent siblings. Various parenting roles were identified, including Nurturer, Advocate, Educator, and Social Co-ordinator, some of which may be unique and/or of heightened significance when parenting an adolescent with ASD. The paper discusses the influence of parental roles on family functioning; the challenging aspects of parenting an adolescent with ASD; the coping strategies used by parents; and parental advice for parents and clinicians. Understanding the unique issues for parents of adolescents with ASD is important for providing evidence-based clinical support to these families.

Experiences of parents of adolescents with and without autism spectrum disorder: Roles, responsibilities, challenges, and coping strategies.

6.2 Introduction

Adolescence is a critical period of development, involving a range of social, emotional, physical, and cognitive changes, as well as transitions into high school and increasing expectations, roles and responsibilities (Levesque, 2011). Adjusting to these changes can result in vulnerabilities to stress, anxiety, and other emotional issues (Smith Myles & Simpson, 1998). Adolescence is considered particularly challenging for individuals with Autism Spectrum Disorder (ASD)¹² due to the scope and socio-emotional nature of many of the developmental changes inherent to this period (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Levy & Perry, 2011; White & Roberson-Nay, 2009).

For parents of individuals with ASD, adolescence is considered one of the most challenging developmental stages (Chan & John, 2012; Gilchrist et al., 2012). Some of the challenges characteristic of adolescence include managing behavioural problems and sexual developments; ongoing coping with the social and emotional deficits inherent to the condition; managing the increased academic, social, and cognitive demands of high school; and planning for future residential, vocational, and leisure services (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hendricks & Wehman, 2009; Humphrey & Lewis, 2008). In addition, higher levels of depression, anxiety, worry, embarrassment, and emotional exhaustion have been associated with parenting an adolescent with ASD, compared to NTD adolescents and adolescents with other conditions (Hartley, Seltzer, Head, & Abbedutto, 2012; Hayes & Watson, 2013;

¹² Individuals with ASD experience persistent and significant social communicative impairments, as well as restricted and repetitive behaviours and/or interests (American Psychiatric Association [APA], 2013).

Rao & Beidel, 2009). For example, a study investigating the psychological wellbeing of fathers of adolescents with Downs Syndrome, Fragile-X Syndrome, and ASD found the fathers of adolescents with ASD reported significantly higher levels of depressive symptoms than the other groups (Hartley et al., 2012)

Despite the challenges of parenting a child with ASD, recent studies recognise the opportunities for enrichment and growth that this role can provide (Altieri & von Kluge, 2009; Phelps, Hodgson, McCammon, & Lamson, 2009). For example, having a child with ASD has been positively related to adaptive coping processes, such as accessing social support, self-efficacy and effective organisation of family activities (Bayat, 2007; Heiman & Berger, 2007). Some research indicates that as children with ASD grow older, parents can become more confident in their ability to cope with their child's needs and therefore more content with their role as a caregiver (Benson, 2014; Phelps et al., 2009). Other research has found that some relationships within the family system (FS) become strengthened when there is a family member with ASD (Fong, Wilgosh, & Sobsey, 1993; Rivers & Stoneman, 2003). However, the extent to which such findings translate to having an adolescent family member with ASD remains unclear.

More specifically, research is needed investigating the parenting roles undertaken by mothers and fathers for their adolescent child with ASD, and further, how these parenting roles differ to those provided for NTD adolescent children. First, research indicates that parenting an adolescent with ASD requires a greater level of overall caregiving compared to parenting an NTD adolescent (Cridland, Jones, Caputi, & Magee, 2014a; Fong, Wilgosh, & Sobsey, 1993). For example in a recent study, mothers of adolescent girls with ASD reported high levels of caregiving responsibilities continuing from childhood which they considered more complex and time demanding

than those provided by mothers of NTD adolescents (Cridland et al., 2014a). Such responsibilities covered a range of domains such as being connected with the school and other activities, helping with homework, facilitating hygiene routines, and undertaking high levels of planning for social activities (Cridland et al., 2014a).

Preliminary literature in this area also indicates that parenting an adolescent with ASD involves a range of caregiving roles that are unique or of increased importance compared to parenting a NTD adolescent (Fong, Wilgosh, & Sobsey, 1993; Rocque, 2010). Such roles include managing behavioural difficulties (e.g., frustrations from disruptions to daily schedules, obsessive and/or impulsive behaviours) and providing advocacy to professionals, support services, schools, and members of the community and extended family (Cridland et al., 2014; Fong, Wilgosh, & Sobsey, 1993; Neely-Barnes, Hall, Roberts, & Graff, 2011).

Given the range of challenges inherent to parenting an adolescent with ASD and the related roles and responsibilities, research is warranted investigating the coping strategies used by these parents. Existing research indicates parents of children with ASD utilize a range of coping strategies, including both formal (e.g., ASD specific and non-specific support groups, respite services, and professional counselling) (Luther, Canham, & Cureton, 2005; Rivers & Stoneman, 2003) and informal supports (e.g., time spent with their spouse, friends and family) (Heiman & Berger, 2007; Rao & Beidel, 2009; Solomon & Chung, 2012; Weiss, 2002). Following this, research indicates most parents adopt a range of coping strategies as they each provide different types of support. For example, spousal support is considered to provide emotional and practical assistance (Rao & Beidel, 2009; Solomon & Chung, 2012); whereas ASD support groups are said to provide educational, emotional, and practical support (Luther, Canham, & Cureton, 2005; Rivers & Stoneman, 2003).

However, the extent to which parents of adolescents with ASD find the coping strategies identified by parents of children with ASD useful remains unclear. For example, Beresford (1994) posited that the importance of support groups may decrease with the increasing age of the child with ASD because parents develop greater understanding of ASD over time. Research investigating the coping strategies utilized by parents of adolescents with ASD is warranted given this gap in the literature.

6.3 Study Aims

The aim of this study was to investigate the parenting experiences of mothers and fathers with an adolescent son with ASD, compared to their experiences of parenting a NTD adolescent child. In doing so, the study utilized a Family Systems (FS) approach by involving multiple family members in the research design (i.e., mothers, fathers, NTD adolescents, and adolescents with ASD) and considering the roles of parents within the context of the FS. The FS approach offers a suitable conceptual framework for researching families living with ASD given the complexity and heterogeneity of this condition and the influence it has on all family members (Johnson, Frenn, Feetham, & Simpson, 2011; Lozzi-Toscano, 2004). The use of FS approaches also follows calls for more theoretically driven, family-focused ASD research (Cridland et al., 2013; Jensen & Spannagel, 2011; Orsmond & Seltzer, 2007).

In investigating the parenting experiences of mothers and fathers with an adolescent son with ASD, the research aimed to explore both challenging and rewarding aspects. Additionally, the study aimed to explore how the parenting experiences and roles undertaken differed between those provided for their adolescent son with ASD compared to their NTD adolescent son. Third, the study aimed to explore the coping

strategies used by parents to facilitate coping with the demanding aspects of parenting an adolescent with ASD.

6.4 Method

Sample

The sample consisted of 26 participants from eight families. This included mothers ($n=8$), fathers ($n=7$), adolescents with ASD ($n=7$), and adolescent NTD siblings ($n=4$). Eligibility criteria for the families included two parents who identify as the primary caregivers with at least two adolescent children (one NTD individual and one son¹³ with ASD); all family members living at home a minimum of five days per week; both siblings attending the same school; only one family member formally diagnosed with ASD; and all family members having knowledge of the ASD diagnosis. In the sample, all individuals with ASD were formally diagnosed with Asperger's Syndrome (AS), which, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM), fourth edition (APA, 2000) is a form of high functioning Autism¹⁴.

The criterion of attending mainstream school was established to promote homogeneity in the sample (i.e., ability to reflect on secondary school experiences and all adolescents having the level of functioning and adaptive behaviour required to attend mainstream schooling). The rationale for focusing on males with ASD was based on the current predominance of males diagnosed with the condition (Holtmann, Bölte, & Poustka, 2007; Krahn, & Fenton, 2012) and previous recommendations to acknowledge

¹³ The rationale for focusing on males with ASD was based on the current predominance of males diagnosed with ASD (Holtmann, Bolte, & Poustka, 2007; Krahn & Fenton, 2012) and previous recommendations to acknowledge the influence of gender on research findings (Card, Stucky, Sawalani, & Little, 2008; Cridland, Jones, Caputi, & Magee, 2014a; Hsiao, Tseng, Huang, & Gau, 2013).

¹⁴ Given the removal of subcategories within the autism spectrum in the DSM-V (APA, 2013), participants in this study are referred to as having ASD. However, terms associated with AS (e.g., Asperger's, Aspie) have been retained in direct quotations from participants in order to accurately portray their comments.

the influence of gender on research findings (Card, Stucky, Sawalani, & Little, 2008; Cridland et al., 2014a; Hsiao, Tseng, Huang, & Gau, 2013).

Additional demographic information is presented in Table 6.1.

Table 6.1: *Demographic information*

Family identifier	Participating family members				Individual with ASD age (years), gender	Individual with ASD school grade and class type	NTD sibling age (years), gender	NTD sibling school grade/employment	Parent education level and employment status		Parent Ethnicity	Annual Household Income
	Mother	Father	Individual with ASD ^a	NTD ^b sibling					Mother	Father		
Family 1	Yes	Yes	Yes	Yes	14, male	8, mainstream classes with ASD support unit	16, female	11, mainstream classes	University, Part time work	Technical college, Full time work	Australian / European	\$80000
Family 2	Yes	Yes	Yes	Yes	14, male	8, mainstream classes	16, female	10, mainstream classes	University, Part time work	High School, Part time work	Australian	\$60000
Family 3	Yes	No	Yes	Yes	15, male	9, mainstream classes with ASD support unit	17, female	11, mainstream classes	Technical college, Part time work	Technical college, Part time work	Australian / European	\$40000
Family 4	Yes	Yes	Yes	No	13, male	7, mainstream classes	14, female	8, mainstream classes	University, Full time work	Technical college, Homemaker	Australian	\$80000
Family 5	Yes	Yes	Yes	No	12, male	7, mainstream classes	18, male	Trade school	University, Part time	University, Full time	Australian	\$90000
Family 6	Yes	Yes	No	No	14, male	8, mainstream classes	19, male	University	Technical college, Part time work	Technical college, Full time work	Australian	\$70000
Family 7	Yes	Yes	Yes	No	16, male	10, mainstream classes	18, male	Trade School	High school, Part time work	Technical College, Full time work	Australian	\$80000
Family 8	Yes	Yes	Yes	Yes	15, male	9, mainstream classes	17, male	12, mainstream classes	University, Full time work	University, Full time work	Australia / European	>\$100000

Note. ^aAutism Spectrum Disorder ^bNeurotypically developing

Procedure

Ethical approval was granted by the University's Human Research Ethics Committee (Appendix L) prior to commencing the participant recruitment process. Participants were recruited through local secondary schools and community groups by responding to study advertisements (Appendix P). Following ethical standards for research with children, written consent was obtained from the participants and their parents (Appendix N). In order to promote voluntary consent, involvement of all family members was not required for a family to be eligible for participation.

Semi-structured interviews (Patton, 2002) were conducted to achieve a detailed understanding of parental experiences when raising an adolescent with ASD without imposing prescribed categories. The interview guide was developed based on a review of relevant interview guides used in previous studies (Benderix & Sivberg, 2007; Carrington & Graham, 2001; Mascha & Boucher, 2006; Vliem, 2009) and through multiple discussions amongst the research team. Interview questions were generally related to experiences of being an adolescent with ASD/having an adolescent family member with ASD (e.g., 'Do you think being a teenager with ASD/having a teenage family member with ASD makes you different from other teenagers/families?', 'What are some challenges/positive aspects of being an adolescent with ASD/having an adolescent family member with ASD?'), with some questions relating specifically to the roles and responsibilities of parents (e.g., 'In what ways do you/does your Mum/Dad help your son/you/your brother?', 'Who in your family do you/your adolescent family member with ASD find helpful in difficult situations?'). A copy of the interview guide is available from the corresponding author (see Appendix O).

Based on research recommendations (Cridland, Jones, Caputi, & Magee, 2014b), the interview guide was pilot tested on one family with an adolescent family member with ASD¹⁵. Minor wording changes to questions resulted from pilot testing.

Interviews were conducted based on recommendations outlined in Cridland et al (2014b [Appendix A]), including conducting interviews with individual participants in a private space within the family home (e.g., study or quiet living area); conducting interviews at a preferred time for participants; and conducting interviews at an appropriate pace to facilitate accurate interpretation of interview questions. Interviews lasted for an average of approximately 60 minutes (range 40-150 minutes). Interviews were audio recorded for transcription.

Data Analysis

NVivo (QSR International, 2012), a qualitative data management program, was used to manage the data. The data were analysed following the inductive coding process outlined by Braun and Clarke (2006). This process included familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final coding of themes (Braun & Clarke, 2006). Credibility checks involved one member of the research team and one independent checker reading all transcripts with the potential themes identified by the first author. No major changes to the themes identified by the first author resulted. Consultation amongst the research team followed and included finalisation of theme descriptions and selection of most relevant quotes.

¹⁵ The interview data from pilot testing was not included in the findings reported in the study.

This method of credibility checking, also referred to as ‘investigator triangulation’ (Guion, Diehl, & McDonald, 2011), was employed over traditional member checking for various reasons. More specifically, there were concerns that, despite de-identification of transcripts, individuals involved in member checking may be able to identify other participants based on experiences discussed in the interviews. This issue was particularly pertinent in recognizing other family members’ transcripts. However, this issue was also relevant for recognition of other participants given the local community within which the sample was recruited. Associated with this, participant anonymity was important in obtaining accurate data, whereby participants may have felt reluctant to speak openly in interviews if there were concerns about being identified through member checking processes.

In regards to positionality, the co-authors and independent checker had various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences. Such varying experiences were important in minimising potential biases in data interpretation (Whittemore, Chase, & Mandle, 2001).

Other strategies employed to enhance the integrity of data analysis included the first author having prolonged engagement with the data (including interview administration and transcription) (van den Hoonaard, 2002) and the three methods of bracketing outlined in Tufford and Newman (2012). Specifically, the bracketing methods included the first author keeping memos during data collection and analysis as a means of examining and reflecting on their engagement with the data, the first author engaging in discussions with an outside source to bring awareness to preconceptions and potential biases, and the first author keeping a reflexive journal during all stages of the research process to sustain a reflexive stance (Tufford & Newman, 2012).

As this was an exploratory study, it was not the aim to achieve data saturation of all themes. In order to convey the strength of themes, the number of participants who discussed each point is presented.

6.5 Results

Results are reported according to three key themes; parental roles, the challenging aspects of parenting an adolescent son with ASD, and the coping strategies used by parents. Within each theme there are several subthemes, indicated with subheadings. Direct quotations are presented in indented paragraphs, in which square brackets ([]) indicate information added by the primary researcher for clarification and ellipses (...) indicate material omitted for conciseness. For purposes of confidentiality, all names have been changed.

Parental Roles

Clarity of parental roles. When asked, all participants (26/26) were able to identify which parent they thought was primarily responsible for at least one role in the family. However, the level of awareness and clarity about such responsibilities varied between individual participants and families as a whole. The division of roles occurred for a range of reasons such as availability to fulfil a role, or personal characteristics making one parent more suitable than the other for a specific role:

“I think everyone fills different roles... I’m the one that will fix it, the practical things. And I’m the cuddler, the nurturer... [His Dad] is more like a buddy that just takes him away from the situation and gives him another distraction... [and he is] the joker.” (Mother, Family 2)

“...he would go to Mum... She’ll give him advice with social things. If it’s homework, she’ll sit down and do it with him. If it’s computer things he will go to Dad because he’s the ‘I.T.’ guy...” (Brother, Family 8)

“...if Dad was here and Mum wasn’t I’d go to him but if Dad wasn’t and Mum was I’d go to her, something like that... I mostly go to my Dad really, because my Mum is always at work.” (Adolescent with ASD, Family 1)

Functioning of parental roles. Whilst participants identified roles that were predominantly undertaken by a specific parent, there was also discussion about role permeability or flexibility; where parents would share or adapt into different roles if needed:

“Anytime that David [my son with ASD] becomes cranky or illogical, Peter [his Dad/my husband] doesn’t get it all... [Then] I will intervene and say, ‘You two are struggling and you need time-out’ and he does that for me too when I get cranky he will say, ‘Look, you too aren’t getting on, let’s split it and I will take over.’ So we tag team it a bit.” (Mother, Family 8)

“[My husband] and I work really well as a team... no-one sits down and lets the other person do everything, we’re like, ‘I’ll do this and you do that, I’ll bring the washing in and you can start dinner, I will go and see who has got homework’, You know? Otherwise we wouldn’t cope and we wouldn’t be a happy family.” (Mother, Family 7)

Conversely, some participants discussed uneven distribution of roles between parents and apparent inflexibility within the FS to alter the distribution of roles to a healthier balance. The implications of one parent being responsible for too many roles included over-functioning of that parent and feelings of under-appreciation and even burn-out:

“...the support teacher suggested five hours of stuff that I can do to support my son each day, I don’t think he gets that I work full time and that I am already stressed out to the max. I do fifty hours a week at work, I’m doing everything at home, I don’t actually have a lot more to give. So these ‘helpful’ suggestions are not helpful. I’m drowning already and already feeling immensely stressed and you want me to do more?... I’m already at full stretch. I’m doing as much as I can do. I’m at my wits end...” (Mother, Family 4)

“I’m the organiser and the fixer. I’m sort of a bit of the foreman. I cook and prepare all the meals. I make sure everyone is organised and sort of like the secretary/administrator type thing. I pay all the bills, deal with the finances... I have a lot of the stressful stuff and all

the organising and keeping everyone on tasks... I am the one who makes all the decisions so sometimes I would like to share that responsibility.” (Mother, Family 2)

“It’s generally my instinct to go to Mum for most problems... I tell Mum what has happened and she will try to help me sort it out.” (Adolescent with ASD, Family 8)

All parents (15/15) discussed that their various roles and responsibilities in parenting their adolescent with ASD necessitated a higher level of involvement in comparison to their roles of parenting their NTD adolescent children:

“It is more hands-on... [in] virtually everything; learning, behavioural, everything. [For example] even though he knows he has a shower and does his teeth and that sort of thing, you have to keep reminding him to do it. He won’t just do it off his own back.” (Father, Family 5)

“When your children are younger the amount of support and time you give is a lot and as your children get older you have more and more freedom. I don’t have as much freedom as the parents who don’t have a children with AS. A lot more of my time is tied up with him. So I don’t have much freedom.” (Mother, Family 8)

Specific parental roles. The following themes relate to roles undertaken by the parents discussed during the interviews. More specifically, the roles identified include nurturer, advocate, educator, and social co-ordinator.

Nurturer. All families (8/8) discussed the role parents played in providing emotional support. Being a nurturer was described as a role provided to both their adolescent children; however, unique aspects regarding providing emotional support to an adolescent with ASD were noted. These unique aspects included providing nurture for ASD related issues, sharing of affection more openly, and teaching socially appropriate ways to show emotions. This nurturing role was discussed as being undertaken by both parents, however some participants reported that mothers were the primary parent for

providing emotional support:

“[When Matthew is upset] he would probably find Mum to be the most helpful because it seems like she’s the one that understands AS most and would understand him most... I think he would rather Mum because Mum is Mum... she kind of just helps him talk about it and breaks it down... and he just opens up to her about things.” (Sister, Family 1)

“...he’s just very loving and he’s always been loving... Definitely [more affectionate than my NTD adolescent]! ...I don’t mind him being cuddly... [But] the other day... he grabbed my hand and was walking along holding it and I’m thinking, ‘You’re as tall as me, people will think we are dating!’ ... I love it but sometimes it’s a bit hard... I explain that we can be very loving at home but not out in the public.” (Mother, Family 6)

Advocate. Participants from most families (7/8) discussed various ways parents advocated for their adolescent son with ASD. Predominant areas of advocacy included explaining the needs of their son to others and managing misunderstandings at school:

“She’s always on the phone [to the school] saying things like, ‘Yes, but don’t you realise what he’s like?!’... or maybe he’s done something wrong at school and he’s in trouble and she might help calm him down about it and then go to the school and see what can be done... I’m always ready to go down [to the school]... I hate it when I hear little bits and pieces that go on. It makes me angry- I want to go straighten it out, particularly if someone starts picking on him. I hate that.” (Father, Family 2)

“I am more involved with school, I have to go up there and talk to the teachers and work out a plan for Adam and how they can help him do his work.” (Father, Family 4)

Educator. All families (8/8) discussed various ways parents played the role of educator for their adolescent son with ASD. One key area of education involved that of social skills development. Many participants discussed how parents had provided this role for their son with ASD since childhood, however noted that it had become more complex due to the social expectations of adolescent functioning. In our sample, educator roles were undertaken by both mothers and fathers:

“...we went through a stage where he was touching himself... we had to talk about when and where you do those things... I just sort of said it was a normal thing but private and talked about how it might make other people feel uncomfortable if you do it in front of other people... And he is fine with that. He’s pretty good like that- if you explain the rules of society to him and he understands it then he will just adjust.” (Mother, Family 8)

“Occasionally I have had to pull Adam aside and explain some type of social nuance that he hasn’t understood... suddenly the expansion of his world into high school [has been] difficult for all of us I feel... You have to break down every single step of every single process... You have to be prepared to go into yourself and figure out why we do these things...” (Father, Family 4)

“[Dad understands me because] if I’ve done something wrong he doesn’t go off at me. Most of the time he explains what I have done wrong and how to do it...” (Adolescent with ASD, Family 3)

A second area of education involved helping their adolescent son with ASD with school work. This role ranged from encouraging their son to do their homework to sitting down with their son and helping them with specific activities. Related to this, many of the families (5/8) highlighted homework to be one of their biggest daily challenges:

“When he’s given any homework that’s an issue for him because school is school and home is free time and play time... He doesn’t believe he should have to do anything at home!... [With homework we help by] pointing him in the right direction because they can go off on the wrong tangent very easily.” (Father, Family 1)

“Usually for stuff like with homework and stuff I usually just go to Mum or my older sister... It’s pretty helpful- I still don’t really like it but it helps.” (Adolescent with ASD, Family 2)

“With homework Mum and Dad tend to do a lot of helping. Like they used to help me... but they help in a different way like if they helped me with maths homework it was because I was saying, ‘I don’t understand this, can you help me?’, whereas for him its making sure he does it and making sure he doesn’t get distracted.” (Brother, Family 8)

Social Co-ordinator. Many of the parents (11/15) discussed the importance of organising and monitoring social activities for their adolescent son with ASD, compared to

their NTD adolescent. Discussions indicated this role entailed organising appropriate social activities, monitoring during the activity, and managing any negative outcomes:

“I do a lot more different things than a normal Mum would do probably. Like for example he went to a friend’s house... and I had to ask a lot of questions about where it was, who was going to be there, are they going to be supervised, and all that. Whereas a normal Mum would just say, ‘Well as long as you are going to drop them off and pick them up!’... if it was Christie [my NTD adolescent daughter] I wouldn’t be like that.” (Mother, Family 3)

“...other teenagers would just call their friends, tell them to come over and then go down to the beach, it’s just not as easy for Matt... It’s always a fight when he wants to go somewhere... [such as] the mall because I know that’s not a good place for him... it’s like they’re still in primary school in their head but they want independence and stuff too.” (Mother, Family 1)

Associated with the role of social co-ordinator was a need to motivate their son to participate in social activities. Reasons for motivating their son to be involved in social activities included social learning opportunities, preparation for the future, and opportunities for new experiences. Some parents contrasted this responsibility with their experience of parenting their NTD adolescent, who did not need such motivation:

“He would prefer to stay at home and I’m the one pushing him to go to social club... because otherwise he would probably just sit on his computer... we’ve just tried to make him happy and we’ve tried to encourage him to do different things... We have to prepare him for the future...” (Mother, Family 7)

“I think a really big decision we had to make was how we were going to deal with his desire to live a reclusive life. If we let him he would spend every moment on the computer or in his room. We don’t want that for him but seeing him struggle with the world is something we also don’t want. So on the one hand he can stay in his room and live a dysfunctional life, but he’s happy, or we can encourage him to live in the world and have friends and a future. But with that also comes heartache.” (Father, Family 4)

Challenging aspects of parenting an adolescent with ASD

Puberty. A range of issues associated with puberty were highlighted as challenges to be managed during this period. Specific issues included managing strong adolescent

emotions, implications of their son's increasing physical size, their son's confusion about bodily changes which sometimes resulted in socially inappropriate behaviour, and difficulties adjusting to the increasingly complex hygiene routines associated with adolescence:

"He wants to show me anywhere and at any-time that he has pubic hair. He doesn't understand that you can't do that sort of thing in public... It's more complicated than it was with my other boys ...like other kids tend to know that that's not socially appropriate by that age..." (Mother, Family 5)

"...getting him to wear to wear deodorant [is a challenge]... Unless you're on his back constantly it doesn't happen.... So I'm just trying to say it every day and if I keep saying it then maybe one day he'll do it himself... I think that's part of his Autism." (Mother, Family 6)

"He gets frustrated, he gets upset, he gets angry. Sometimes he gets angry and he doesn't know why he is angry... and no matter what I say to him he takes any criticism of his behaviour as me being angry at him... I'm just trying to help." (Mother, Family 2)

"I think that he is realising his strength and that he is getting bigger and that he thinks he can do what he wants because he is getting older and going through puberty ...it used to be that Mum could restrain him and hold him back if he is punching or whatever but now it has to take three of us to hold him because he is that strong..." (Sister, Family 3)

Judgemental society. Many parents (11/15) discussed experiences where they or their partner had felt negatively judged due to their son's behaviour. Areas of most concern included feeling scrutinised by professionals (e.g., teachers and health practitioners) and members of the public. Further, parents felt these experiences were becoming worse as people were less accepting of socially inappropriate behaviour displayed by an adolescent compared to a younger child:

"People really do judge you... you feel like you're being scrutinised over everything... [and] when they're little, people might think it's cute, but it's not cute when they don't grow out of it! ... I feel people's judgements come back onto me that I'm a bad mother." (Mother, Family 7)

“...today at the doctor he was showing me how to talk to Ken and address how he must be feeling and just think, ‘Um, I know!’ But it [also] makes me start doubting myself.” (Mother, Family 5)

*“...we went to the aquarium... [and he] smacked his head on the glass and he’s screamed and yelled out, ‘Argh f***, me head!’ And he started having a go at me then... And that is just embarrassing because here’s your kid swearing... [and] it makes it harder for us because he’s not little anymore.” (Father, Family 5)*

Ongoing ‘grief’ process. Some parents (7/15) discussed an ongoing process of adjustment with being the parent of an individual with ASD, which had continued into adolescence. The most common term used by parents to describe this process was ‘grieving’. Salient aspects of this process during adolescence included worrying about the future (i.e., being able to financially support their child into adulthood) and coping with the psychological and physical demands of parenting an adolescent with ASD:

“You do go through grieving and I think there are still a lot of times when you want him to fit into the mainstream stuff and it’s mostly for his own wellbeing, like it would make his life easier. And it’s hard enough as it is to go through teenage years with your kids but going through them with Asperger’s as well just adds another layer and makes it just that much harder. Like you worry how he’s going with high school and you’re looking towards the future all the time... There’s that constant worry, like initially when he got diagnosed it was all about figuring out ways to make him happy but now it’s all figuring out ways to improve his future.” (Mother, Family 5)

“I’m an emotional person so I will come out here and bawl at Roger. I will cry about, ‘Why did this happen to our baby?’ and ‘Why is this so unfair?’ It is grief... And with teenage years there are changes all the time and you think, ‘Oh God, this is not what I wanted for him’ but I just try to hope...” (Mother, Family 7)

Strategies for coping

‘Taking a break’. The coping strategy most frequently discussed by parents (10/15) was having ‘taking a break’. This strategy generally involved having time to oneself to recuperate and/or to engage in an enjoyable activity. The implementation of this

strategy ranged from organised weekly activities to ‘in the moment’ separation from a frustrating situation:

“For me I just need to take some time out. Just time away, it might be just watching TV or leaving the room and doing something else to get some separation.” (Father, Family 7)

“I don’t have a huge amount of spare time and when I do, I mainly just take time out and read and relax... I just shut myself away from everyone else and be alone...” (Father, Family 2)

Whilst acknowledging the importance of taking time for themselves, some parents described feeling guilty for doing so and/or felt if they took ‘time-off’ it would adversely impact other responsibilities. Notably, mothers more frequently discussed feelings of guilt compared to fathers:

“I don’t have much spare time. I like to read detective stories but more often I listen to them on audiobooks so I can do the housework at the same time. [If I had a day off] I’d probably choose to reduce my stress levels by working.” (Mother, Family 4)

“[I enjoy] sewing, reading, cooking, just being calm. I can’t remember the last time I was alone but I like that too... [But if I get ‘alone time’] I usually feel guilty and then end up cleaning up the house anyway. I can never really relax, there’s always catching up on chores to do.” (Mother, Family 5)

Time with partner. Spending quality time with their partner was identified as a coping strategy by the majority of parents (9/15). Some parents felt they had more opportunity to do so now that their child with ASD was old enough to stay at home by themselves:

“It has been over the last year I suppose that we have felt pretty comfortable leaving David at home... it sort of frees us up to go and do something and we don’t have to organise someone to look after him while we go to the shops for example.... It gets us back to when we were first married and able to do all these things on our own...” (Father, Family 8)

“I like it when we go for walks and just being able to sit quietly without any interruptions. It’s few and far between but I like that. I just like hanging out with her.” (Father, Family 2)

Confiding in someone. Confiding about the challenges of parenting an adolescent son with ASD was discussed by many parents (8/15). The majority of these parents said they confided in their partners. However, others reported that they found other family and/or close friends more helpful. Confiding in someone was found most helpful when the person listened and offered a supportive attitude. It was deemed unhelpful when participants felt judged or when the confidant tried to ‘take-over’. Participants expressed mixed opinions towards the efficacy of being offered strategies or advice; with some finding advice helpful and others finding it frustrating:

“My best-friends [help me]... They ask me questions which put me back into problem solving and coming up with strategies to solve the situation.” (Mother, Family 8)

“[I go to my husband]... He’s just there for me and we’ll both work off each other... Or when I get real down he’ll say something like, ‘He’s not dying, we’ll get through this. He’s always got us, he’ll be right.’ And you go, ‘Yeah, yeah, you’re right! I’ll make sure he’s alright’.” (Mother, Family 7)

“I tend not to talk to John [my husband] about it because he’ll just get angry and be unhelpful... [But] sometimes I do need to talk about it and let it out...I tend to talk to Mum but she sort of gets a bit, ‘Oh well, maybe your Father and I should come... [to help]’ [My best-friend is] good because she listens... and she lets me vent and that’s all I want.” (Mother, Family 2)

Involvement in an ASD support group. Being involved in an ASD support group was a coping strategy identified by some parents (6/15). Reasons ASD support groups were deemed helpful included learning behaviour management strategies, providing a social outlet for their son, and receiving emotional and practical support from other parents of adolescents with ASD:

“It [the ASD support group] has been really good... I was able to tell them about his major meltdown and you pick up different things about what works and different supports... It’s been great for Ben as well because he can be himself and he can use his big words and the other kids don’t look at him funny because they all understand him and they can have a conversation with him and they’re not thinking he is strange.” (Mother, Family 6)

“...meeting with the [ASD support] group has been helpful and makes me put things in perspective... [Its] a place where you know the kids are being looked after by professionals and so the parents can talk without worrying. It’s where you can vent in a safe environment with like-minded people... I think he [my husband] probably found it a lot harder initially to understand the whole thing [regarding ASD], until he started going to the parent’s social club and he could see that the other parents were going through the same things and it made him see that it was real.” (Mother, Family 5)

Use of humour. Humour was discussed by many parents (8/15) as a way of managing challenging situations, dealing with personal frustrations, and/or bonding with their son with ASD. Notably, in the families who discussed this strategy, humour was used predominantly by fathers:

“[To help in challenging situations] I kind of try and make light of it... I hope it is [helpful]. I don’t know, you try not to be cranky with him because you know how bad the frustration can get... [And making jokes] will kind of cover me from getting cranky with him too...” (Father, Family 2)

“They get on like brothers... because they both throw the sarcasm back at each other and play tit for tat. They do muck around and have a wrestle and what-not.” (Mother, Family 6)

Parental reflections

Throughout the interviews most parents (12/15) described an accepting and/or positive attitude they had developed towards being the parent of a child with ASD. Parents discussed how these attitudes had helped them cope with the various challenging aspects of parenting an adolescent with ASD. Further, several parents (7/15) discussed how their positive attitude had developed over time:

“I’m probably more at ease now because you sort of know what is going on. I’ve got more understanding of things that have happened like with his behaviour or the way that he is.” (Father, Family 5)

“Yes there are certain particular challenges [in parenting an adolescent with ASD] but does it necessarily mean we are a whole lot worse off than other families? I’d say no, we are just different...” (Mother, Family 4)

“It’s better [now] because we’ve grown with him and have that understanding and awareness of it... if anyone has a problem then it’s their issue. That’s the way I’ve looked at it.” (Mother, Family 1)

“David is my gift- he really makes me change the way I see the world. I just wish he would mellow a little bit and get through these next few years quickly!” (Mother, Family 8)

Parents were also given the opportunity to discuss things they ‘wish they knew’ as their child was transitioning into adolescence and ‘advice’ they would provide to other parents and clinicians. Their ‘advice’ ranged from ways to understand and interact with their adolescent with ASD to self-care strategies. Additionally, advice covered a range of the parental roles discussed earlier such as being available to provide nurturance and emotional support to their adolescent son with ASD:

“My advice to younger families would be enjoy the quirkiest aspects of AS because some people can be so caught up on ‘normal’... Expectations of normal and that you should be doing certain things and [that] your son should be doing certain things should be avoided like the plague.” (Mother, Family 4)

“I know from my other kids and my other experiences that there is a lot of teenage interplay with these years, regardless of the AS. Don’t think that it is all AS; there are hormones raging around on top of everything else.” (Mother, Family 7)

“...listen to him and show that you’re listening to him because they need that I think...” (Father, Family 1)

“Take each day as it comes and deal with the problems as they come along. Just be there for them and talk to them and it might be a rocky road but just support them as best you can...” (Mother, Family 6)

“It’s all just about learning. You just have to adapt. But everyone is different in the way they adapt. And it’s all just about tolerance. It’s

all a learning experience like how to react and how he will react in different situations... ” (Father, Family 6)

“Just try to spend as much time as much with them because they are not teenagers for long and these years are crucial- they need guidance.” (Father, Family 7)

6.6 Discussion

This study investigated the experiences of parents with a NTD adolescent and an adolescent with ASD, with a particular focus on parental roles and responsibilities, the challenging aspects, and the coping strategies used by parents. Interviews were conducted with mothers, fathers, NTD adolescents, and adolescents with ASD from eight families. Investigating the parenting roles and responsibilities involved in raising an adolescent with ASD is important in enhancing our understanding of how families living with ASD function. Additionally, understanding parenting roles and responsibilities in this context is important in being able to provide clinical support services to these families.

Parental roles

Various parenting roles were identified by the participants, including Nurturer, Advocate, Educator, and Social Co-Ordinator. According to FS approaches, some of these parenting roles are common to most families, such as providing nurturance, advocacy, and education (Becvar & Becvar, 1982; Bowen & Kerr, 1988; Carter, 1980). Other identified roles seemed to be unique to parenting an adolescent with ASD, such as organising and motivating their son to be involved in social activities. Additionally, there were unique components to some of the more common parenting roles. For example, teaching of socially appropriate behaviour is a significant role undertaken by parents of NTD children, however is generally of less importance during adolescence (Fong et al., 1993; Howard et

al., 2006). This is in contrast to parents of adolescents with ASD, for whom this role remains salient as their children develop into adolescence.

Traditionally, the allocation of parenting roles is seen as being based on gender roles, with mothers typically understood to provide expressive support (emotional and affective support), and fathers to provide instrumental support (practical, hands-on support) (Pickhardt, 2007; Seligman & Darling, 2007). In this sample, there was some evidence of role allocation based on traditional gender roles; as mothers were predominantly identified to fulfil expressive support needs (i.e., role of Nurturer). However, both parents were identified as providing instrumental support, such as advocacy, education, and co-ordination of social activities. Other forms of instrumental support (e.g., financial support) were not discussed by participants, so it is unclear whether they followed traditional gender roles. However, the applicability of understanding role allocation based on traditional gender roles may be limited as contemporary gender roles are generally more flexible (Pickhardt, 2007). This is evident in the current sample, as mothers in two families were identified to be the primary earners.

Clarity around role responsibilities may be a more valid indicator of family functioning than traditional gender role allocation. Following this, all participants were able to identify at least one parenting role fulfilled predominantly by one particular parent. The ability to identify role responsibility can be considered an indication of positive parental role clarity in all eight families. It may be that the clarity of parental role responsibilities is of heightened importance in families living with ASD given the demands of having a family member with ASD. Further investigation into this issue is warranted.

Role dispersion is another component of role functioning. According to FS approaches, dispersion of roles is considered positive when roles are perceived to be shared fairly between family members (Bowen, 1978, 1995; Bowen & Kerr, 1988). ‘Fair’

dispersion of parenting roles is considered when both parents feel they have an appropriate responsibility load, rather than an objective measure of role dispersion (Bowen, 1995). In our study, a degree of dispersion of parenting roles was evident in all families; however, some participants perceived ‘unfair’ distribution of some parental responsibilities. For example, in Family 4, the mother identified that she was the primary earner as well as being responsible for the majority of care for her adolescent son with ASD. Discussions indicated that the mother felt under-appreciated and burnt-out in fulfilling her roles at both home and work. The interview with the father in Family 4 indicated that he felt helpless regarding how to adequately assist his wife, and as a result had withdrawn from some of his roles within the FS. The literature indicates that this ‘disconnect’ is a common relationship pattern that can develop in parents raising a child with a disability (Morgan, 1988; Seligman & Darling, 2007). That is, one parent withdraws (physically, emotionally, or psychologically) from the FS when feeling overwhelmed, leaving the other parent with a greater burden of care, which results in them ‘overfunctioning’ in their parenting roles (Morgan, 1988; Seligman & Darling, 2007). Research indicates that mothers of children with ASD who work may be particularly vulnerable to ‘overfunctioning’ in their parenting roles (Smith et al., 2010).

Inherent to understanding family roles within a FS framework is the recognition that families are fluid systems, and thus able to change. The dynamics of a negatively functioning FS do not have to stay static; rather they can change into a more positively functioning system for all family members. Identifying common patterns in functioning in families living with ASD may guide the development of clinical interventions to assist families in developing positively a functioning FS. Findings from this study indicate that fair dispersion of roles is an important component of family functioning. From this, a useful component of clinical interventions may involve assessing the dispersion of

parenting roles and providing strategies to adjust the role distributions if deemed necessary by the family.

Positive and challenging aspects of parenting an adolescent with ASD

The main challenges of parenting an adolescent with ASD identified in this study were associated with puberty. More specifically, these included managing their son's strong emotions, increasing physical size, and bodily changes. Behavioural difficulties, such as temper tantrums, aggression, self-abusive behaviours, and impulsive self-stimulatory behaviours, have been identified as major challenges for parents of adolescents with ASD (Fong et al., 1993). Further, as in our sample, the adolescents' increasing physical size has been identified as a key factor leading to greater difficulty managing their behaviour (Fong et al., 1993). Consequently, some participants felt that they received more negative judgement by others with the increasing age of their son. This may be because society is less tolerant of socially inappropriate behaviour displayed by an adolescent compared to a younger child.

Despite the many challenges of parenting an adolescent with ASD, some parents mentioned positive aspects, such as humorous incidents and sharing of affection. Additionally, the majority of parents conveyed accepting, and at times positive, attitudes towards being the parent of an individual with ASD. These adaptive attitudes appeared to be facilitated by a greater understanding of ASD, positive construal of challenges, and recognition of positive aspects of ASD in general. In line with this, the literature acknowledges a positive shift in parents' attitudes towards having a child with ASD that often occurs over time (Altiere & von Kluge, 2009; Fong et al., 1993; Hines, Balandin, & Togher, 2012). Despite these positive attitudes, the majority of the interviews were dominated by discussion of the challenging aspects of parenting an adolescent with ASD.

Related to this, parents discussed an ongoing process of adjustment, which some referred to as ‘grieving’, associated with being the parent of an individual with ASD. In the literature, this experience has been referred to as Ambiguous Loss, which is complicated or unclear loss occurring when a person is physically present yet psychologically absent or different (Boss, 1999, 2004; O’Brien, 2007). Ambiguous Loss has been acknowledged to occur in some families living with ASD during the diagnostic process (Cridland, Jones, Magee, & Caputi, 2013; O’Brien, 2007; Solomon & Chung, 2012). However, to our knowledge, Ambiguous Loss has not been recognised to continue into adolescence.

We posit that the experience of Ambiguous Loss may be an ongoing process for families living with ASD and may re-emerge as new developmental periods uncover new issues to be processed. In our sample, issues to be processed inherent to adolescence included coping with the psychological and physical demands of adolescence, such as puberty related issues, and uncertainty about how to best support their adolescent into adulthood. Importantly, we posit that the re-emergence of feelings of Ambiguous Loss during this adolescence may limit parents’ opportunities to acknowledge the positive aspects of ASD during this period.

Coping strategies used by parents of adolescents with ASD

A range of coping strategies were discussed by parents, including having time to themselves, spending time with their partner, confiding in their partner or significant other, and attending ASD support groups. Most parents discussed using a range of coping strategies, even if they identified relying more on some strategies over others. This finding is in line with literature which proposes that different coping strategies provide different types of support. More specifically, spousal support is considered to provide emotional and practical assistance (Altiere & von Kluge, 2009; Fong et al., 1993; Heiman & Berger,

2007; Rao & Beidel, 2009; Sivberg, 2002; Solomon & Chung, 2012; Weiss, 2002); whereas ASD support groups are said to provide formal (e.g., information), informal (e.g., friendship, emotional support), and practical (e.g., respite, financial services) support (Altieri & von Kluge, 2009; Luther, Canham, & Cureton, 2005; Phelps et al., 2009; Rivers & Stoneman, 2003; Seligman & Darling, 2007).

The coping strategies identified by participants are consistent with the common strategies recognised in the research literature by parents of younger children with ASD (Bradford, 2010; Gupta & Singhal, 2005; Higgins, Bailey, & Pearce, 2005; Luther et al., 2005). However, the findings of this study may be considered pertinent because they establish that parents of adolescents with ASD also find these common coping strategies useful; findings which have previously not been recognised. For example, Beresford (1994) posited that the importance of support groups may decrease with the increasing age of the child with ASD because parents develop greater understanding of ASD over time. The results of this study, however, indicate that support groups remain an important coping strategy for parents with adolescent children with ASD.

Despite the range of strategies identified by parents, some parents reported feeling guilty for adopting coping strategies (such as taking time for themselves) because they felt these activities decreased their availability to complete parental or work responsibilities. Solomon and Chung (2012) state that parental feelings of guilt when undertaking self-care activities are common in parents of children with ASD; they highlight the need for clinicians to coach parents into participating in self-care activities in order to reduce carer fatigue and increase resilience and general wellbeing. The increased opportunities to leave their adolescent with ASD at home, as discussed by parents in this study, may be used as a factor to coach parents into participating in coping strategies.

6.7 Strengths and limitations

A primary strength of this study was the involvement of multiple family members, including mothers, fathers, and adolescent children within a FS framework. This inclusive aspect of the methodology allowed for a multifaceted investigation, which is suitable for increasing our understanding of complex family issues (Bayat, 2007; Dew et al., 2008; King et al., 2006). The use of a qualitative methodology may also be considered a strength of the study, as there is currently a dearth of literature incorporating the direct perspectives of individuals with ASD and their families (Carrington, Templeton, & Papinczak, 2003; Cridland et al., 2013; Fong, Wilgosh, & Sobsey, 1993; Vliem, 2009). However, future investigations may benefit from utilizing mixed method approaches in order to quantify some of the findings of this study, such as the relative proportion of parental time devoted to caring for their adolescent with ASD compared to a NTD adolescent.

This study utilised a homogeneous sample of two-parent families with both an adolescent son with ASD and a NTD adolescent. The sample was also relatively homogeneous in terms of racial and socio-economic backgrounds. Whilst the homogeneity of the sample may limit the generalizability of findings to other families (for example it is unclear how relevant the findings are for families with multiple adolescents with ASD, with a daughter with ASD, or for sole parent families), the benefits of the specific sample warrant its use. First, the specific sample allowed for the roles of parenting an adolescent with ASD to be recognised, which is not suited to a broad, large scale study (Ma, 2000; Potter & Hepburn, 2005). Second, parents in this sample were unique in their ability to reflect on the differing parenting roles required for both a NTD adolescent and an adolescent son with ASD.

6.8 Conclusion

Understanding of the unique issues for parents of adolescents with ASD is critical for providing effective clinical support services (Nealy, O'Hare, Powers, & Swick, 2012). The results of this study suggest many possible directions for such services, including assessment of roles and their impact on family functioning, psycho-education for families with prepubescent sons with ASD regarding common adolescent-related challenges, strengths based programs to facilitate greater recognition of the positive aspects of ASD, and the importance of both formal and informal social supports for parents of adolescents with ASD. The most efficacious clinical support services are likely to have an integrative approach which allows for the complex interrelations amongst issues within the FS to be recognised (Solomon & Chung, 2012).

6.9 References

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CHAPTER 7: FAMILIES LIVING WITH AUTISM SPECTRUM DISORDER: ROLES AND RESPONSIBILITIES OF ADOLESCENT SISTERS

Cridland, E.K., Jones, S.C., Stoyles, G., Caputi, P., & Magee, C.A. (accepted November 2014). Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. *Focus on Autism and Other Developmental Disabilities*.

7.1 Abstract

There is currently a limited understanding of adolescent sibling relationships where an Autism Spectrum Disorder (ASD) is present. This research gap remains despite preliminary findings suggesting that neurotypically developing (NTD) siblings undertake extra care-giving responsibilities and experience differential treatment from family members. Using a Family Systems approach, this qualitative study investigated NTD adolescent sisters' roles and responsibilities for their younger adolescent brother with ASD from the perspectives of 11 family members (including NTD sisters, brothers with ASD, mothers, and fathers). Findings indicate the sisters undertook various care-giving roles and responsibilities, particularly at school, which had both positive and negative influences on the family system. Additionally, sisters perceived they undertook unfair household responsibilities, received reduced parental attention, and desired both distance from and engagement with their families. These perceptions varied amongst other family members. Implications of these findings and potential strategies for best supporting adolescent NTD siblings are discussed.

Families Living with Autism Spectrum Disorder: Roles and Responsibilities of Adolescent Sisters

7.2 Introduction

Each family has its own pattern of functioning; with varying degrees of emotional closeness, cognitive engagement, physical health habits, social connectedness, communication styles, and expectations of others (Bowen, 1995; Bowen & Kerr, 1988; Carrillo, 2012). Each family also has a unique distribution of family roles and responsibilities amongst its members (Bowen, 1995; Whitchurch & Constantine, 1993). Despite this heterogeneity, there are common factors regarding the functioning of roles and responsibilities inherent to most family systems (FS). For example, roles considered necessary for most families include provision of emotional, financial, and practical supports (Becvar & Becvar, 1982; Bowen & Kerr, 1988; Carter & McGoldrick, 1980). Additionally, in most families, parents undertake greater caregiving and household responsibilities than children (Bowen, 1995; Francis, 2001). There are also various elements by which the functioning of roles and responsibilities are generally evaluated, such as the degree to which family members consider the distribution of roles and responsibilities to be fair, the level of flexibility in role distribution given changes in the FS, and level of clarity about the requirements of each role (Davis & Gavidia-Payne, 2009; Whitchurch & Constantine, 1993).

A range of factors can influence the functioning of roles and responsibilities in a FS, such as disability, chronic illness, parenting style, family dynamics, and culture (Bowen, 1995; Ferrari & Sussman, 1987; Seligman & Darling, 2007). For families living with

Autism Spectrum Disorder¹⁶ (ASD), family roles and responsibilities may be influenced by the increased time-demands required for basic caregiving duties for the individual with ASD, such as meal preparation, toileting, and hygiene routines. Further caregiving duties include increased working hours due to financial costs of ASD related services and increased travel times required for specialty education and vocational services (Attwood, 2007; Heiman & Berger, 2007; Macks & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005). Given the pervasive influence FS having a family member with ASD has on the FS, these families can be referred to as families living with ASD (Cridland, Jones, Magee, & Caputi, 2013; Neely-Barnes, Hall, Roberts, & Graff, 2011).

Regarding the roles and responsibilities undertaken by neurotypically developing (NTD) siblings in families living with ASD, research indicates these individuals often undertake significant care-giving responsibilities and in-turn receive reduced parental support (Benderix, & Sivberg, 2007; Carrillo, 2012; Dellve, Cernerud, & Hallberg, 2000; Dyson, 1999). This pattern of role functioning has been referred to as ‘parentification’ (Bowen, 1995), and is considered to be particularly prone for older siblings in families living with ASD (Morgan, 1988; Seligman & Darling, 2007). Reasons contributing to siblings of individuals with ASD undertaking parentified roles may include siblings’ heightened awareness of the care-giving demands placed on parents, as well as siblings’ increased capability of undertaking greater household duties (Benderix & Sivberg, 2007; Seligman & Darling, 2007).

The impact of these roles and responsibilities on siblings’ wellbeing remains inconclusive; with some research reporting negative effects (Macks & Reeve, 2007; Orsmond & Seltzer, 2007, 2009; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009;

¹⁶ Individuals with ASD experience persistent deficits in social communication and social interaction, and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, [APA], 2013).

Schuntermann, 2009). Other research indicates no negative effects (Kaminsky & Dewey, 2001, 2002; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Still further research suggests that level of understanding and acceptance of ASD may mediate the influence of additional caretaking duties (Carrillo, 2012; Dellve et al., 2000; Moyson & Roeyers, 2012). For example, Dellve et al. (2000) reported that, despite significant caregiving demands, the majority of adolescent siblings described a sense of responsibility toward their brother which had developed due to an increased level of understanding and acceptance of their brother's condition. Similarly, a retrospective study of NTD adult siblings reported that 50% of siblings identified positive influences of having a brother with ASD which were not recognised during childhood (Carrillo, 2012). Strong peer friendships may be another mediating factor facilitating positive coping in siblings during adolescence (Macks & Reeve, 2007; Orsmond & Seltzer, 2007).

There are several reasons warranting investigation of the roles and responsibilities undertaken by NTD adolescent siblings who have an adolescent sibling with ASD. First, the majority of existing research has focused on childhood samples (Carrillo, 2012; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Vliem, 2009), despite consensus that sibling roles and responsibilities change from childhood to adolescence (Fulmer, Medalie, & Lord, 1982; Henry, 1994; Turnbull, Summers, & Brotherson, 1984). Second, research has investigated sibling experiences at school and home separately (Benderix & Sivberg, 2007; Hodapp, Glidden, & Kaiser, 2005; Kaminsky & Dewey, 2001; Mascha & Boucher, 2006; Moyson & Roeyers, 2012). However, to our knowledge, no research has considered these domains in conjunction with each other. Third, it remains unclear how to best support adolescent NTD siblings of individuals with ASD (Petalas et al., 2012; Vliem, 2009), particularly regarding the caregiving roles they provide for their sibling with ASD. This

study aims to investigate ways to support these individuals, from the perspectives of the adolescent NTD siblings themselves, and their families.

The present study investigates the experiences of adolescent girls with a younger, adolescent brother with ASD, paying particular attention to the roles and responsibilities they undertake at school and home. Based on the existing literature, it is expected that NTD adolescent sisters will undertake a range of family roles and responsibilities, which may indicate elements of parentification¹⁷. Further, it is anticipated that some of these roles will be associated specifically with their brother with ASD. Moreover, it is anticipated that roles will be undertaken both at home and school. However, given the dearth of literature considering sibling roles at home and school, the way both roles interact is unknown.

This study further investigates adolescent sisters' roles from the perspectives of multiple family members, in order to gain a multifaceted and holistic understanding of family functioning. Based on previous literature, it is hypothesised that the perceptions of family members will vary (Guite, Lobato, Kao, & Plante, 2004; Phelps, McCammon, Wuensch, & Golden, 2009b; Smith et al., 2010). However, the nature and extent to which family members' perspectives vary, regarding adolescent sisters' family roles and responsibilities, remains unclear.

7.2 Method

Sample

A specific sample was recruited in recognition of the influence of sample characteristics on research findings (Kaminsky & Dewey, 2002; Meadon & Stoner, 2010; Orsmond & Seltzer, 2007; Rao & Beidel, 2009). More specifically, participants included NTD adolescent sisters, adolescent brothers with ASD, mothers, and fathers.

¹⁷ Research hypotheses are alternatively worded as research aims in Appendix V, Section 4.

Eligibility criteria for the NTD sibling included being female, attending mainstream schooling in Grades 8-11 (age range 12-17 years), and being older than their brother with ASD. The rationale for focusing specifically on sisters who were older than their sibling was based on preliminary research indicating siblings who are female and older than their sibling with ASD may be particularly vulnerable to undertaking parentified roles and may experience higher emotional sensitivity and social isolation (Hastings, 2003; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Orsmond & Seltzer, 2009; Stoneman, 2005; Verte, Roeyers, & Buysse, 2003).

Eligibility criteria for the brother with ASD included having a formal diagnosis of ASD¹⁸, attending mainstream schooling in Grades 7-10 and being the only family member with a formal ASD diagnosis. The rationale for focusing on brothers with ASD was based on the current predominance of males diagnosed with ASD (Holtmann, Bölte, & Poustka, 2007; Krahn, & Fenton, 2012) and previous recommendations to acknowledge the influence of gender on research findings (Card, Stucky, Sawalani, & Little, 2008; Cridland, Jones, Caputi, & Magee, 2014a; Hsiao, Tseng, Huang, & Gau, 2013).

Other eligibility criteria included families with two parents who identified themselves as the primary caregivers, all family members living at home a minimum of five days per week, and all family members having knowledge of the ASD diagnosis. The final sample consisted of 11 participants from three families (three adolescent with ASD, three NTD adolescent sisters, three mothers, and two fathers). More detailed demographic information is presented in Table 7.1.

¹⁸ All participants had received a formal diagnosis of Asperger's Syndrome from either a paediatrician or psychologist based on ASD criteria in the DSM-IV (APA, 2000). Given the classification changes in the DSM-V (APA, 2013), these diagnoses are referred to here as ASD.

Table 7.1: *Demographic information*

Family number	Individual with ASD ^a age / school Grade	NTD ^b sister age / school Grade	Parent interviewed	Family Ethnicity	Annual Household income
1	Age 15 / 9 th Grade mainstream classes	Age 17 / 11 th Grade mainstream classes	Mother and Father	Australian	\$60000
2	Age 15 / 9 th Grade mainstream classes with ASD support unit	Age 16 / 10 th Grade mainstream classes	Mother and Father	Australian/Irish	\$80000
3	Age 13 / 7 th Grade mainstream classes with ASD support unit	Age 16 / 10 th Grade mainstream classes	Mother	Australian	\$40000

^a Autism Spectrum Disorder ^b Neurotypically developing

Procedure

Ethical approval was granted by the University's Human Research Ethics Committee (Appendix L) prior to commencing the participant recruitment process. Participants were recruited through local secondary schools and community groups. The broad research aims were explained to eligible participants in an information sheet (Appendix M) and an introductory meeting with the first author. Following ethical standards for research with children, written consent (Appendix N) was obtained from both the participants and their parents. More specifically, following guidelines for conducting qualitative research with individuals with ASD and their families (Cridland, Jones, Caputi, & Magee, 2014b [Appendix A]), it was not a requirement for all family members to provide consent in order for the family to be eligible for the study. This criterion was put in place to reduce the possibility of some family members feeling pressured to provide consent (Cridland et al., 2014b).

The first author conducted the interviews. The interviews were conducted following recommendations outlined in Cridland et al (2014b). These recommendations included conducting interviews with individual participants in a private space within the family home (e.g., study or quiet living area), conducting interviews at a preferred time for participants, and conducting interviews at an appropriate pace to facilitate accurate interpretation of interview questions (Cridland et al, 2014b). Interviews lasted for an approximate average of 60 minutes (range 40-150 minutes). Interviews were audio recorded for transcription.

Instrument

An interview guide was developed based on a review of the literature and through multiple discussions with the authors. Based on research recommendations (Cridland et al.,

2014b), the interview guide was pilot tested on one family who met the research eligibility criteria¹⁹. Minor wording changes to questions resulted from pilot testing.

The interview included several ‘warm-up’ questions (related to hobbies and interests) aiming to relax the participants and increase rapport with the interviewer (Cridland et al., 2014b). Rather than focusing directly on family roles and responsibilities, questions were generally related to experiences of being/having an adolescent family member with ASD. Questions were designed to elicit both positive and negative experiences, attitudes, and feelings. In order to investigate participants’ perceptions about other family members’ experiences, we asked a range of socio-emotional inference questions, which assessed an individual’s understanding of another’s experience (Artar, 2007), such as ‘How do you think they felt?’. There was also scope for flexibility in topics that were discussed, as well as follow-up questions to encourage elaboration. Before concluding the interview, participants were encouraged to raise any additional topics that they felt were important in understanding their experiences. For sample interview questions see Appendix O.

Data Analysis

NVivo (QSR International, 2012), a qualitative data management program, was used to manage the data. The data were analysed following the inductive coding process outlined by Braun and Clarke (2006). This process included familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final coding of themes (Braun & Clarke, 2006)²⁰. A formal measure of inter-rater agreement was not employed. Rather the process involved

¹⁹ The family involved in pilot testing was not included in the final sample.

²⁰ Additional information outlining data analysis procedures including thematic coding procedures and data integrity and credibility strategies employed are elaborated in Appendix V, Section 5.

one member of the research team and one independent checker reading all transcripts with the potential themes identified by the first author. No major changes to the themes identified by the primary researcher were identified as being necessary by either member check. Following the procedure outlined by Braun and Clarke (2006), a final consultation with the research team followed to discuss specific theme descriptions and selection of most relevant quotes

7.4 Results

Four key themes emerged from the process of data analysis described above. The themes were roles at school, roles at home, tension between engagement and distancing with the family system, and adolescent adjustment to having a brother with ASD. Direct quotations are presented in indented paragraphs, in which square brackets ([]) indicate information added by the primary researcher for clarification and ellipses (...) indicate material omitted for conciseness. For purposes of confidentiality, all names have been changed.

Roles at school

This theme captured participants' beliefs about the unique roles that the sisters had become involved in for their younger brother at secondary school. Overall, the roles involved advocating for their brother with teachers and peers. Various terms were used among the family members to describe these roles including; "big sister", "mother-hen", "maternal", "protector" and "body guard". The following quote summarises the nature of this role from the perception of one mother:

"She's very protective... a bit of a mother-hen with Jayden... She's very maternal but like it's a funny word to use with siblings but it's the only word I can think of. She's very loving and her protectiveness with Jayden is something she's had to do all the way through her life... because she thinks that's her role." (Mother, Family 2)

More specifically, one of the roles undertaken at school involved liaising with teachers about issues concerning their brothers. The responsibilities of this role encompassed educating teachers about ASD, passing messages between teachers and parents, and managing miscommunications on behalf of their brother. Eight participants discussed this role:

“Well, lots of teachers always come to me because they all don’t know, when they should know, that he is Autistic. One time he went to say something to a teacher but he said to her that she looked arousing. And she came to me and I said that I was positive that he doesn’t even know what that word means but has just heard it somewhere and said it as being nice. It’s hard to explain to a teacher because they never really get it as someone who hasn’t had the same opportunity to feel it.” (Sister, Family 2)

“...she’s always got teachers coming to her asking and wanting to know why something hasn’t been done or where is he [or] what’s happening at the moment? She’s always been bombarded with questions like that through school.... it’s a real big sister kind of thing but she’s only 18 months older than him so it’s pretty hard I imagine. Like she’s always coming home and sort of saying, ‘Aw the teachers said such and such’ and ‘This teacher wants to know this or that’...” (Father, Family 2)

The other role at school discussed by participants ($n=7$) involved dealing with other students. A major responsibility of this role involved protecting their brother from bullies and educating their brother about how to deal with other students:

“...if there’s a problem then I will go sort it out with him, not for him but with him so that he understands how to deal with the problem... I do like it because it is kind of saying, ‘Hey step back, that’s my brother you’re messing with’.” (Sister, Family 3)

“...being at school makes it hard for me because people are always like, ‘What’s the go with your brother?’ And I’m just like, ‘Leave him alone he has Autism, he just doesn’t understand.’ It’s just hard... it makes me sad.” (Sister, Family 2)

“...She would never stand there and watch anybody get teased or bullied without saying something but in particular Jayden, she would well and truly step in. I suppose she has a good morality about those sort of things but maybe not the best way of executing it at the same time.” (Mother, Family 2)

Another responsibility of dealing with other student undertaken by the sisters was educating other students about ASD:

“Like at the start of the year everyone was saying like ‘You’re Robert’s sister, he’s a bit weird’ and I would go, ‘Yeah you know what, he has Autism’ and that’s when they would ask me what it is and I’d tell them and then they’d be like, ‘Oh, I didn’t know that’ and then they would stop saying what they were saying. So they have to understand and that makes me feel good.” (Sister, Family 3)

As evident in participants’ comments, there were mixed attitudes about being associated with these roles at school. The majority of family members ($n=7$) discussed both positive and negative impacts on the sisters, resulting in some ambiguity about the roles. The positive impacts included feeling good about themselves, being able to help their brother, and being able to help others both understand their brother and ASD:

“[Explaining ASD to other students means] they wouldn’t tease him... so that would be helping me and making me feel better and makes me not think so much about the bad things.” (Sister, Family 1)

“It makes her feel really good because, as I said, she has this mother-hen-type personality and it does make her feel like she has a role I suppose. It makes her feel important to somebody, to him, to me. It makes her feel she has the role as the big sister, the protector.” (Mother, Family 2)

The main negative impact discussed by the sisters was that although they were undertaking a care-giving role, their brothers often did not listen to them:

“[Sometimes when I try to help him he] just doesn’t listen and does it anyway and it gets me more annoyed and frustrated.” (Sister, Family 3)

“At school there were boys asking him for money [and]... I got frustrated with him because he kept doing it even after I told him it was a scam. I’d have to go stand with my brother to make sure he didn’t give him any more money... it feels upsetting that people would try to use my brother and make him vulnerable.” (Sister, Family 1)

Negative impacts of the sisters' roles at school recognised by other family members included the sisters feeling burnt-out and having to cope with the negative consequences of trying to help:

"[Sometimes when she tries] to help him he'll do nasty things to her like call her names to make other people laugh.... He doesn't understand that people are laughing at him and not with him... She knows why he does what he does and she still helps... [So] as much as that's a good thing I feel that can also be a bit of a burden... [and] I also feel a little bit sad for her that she feels like she needs to take on that role of having to watch him. She's always having to watch him and be aware of what's going on and having to fix something. So it is a bit of a burden as well." (Mother, Family 2)

"She's over it but she knows to answer the [teachers'] questions if she can... She knows not to just ignore them or just go, 'I don't know'.... I feel pretty proud that she can do it and that she deals with it but still it's a pretty heavy responsibility really and also not knowing if she should say this or shouldn't. So it can be a bit of a burden for her." (Father, Family 2)

Interestingly, all of the brothers ($n=3$) said they were unsure of whether their sisters looked after them at school:

"I don't know in that department [if my sister helps me] because I'm not always around her and she's not always around me.... I don't really remember getting myself into a situation and going to her [for help]." (Brother, Family 1)

The sisters differed in their perceptions regarding the awareness that their brothers had about the things they did to help their brothers at school, ranging from feeling appreciative to not being aware:

"He does feel grateful; he just shows it in his own way." (Sister, Family 3)

"I don't think he ever really takes much notice of me." (Sister, Family 2)

In summary, the sisters played various roles for their brother at school including advocating for their brother with teachers and peers, liaising between the teachers and their

parents, managing miscommunications; protecting their brother from bullies, and educating their brother about how to deal with other students. Overall there were mixed attitudes about undertaking these roles, resulting in some ambiguity about the responsibilities.

Roles at home

This theme captured participants' beliefs about the roles undertaken by the sisters at home. All the sisters ($n=3$) perceived that they were responsible for a greater amount of household duties compared to their brothers. At other times they recognised valid reasons for this increased responsibility; other times they felt the job distributions were unfair:

"[Sometimes the job distributions are not fair because my brother] could have been playing on the PlayStation all day and I could have put the dishes away and vacuumed and then Mum could say, 'Oh Hannah and you help me chop up the food for dinner?' And I could be like, 'Why don't you ask him to do it? I've just done all this...' And then they get a bit angry at me.... I've felt like that so many times.... I really don't know what the reason is because [he is] quite capable of doing the things that I do... so I don't understand why they ask me to do it and not share it out evenly." (Sister, Family 1)

"Jayden doesn't do much at all... I think I do more than Jayden all the time because he never comes up from his room. [Also] if we need to get ready for something, half the time I will have to pick him out clothes because he can't really do it." (Sister, Family 2)

"Robert does nothing, he gets in a fight with Mum when she asks him to do something and she always gives in because of his anger. [But] I don't mind, I would rather do more than him get angry which is what happens anyway." (Sister, Family 3)

The sisters' perceptions were not echoed by all the parents, with only one parent recognising that she often asked her daughter to do more household chores than her son:

"[My son with ASD will] do whatever I ask him to do, not a problem. In fact, like one time I was like, 'Matthew can you bring the washing in?' And he was like, 'Oh, it's already in Mum', and I was like 'Oh! Ok' So yeah he'll do whatever I ask him to... [But] I probably do get Hannah to do more..." (Mother, Family 1)

“[She] is messy. She will do things if she gets paid, and then she’ll only do a half-hearted job.” (Mother, Family 2)

“[My son with ASD] empties the garbage bin, if I ask him to wash up he would, if I asked him to clean something up he would, he’s done washing, he’s done cooking. Christie is the total opposite. She does nothing. She’s a teenager and a girl... I would say I do the most [around the house] and Christie would do the least.” (Mother, Family 3)

One of the mothers reflected on the differing roles that her daughter undertakes for her brother when at home compared to school. More specifically, she felt her daughter did not continue the protective role at home. She attributed this change to her daughter perceiving her brother to be safer at home compared to school, and feeling tired from the caregiving role undertaken at school:

“At home she can put him in his place. She will tell him where to go, whereas at school she would never really do that... She will say things here [at home] that she probably wouldn’t at school because she knows she wouldn’t want to upset him at school because he doesn’t have any safe zone. Whereas at home she knows he will just go back down to his room and do his thing and that’s ok...[After school] I think she’s ready to not be the big sister. I think she just wants to relax.” (Mother, Family 2)

In summary, the participants perceived that the various caregiving responsibilities undertaken by the sisters for their brother at school were not continued at home. However, the sisters perceived that they were responsible for a greater amount of general household duties compared to their brother. Notably, the majority of parents did not agree with this perception.

Tension between engagement and distancing with the family system

This theme captured the sisters’ discussions about a conflicting desire for both engagement and distance within their family. All sisters ($n=3$) described cherishing quality

family time and explained that the importance of this time continued even as they were getting older. In addition, sisters discussed the ways their family time was impacted by the interests and mood of their brother with ASD:

“We were all mucking around last night and it was pretty fun because we got to sit down and talk with the whole family without fighting, so that was a good night.... We would have plenty more nights like that if he didn’t act the way he does. Like being angry and a sticky-beak.” (Sister, Family 3)

“If Matthew doesn’t like it [the family activity] then he would be grumpy and sulky the whole time and that’s just too difficult for Mum and Dad to deal with. So they like to generally pick something that he would like...” (Sister, Family 1)

Of particular importance to the sisters was having quality one-on-one time with their parents. All the sisters said they valued time spent alone with their parents and discussed how this need continued even as they grew older:

“I like to do anything with Mum. I like driving with Mum and visiting her at school when she’s on canteen. I like going shopping with Mum and just having her to myself basically. I really like one-on-one time with her.... [And] I like to spend time with Dad. I like to be at home with just Dad. Like if he picks me up from school if I’m sick or something and I’m at home with just Dad.” (Sister, Family 1)

“I like to go and have a coffee with her and just talk... I just like to talk and talk and talk with her- just me and her time.” (Sister, Family 3)

In addition to cherishing time with family, all sisters ($n=3$) described experiencing a conflicting desire to distance themselves from the FS:

“I do like to hang out with my friends and boyfriend. I also like to spend time with my family, but not as much as before.” (Sister, family 1)

In summary, the sisters all described experiencing tension between desiring to both distance and engage themselves with the FS. In particular, the sisters discussed the

importance of having quality one-on-one time with their parents and indicated that the opportunities to do so were sometimes limited by living in a family with ASD.

Adolescent adjustment to having a brother with ASD

This theme captured participants' discussions about the adjustments the sisters' needed to make in having a brother with ASD during adolescence. More specifically, family members were asked whether the sisters' perception of having a brother with ASD had changed since they were in elementary school. The most frequent response ($n=7$) was that the sisters had acquired more knowledge about ASD, which had contributed to them being more understanding of their brother:

"In primary [elementary] school I just pretty much knew that Matthew was different and that's about it. I had no knowledge of Asperger's whatsoever. So it's so different now... I just am more understanding of what he is like and what the best thing to do about it is, how to converse with him more and what he likes and doesn't like." (Sister, Family 1)

"...when he was first diagnosed... I just didn't really get it because I was too young. Now that I've gotten older I understand it more." (Sister, Family2)

The increased understanding of their brother was also perceived to make the sisters more understanding of others in general:

"I think it makes her realise that people are different and ... that you have to have patience to deal with different people." (Father, Family 1)

Overall, sisters displayed resilience to the challenges of being an adolescent sister of an individual with ASD. This resilience was evident in various ways, such as positive meaning making, normalisation, and acceptance:

"To me he's normal because I've just grown up with it... I couldn't imagine Matthew any other way really... I'm just glad he's like this because it makes it different, like a different way of growing up. It's

good... But in everything else I guess I'm just your average teenager."
(Sister, Family 1)

"It makes me understand a lot more about him and Autism. It gives me a challenge... I think challenges are here to test you on how you react to it. And Robert sets challenges for me, definitely!" (Sister, Family 3)

In addition to the positive aspects, all sisters ($n=3$) discussed difficulties with having an adolescent brother with ASD. These difficulties included feeling their brother received special treatment (e.g., more allowances regarding food), challenges associated with their brother not following social conventions (e.g., volume of speech), and their brother's rigidity (e.g., minimal flexibility when following rules to a game). However, the most frequently discussed negative impact was a perceived reduction in attention from parents. This impact was of high importance to the sisters, given the significant value they placed on time spent with parents, as discussed earlier. All the sisters ($n=3$) discussed reduced attention from parents. However, the level of acceptance and reasons attributed to it varied:

"[When he was diagnosed I felt] confused and angry because no one would focus on me, it was all about him... [I thought that would change but] it has just stayed like that... It sucks a lot of the attention [meaning] no-one is really there for me. No-one really pays attention to me... and I feel like it has gotten harder since he has gotten older."
(Sister, Family 2)

"...he gets a lot more attention, like if Mum and I are sitting and talking he will come in and Mum will lose track of what we are talking about and focuses on him. Rather than ignoring him and focusing on me and her." (Sister, Family 3)

The sisters discussed multiple strategies they use to help them manage the challenges of having an adolescent brother with ASD. These strategies primarily included getting practical and emotional support from family (generally their Mother) and close friends:

"I go to Mum, I tell Mum because then she'll do something about it. Like I've felt like that before [when I've had issues at school with my brother] and I've just told Mum about it and she has mentioned it to the school... [but] sometimes Mum is the cause of my frustration so I go to my best-friend and I just tell her about everything... and I just

say, 'I can't deal with this'... They pretty much help just by listening.' (Sister, Family 1)

None of the sisters discussed seeking formal support as a strategy they had used previously. However, two sisters described a desire to have someone separate from their family to talk freely with about the challenges of having an adolescent brother with ASD:

"[It would be helpful for] someone to be there who wouldn't get angry or judge me for wanting to talk about it and for wishing that he doesn't have it [ASD]." (Sister, Family 2)

In summary, the majority of sisters said that over time they had developed more knowledge about ASD and were more understanding of their brother. Further, whilst many challenges of being an adolescent sister of an individual with ASD were discussed, resilience was also evident through positive meaning making, normalisation, and acceptance.

7.5 Discussion

To our knowledge, this is the first study to investigate family roles and responsibilities undertaken by NTD adolescent sisters for their brother with ASD at home and school. The study used a qualitative approach and involved various family members, including adolescents with ASD, permitting an in-depth and multidimensional investigation. Based on available literature, it was hypothesised that sisters would undertake a range of caregiving roles and responsibilities at both school and home. Additionally, it was hypothesised that perceptions about these roles and responsibilities would vary amongst family members. Both hypotheses were supported in the interviews. The key findings are considered below in the context of existing literature, followed by discussion of potential strategies for supporting NTD adolescent siblings in families living with ASD.

Findings indicated the sisters undertook various responsibilities for their brother at school. In line with existing research, the sisters reported that these responsibilities had become more prominent as they grew older and, in particular, when their brother entered secondary school (Benderix & Sivberg, 2007; Dellve et al., 2000; Dyson, 1999).

Participants described a range of mixed feelings and experiences related to these roles. The main positive aspect involved experiencing feeling good about helping their brother and others. However, the sisters also reported feeling burnt-out from responsibilities, receiving limited appreciation from their brothers, and experiencing occasional negative outcomes of helping (e.g., receiving criticism for attempting to help). These mixed feelings about sibling care-giving roles are echoed in existing literature (Benderix & Sivberg, 2007; Dellve et al., 2000).

Regarding roles at home, all sisters perceived that they were responsible for a greater amount of household duties compared to their brothers, while the majority of parents' views were in direct contrast to this. These differing perceptions may be attributed to higher parental expectations placed on the daughters as more complex tasks seemed to be expected of the daughters. In line with this, many parents felt that it was natural for the sisters to undertake significant caregiving responsibilities, with one mother even commenting that it was in her daughter's nature to be a 'mother-hen'.

Whilst it is natural for adolescent siblings to participate in caregiving roles and responsibilities, the range and degree of caregiving roles undertaken by participating siblings may impact negatively on the siblings and the FS. Such negative impacts may include role confusion (Cridland, Jones, Magee, & Caputi, 2013; Smith, 2000), restriction of healthy adolescent individuation from the FS (Dyson, 1999), and less positive sibling interactions (Schuntermann, 2007, 2009). In other words, siblings who undertake parentified roles may find it difficult to form a sense of self autonomous to their roles

within the FS, and as a result develop resentment towards other family members (Bagenholm & Gillberg, 1991; Nealy, O'Hare, Powers, & Swick, 2012).

Parentified roles undertaken by the siblings were also evidenced in some of the varying opinions between family members. For example, the parents overall were not aware of their daughters' desire for parental support, their value of family time, or their perceptions of unfair role dispersion. These findings highlight the need for open communication between adolescent children and their parents, and challenge the assumption that all adolescents strive for independence and reduced familial support (Field & Hoffman, 1999). Moreover, the findings indicate that parental attention and support for adolescent siblings of individuals with ASD may be critical during adolescence given the greater care-giving responsibilities undertaken during this period.

Another major finding was that the sisters' understanding and acceptance of their brother's ASD had increased over time (Carrillo, 2012; Dellve et al., 2000; Howlin, 1988; Moyson & Roeyers, 2012). Existing literature posits that this increased acceptance may contribute to the siblings' adoption of greater caregiving responsibilities (Dellve et al., 2000). Alternatively, the increased involvement in caregiving roles over time may facilitate understanding and accepting attitudes towards their brother. The direction of this relationship remains unclear from the current findings and warrants further investigation.

Supporting NTD adolescent siblings

It is important to recognise ways to best support NTD adolescent siblings given the impacts of the caregiving roles and responsibilities undertaken during this period. The family is generally considered the primary sources of support for children, including adolescents, in families living with ASD (Moyson & Roeyers, 2012). However, family may not meet all of the adolescents' needs as siblings may perceive parents as having

limited time to listen to them, or feel guilty about asking for help given their siblings' significant support needs (Moyson & Roeyers, 2012; Pinkerton & Dolan, 2007).

In these circumstances, formal support services are likely to be beneficial. Clinicians can help adolescent siblings in various ways by; providing information about ASD, facilitating strategies to manage challenges, and providing opportunities for siblings to talk freely about their feelings and experiences (Bradford, 2010). This latter role may be especially important during adolescence, given the range of major physical, emotional and social changes during this developmental period, coupled with ambiguous feelings of protection, resentment, guilt and love that they may experience towards their sibling with ASD (Howlin, 1988; Pinkerton & Dolan, 2007). Further, clinical support may help siblings make sense of possible tension between their roles as 'sibling', 'daughter', 'care-giver', and 'adolescent individual' within their FS. In doing so, clinical support may play an important role in awareness raising and sense making of many of the experiences and feelings discussed by the sisters in this study.

Family Systems based therapy may be an effective method of delivering such clinical support. The benefits of such approaches are that under a 'whole system perspective' all individuals have the opportunity to receive individual support, in conjunction with dyad focused, as well as system focused support (Meadons & Stoner, 2010; Pinkerton & Dolan, 2007). Raising parental awareness of issues for their adolescent children may facilitate shifts in familial roles and responsibilities, and thus increase family functioning (Cridland et al., 2013).

Sibling social support groups are another avenue of support that have proven efficacious (Evans, Jones, & Mansell, 2001; Myers & Johnson, 2007; Smith, 2000). Such groups can provide similar opportunities as those offered by individual sessions with the benefit of connecting with other NTD siblings of individuals with ASD. Given the

importance of peer relationships during adolescence, social support services may be particularly beneficial (Pinkerton & Dolan, 2007; Schuntermann, 2007; Vliem, 2009). In line with this suggestion, several siblings in the present study recounted times in which their friends provided the emotional and practical support that their parents could not provide.

It is important to recognise, however, that adolescents may resist formal support services (Rickwood, Deane, Wilson, & Ciarrochi, 2005; Wilson, 2010; Wilson & Deane, 2011). Schuntermann (2009) outlined several reasons for adolescent siblings' resistance, including reluctance to access services that appear similar to those provided to their sibling with ASD, not asking for help in an attempt to reduce burden on their parents, perceiving their parents' expectations for them to be the 'healthy' child in the FS, becoming entrenched in parental roles marginalising their opportunity for support, and failing to recognise their own needs due to the salience of their sibling's needs. Given that none of the sisters in our study reported accessing formal support services, it is possible that they were experiencing some of these barriers. It is critical that families and clinicians are aware of such issues when attempting to provide support to adolescent NTD siblings. Further, it is important that clinicians acknowledge and communicate these unique experiences and potential needs of NTD siblings to the parents, rather than solely focusing on issues directly affecting the family member with ASD.

7.6 Strengths and limitations

This study presents various research strengths and limitations. First, the divergent, and at times conflicting, perspectives among family members regarding the roles of adolescent NTD siblings provides support for the use of multifaceted approaches when

conducting research in this field. Additionally, the qualitative approach permitted a detailed exploration of these issues.

However, it is necessary to interpret the findings with caution due to the small and specific sample as the findings may not be representative of all adolescent sisters who have adolescent brothers with ASD. Following from this caution, the pattern of functioning inherent to the families in this sample cannot be generalised to larger populations. There is a range of factors which may influence the findings such as family dynamics (e.g., size, ages, gender), family cohesiveness, cultural background, and presentation of ASD in the family member (Combrinck-Graham, 1990; Cridland et. al., 2013, 2014b). These factors are worthy of consideration in future investigations. The results nevertheless reflect the subjective views and perceptions of the family members that participated in this study, and may be reflective of other NTD adolescent siblings. In support of this outcome, the experiences discussed were largely consistent within the sample thereby increasing the validity and likely generalizability of the findings.

Findings should also be interpreted with the possibility that participants may have been ‘faking good’ in the interviews by focusing on positive outcomes of living in a family with ASD. In line with this possibility, there was a range of challenges highlighted in the literature that were not discussed by the participants, such as concerns regarding the increasing physical size of adolescent siblings with ASD (Benderix & Sivberg, 2007; Ross & Cuskelly, 2006), management of socially inappropriate self-stimulatory behaviours (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Murphy & Elias, 2006), and concern for their sibling’s future (Petalas et al., 2012). Whilst the lack of discussion may be indicative of the minimal relevance of these topics for these individuals, it is also possible these issues were not discussed due to a desire to portray an image of resilience or positivity.

7.7 Conclusion

This paper presents various themes emerging from discussions with adolescent NTD sisters and their families about their experiences of having a younger adolescent brother with ASD. Key findings were that the sisters undertook various roles and responsibilities both at school and home that influence sibling wellbeing and family functioning. There were both positive and negative experiences and emotions related to these roles and responsibilities, ranging from feeling proud and accepting to feeling frustrated and burdened. It is critical that we attempt to understand the experiences of these individuals and families in order to provide them with appropriate support.

7.8 References

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CHAPTER 8: A PERSONAL CONSTRUCTIVIST APPROACH FOR INVESTIGATING THE DEPENDENCY PATTERNS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: CASE STUDY OF THREE FAMILIES

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A., (under review). A personal constructivist approach for investigating adolescents' with Autism Spectrum Disorder patterns of dependency: Case study of three families. *Journal of Constructivist Psychology*.

8.1 Abstract

This research investigates the utility and practicality of dependency grids for capturing and presenting the dependency distribution patterns of three adolescents with Autism Spectrum Disorder. The investigation also involved family members to explore their level of awareness of the adolescents' dependency preferences. The grids were analysed using a range of measures including the Uncertainty Index and partial order scalogram analysis. Findings indicate the adolescents had various ways of dispersing their dependencies amongst their resources and differed in the types of support most utilised. Additionally, family members differed in their awareness of the adolescents' preferences. The benefits and drawbacks of the adolescents' dependency distribution patterns are discussed, as well as the implications of these patterns for family members. Ways in which dependency grids may be further utilised with this population in research and clinical contexts are also considered.

A personal constructivist approach for investigating the dependency patterns of adolescents with Autism Spectrum Disorder: Case study of three families

8.2 Introduction

Our dependence on others is evident across all stages of life, from infancy to senior years. Similarly, our dependencies cover all aspects of life, from the fundamental needs of food and shelter to the more complex desires of affection and friendship. Whilst the degree and nature of our dependencies may change over time, we remain integrally and complexly reliant on others throughout life.

The issue of interest when investigating an individual's dependency needs is their pattern of dependence on others. Based on a personal constructivist understanding, patterns of dependence may be understood to fall on a continuum ranging from undispersed to indiscriminate dependencies. Undispersed dependencies are characterised by restricted and inflexible constructions about available resources; whereby resources are rigidly perceived as either suitable or not suitable (Walker, 2005). Individuals with undispersed dependencies may attempt to have all of their needs met by a limited number of individuals (Walker, 2005). This style of dependence often leads to exhausting of resources; ineffectively utilising the help of resources in areas to which they are not well suited; and/or being left vulnerable if their limited resources are no longer available (Beail & Beail, 1958; Walker, 2005). If this occurs, individuals with undispersed dependencies may perceive no-one to be suitable in addressing their needs and become predominantly autonomous, despite the drawbacks of this approach (Walker, Ramsey, & Bell, 1988). At the other end of the continuum, indiscriminate dependencies involve minimal differentiation amongst resources. Essentially, individuals with this style of dependency dispersion do not

allocate their dependencies in a specified manner, leading to reliance on all resources for all challenges (Walker, 2005).

Optimal utilisation of supports is considered to fall in the middle of the dispersion continuum and is characterised by effective dispersion of needs amongst a flexible and adaptive network of resources with a considered sense of which person is most suitable to help with a particular challenge (Beail & Beail, 1958; Chiari et al., 1994; Walker, 2005). This pattern of reliance on others is referred to as dispersed dependencies and, according to Kelly (1955, 1962), is developed by individuals over time as part of the maturation process. That is, children are recognised to be wholly dependent on parents/caregivers for all needs, but with the ongoing elaboration and revision of personal constructions that occurs over time, their dependencies become more differentiated so that ultimately they learn to “satisfy one need here and another there” (Kelly, 1955, p.914). This dispersion process is facilitated by the development of hierarchically structured constructs about others and dependencies (Bell, Winter, & Bhandari, 2010). Such hierarchical organisation of constructions allows us to interpret, understand, and anticipate situations more easily than if each situation was interpreted by its various, individual components (Kelly, 1955).

Dependency distribution is a largely social process; as the development of effectively dispersed dependencies relies on an awareness of others’ perceptions and mindfulness to balance one’s own needs with those of other people (Walker, 1990, 2005). For this reason it is of interest to explore the dependency distribution patterns of individuals Autism Spectrum Disorders (ASD), given the sociality deficits associated with this condition. That is, individuals with ASD evidence persistent and significant social communicative impairments, as well as restricted and repetitive behaviours and/or interests (American Psychiatric Association [APA], 2013). More

specifically, individuals with ASD may exhibit significant social reciprocity difficulties, experience difficulty accommodating changes to routines, and have unique intolerances and/or sudden mood changes (Attwood, 2007; Jensen & Spannagel, 2011). In addition to these core impairments, individuals with ASD often experience a range of sensory sensitivities, gastrointestinal issues, immune system irregularities, and sleep disturbances (Attwood, 2007; Solomon & Chung, 2012). This combination of significant social impairment coupled with physical issues exacerbate the challenging nature of this condition (Gray, 2002; Jensen & Spannagel, 2011; Seltzer et al., 2003).

Given the sociality deficits inherent to ASD, it is unknown how effectively individuals with ASD disperse their dependency needs. Related to this, it is unclear how efficiently individuals with ASD communicate their dependency expectations, meaning family members may have difficulty understanding, and thus fulfilling, the dependency needs of individuals with ASD (Procter, 2000, 2001). Third, individuals with ASD have difficulty developing hierarchically structured construct systems due to their tendency to rely on networks of isolated constructs (Cridland, Caputi, Jones, & Magee, 2013a; Procter, 2001). Given the importance of hierarchically organised constructs for effective construing, it is unclear how effectively adolescents with ASD disperse their dependencies.

Of particular interest here are the dependency distribution patterns of adolescents with ASD, as adolescence is considered to be one of the most challenging developmental stages for individuals with ASD given the range of social, emotional, physical, and cognitive changes inherent within this period (Levy & Perry, 2011; McGovern & Sigman, 2005; Stoddart, 1999). Some key challenges for adolescents with ASD include adjusting to the increased academic, social, and

cognitive demands of high school; exposure to, and participation in, a broader range of social roles; and learning how to manage sexual urges in socially appropriate ways (Cridland et al., 2013a; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Seltzer et al., 2003; Shattuck et al., 2007).

Given the range of challenges integral to this period, identifying and receiving support from others is imperative for the adaptive coping of these adolescents (Beresford, 1994; Fong, Wilgosh, & Sobsey, 1993; Pinkerton & Dolan, 2007). In doing so, an integrative support network is important, as different resources supply different types of support. For example, formal support services can provide practical support such as financial assistance and information whereas informal supports predominantly provide emotional and social support (Bauminger, Shulman, & Agam, 2003; Beresford, 1994; Myers & Johnson, 2007; Phelps, McCammon, Wuensch, & Golden, 2009b). Whilst support networks involve individuals at various levels of the community (Brewin, Renwick, & Fudge Schormans, 2008; Humphrey, 2008; Myers & Johnson, 2007), the family provides the majority of support for adolescents with ASD (Bradford, 2010; Field & Hoffman, 1999; Gray, 2002; Orsmond & Kuo, 2011; Pinkerton & Dolan, 2007; Solomon & Chung, 2012).

The present paper consists of two studies exploring the dependency patterns of three adolescents with ASD, and their family members' awareness of these dependencies. More specifically, Study 1 investigates the dependency patterns of the adolescents with ASD, using dependency grids. Dependency grids are a personal constructivist tool used to explore the resources an individual utilises when confronted by challenging situations (Beail & Beail, 1958; Bell, 2001; Walker, 2005). Further, dependency grids investigate the extent to which the needs of an individual are dispersed amongst others; which situations provoke help seeking by an

individual; and which situations an individual may feel they have insufficient resources to utilise (Walker, 2005; Walker et al., 1988). It was anticipated that the structured nature of the dependency grid would suit the processing style of individuals with ASD, given the proven efficacy of repertory grids with similar populations (Hare, 1997; Hare, Jones, & Paine, 1999; Hare, Searson, & Knowles, 2011; Mason, 2008; Thomas, Butler, Hare, & Green, 2011).

Study 2 investigates family awareness of the adolescents' dependency distributions using a modified version of the Family Grid (Procter, 1985b). Family Grids involve family members completing grids for how they predict other family members would respond. In doing so, they provide a measure of communality (or similarity) between individual grids, which allows us to highlight areas of awareness versus misunderstanding in families (Procter, 1985b).

8.3 Study 1: Investigating the dependency patterns of adolescents' with Autism Spectrum Disorder

The primary aim of Study 1 was to investigate the dependency distribution patterns of adolescents with ASD. The study focused particularly on the adolescents' distribution of needs amongst family members, given the significant role the family plays in supporting adolescents with ASD (Bradford, 2010; Cridland, Jones, Magee, & Caputi, 2013b; Field & Hoffman, 1999). In addition to exploring who the adolescents relied on, Study 1 investigated the types of support preferred by the adolescents, including emotion-focused, problem-focused, advocacy, education, and social support.

To our knowledge, no research data are available about the use of dependency grids with adolescents with ASD. Therefore, a secondary aim of Study 1 was to explore the efficacy of conducting dependency grids with adolescents with ASD.

8.3.1 Method.

Sample. The sample consisted of three adolescents with ASD. Eligibility criteria for the adolescents with ASD included having a formal diagnosis of ASD²¹, being male²², and attending mainstream secondary schooling. In order to increase homogeneity, there were also eligibility criteria for the families of the adolescents, including; families with two adolescent children (one adolescent with ASD and one neurotypically developing adolescent²³); two parents who identify as the primary caregivers; all family members living at home a minimum of five days per week; the adolescent being the only family member formally diagnosed with ASD; and all family members having knowledge of the ASD diagnosis. Additional demographic information is presented in Table 8.1.

Table 8.1: *Demographic information for Study 1 and 2*

Family number	Adolescent: age, School grade	Sibling: Gender (age), Education level	Father: (age) Education level, Current employment status	Mother: (age) Education level, Current employment status
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²¹ All participants with ASD had received a formal diagnosis of Asperger's Syndrome from either a paediatrician or psychologist based on ASD criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM), fourth edition (APA, 2000). Given the classification changes in the DSM-V (APA, 2013); these diagnoses are referred to here as ASD.

²² The rationale for focusing on adolescent males with ASD was based on the current predominance of males diagnosed with ASD (Holtman, Bölte, & Poustka, 2007; Krahn & Fenton, 2012) and previous recommendations to acknowledge the influence of gender on research findings (Card, Stucky, Sawalani, & Little, 2008; Cridland, Jones, Caputi, & Magee, 2014a; Hsiao, Tseng, Huang, & Gau, 2013).

²³ From hereon, the adolescent participants with ASD will be referred to as 'adolescents' and the neurotypically developing adolescent siblings as 'siblings'/'brother'/'sister'.

1	16, 10 th grade	Female (18), Secondary School graduate	(52) Technical college, full-time work	(50) University graduate, part-time work
2	16, 10 th grade	Female (17), 11 th grade	(47) Secondary School graduate, casual work	(44) University graduate, full-time work
3	15, 9 th grade	Male (18), University Freshman	(50) University graduate, full-time work	(51) University graduate, full-time work

^a Autism Spectrum Disorder

Procedure. Ethical approval was granted by the University's Human Research Ethics Committee (Appendix L) prior to commencing participant involvement. A sample of convenience was recruited from participants involved in a previous research study who indicated their interest in being involved in future university research. The broad research aims were explained to participants by an information sheet (Appendix Q) and an introductory meeting with the first author. Following ethical standards for research with children, written consent (Appendix R) was obtained from the participants and their parents.

The dependency grid interviews were conducted based on recommendations outlined in Cridland et al (2014b [Appendix A]), including conducting interviews with individual participants in a private space within the family home (e.g., study or quiet living area); conducting interviews at a preferred time for participants; and conducting interviews at an appropriate pace to facilitate accurate interpretation of interview questions. Interviews lasted for an average of approximately 30 minutes (range 20-70 minutes).

Dependency grids. Adolescents each completed two dependency grids; Grid 1 focused on the people they turn to in challenging situations and Grid 2 focused on the types of support utilised. To ensure consistency between grids, the situations and

resources were supplied²⁴ (Green, 2004; Ryle & Breen, 1972a, 1972b; Winter, 1994). Specifically, supplied situations included both general (e.g., ‘Feeling sad’) and ASD specific (e.g., ‘Have questions about ASD’) issues. See Appendix S for the full list of supplied situations and resources. The supplied situations remained consistent across Grid 1 and 2. Participants were also encouraged to add relevant situations and/or resources, and these additions were included in analysis.

A dichotomous scale for allocating resources to situations was employed, following Kelly’s original methodology (Button, 1985). However, based on recommendations for conducting grids with young people with disabilities²⁵ (Ravenette, 1980, 2005; Thomas et al., 2011), an amended procedure for allocating resources was used. That is, participants sorted ‘resource cards’ according to which resource they would/would not use for each challenging situation, with the first author completing the grid accordingly (Appendix T). Instructions were framed in the present tense to ensure a focus on the adolescent’s current dependency distribution (Talbot, Cooper, & Ellis, 1991). The specific instruction for allocating cards in Grid 1 was, ‘If this challenging situation happened right now, and these people were available, who would you turn to for help?’ and ‘If this challenging situation happened right now, what type of support would you use?’ for Grid 2. These instructions were presented verbally and visually on a ‘resource-card sorting mat’ (Appendix U).

Analysis. The computer program Gridstat (Bell, 2009) was used to analyse the grid data. The Uncertainty Index (Bell, 2001) was calculated as a summary measure of each grid. This index provides a score (from 0-1) of the uncertainty associated with the

²⁴ The supplied situations and resources were derived from interviews conducted with 37 participants (adolescents with ASD, mothers, fathers, and adolescent siblings) from 13 families, discussing common challenges and coping strategies for adolescents with ASD.

²⁵ In some contexts, ASD is considered a disability, more commonly however it is considered a condition (Attwood, 2007; Seligman & Darling, 2007).

allocation of dependencies to each resource. A score of 0 is provided when only one resource is utilised in a situation, representing no uncertainty in dependency allocation; and a score of 1 is provided when all resources are used for a situation. The Uncertainty Index was chosen over the traditional Dispersion of Dependency Index (Walker et al., 1988) as it is not influenced by sample size.

Following this, partial order scalogram analysis (POSAC) (Guttman, 1944) was conducted to model each grid. Specifically, POSAC orders the resource-situation to reflect the hierarchical relationships among resources and then uses an iterative algorithm to find a best-fitting configuration (Bell, 2001). The vertical dimension reflects the number of situations a resource is available for, with those towards the top being depended on in more situations. The POSAC analysis adds ‘ideal’ and ‘minimum’ resources at each extreme of the vertical dimension. The horizontal dimension reflects the differentiation of sets of situations covered by resources.

Several other summary measures proposed by Bell (2009, 2001) were also calculated. The ‘Dependence Total’ reflects the overall number and percentage of resources utilised across all situations, with higher percentages reflecting greater dispersion. The ‘Cognitive complexity’ reflects the differentiation among resources and situations. The breadth of the POSAC hierarchy, referred hereafter as the Breadth index, provides an indication of the degree of differentiation of sets of situations covered by the resources. The depth of the POSAC hierarchy, referred hereafter as the Depth index, provides an indication of the variation in resource availability or complexity of the resource structure. The three most utilised resources and their corresponding percentages are also reported.

8.3.2 Results and discussion.

Grid 1: Dependency dispersion among resources. Summary measures for Grid 1 are presented in Table 8.2. For all measures, higher scores indicate greater dispersion of dependency.

Table 8.2: *Summary measures of Grid 1*

Participant	Uncertainty index	Dependence total (%)	Cognitive complexity	Breadth index	Depth index	Most utilised resources (%)
1	.96	58 (57%)	.67	.42	.65	Mum (24%) Dad (17%) Older sister (17%)
2	.97	52 (61%)	.64	.33	.59	Older sister (27%) Older brother (23%) Myself (23%)
3	.91	58 (49%)	.82	.59	.59	Mum (26%) Dad (21%) Myself (19%)

Overall, the Uncertainty Index indicates the three participants have similarly high dispersions of dependencies amongst resources in Grid 1. Additionally, based on cognitive complexity measures, each grid has moderate to high differentiation among resources and situations; Participant 3 has the most cognitively complex network of dependency distribution. The grids vary, however, in the way the resources are allocated. For example, the distribution pattern for Participant 2 features minimal breadth but moderate depth, indicating modest differentiation of resources amongst situations but various resources available for certain circumstances. Grid 1 for each participant will be considered in detail below.

Participant 1. Participant 1 is a 16 year old male with a diagnosis of Asperger's Syndrome. He attends a mainstream secondary school with an Autism Unit and says he enjoys school. Participant 1 describes himself as a "smart" and "quiet" and enjoys spending time in his room drawing pictures and playing computer games. Participant 1 adjusted the supplied resources by removing the 'other family' and 'someone outside family' resource-cards, saying these were not relevant to him. During the grid interview Participant 1 was observed to rank the resource-cards according to his preferences, and upon completion said he found the activity helpful. Figure 8.1 shows the POSAC representation of Participant 1's grid.

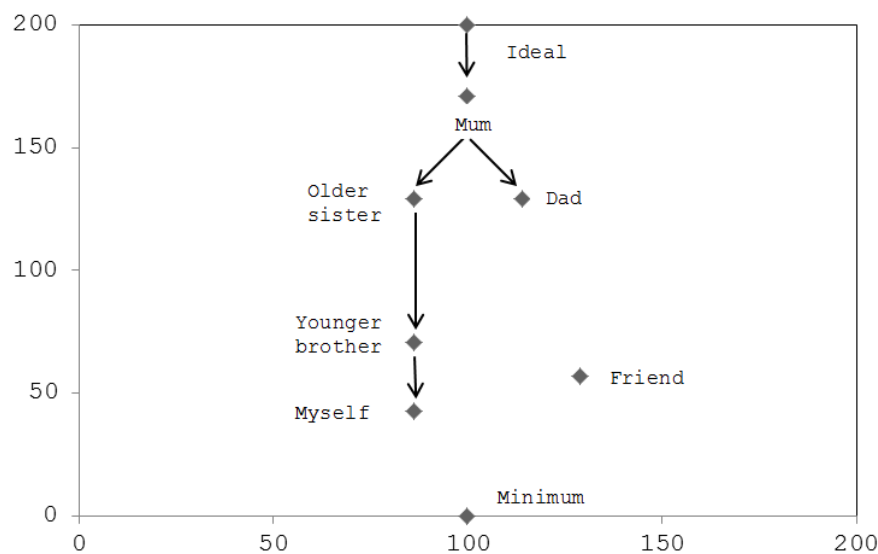


Figure 8.1: *The POSAC representation for Participant 1, Grid 1*

Summary data and the POSAC representation indicate that Participant 1's most heavily relied upon resource was his mother. His dependencies were then divided between his father and siblings and himself. Inspection of the resources indicates Participant 1 relies on siblings, particularly his older sister, across various situations

such as when feeling frustrated, sad and lonely, and when having problems with his parents.

Participant 2. Participant 2 is a 16 year old male with a diagnosis of Asperger's Syndrome and Tourette Syndrome. He attends a local secondary school, which he dislikes due to bullying and having to attend "boring subjects". Participant 2 describes himself as a "happyish" and "funny" and enjoys spending time playing computer games with his older siblings. Participant 2 adjusted the supplied resources by removing the 'other family' and 'someone outside family' resource-cards, saying these were not relevant to him. During the grid interview Participant 2 was observed to have some difficulty generalising about the resources he utilises across situations and was reminded several times that there were no right or wrong answers. Upon completion of the activity Participant 2 commented that he was "exhausted" but happy that he had been able to answer the questions. Figure 8.2 shows the POSAC representation of Participant 2's grid.

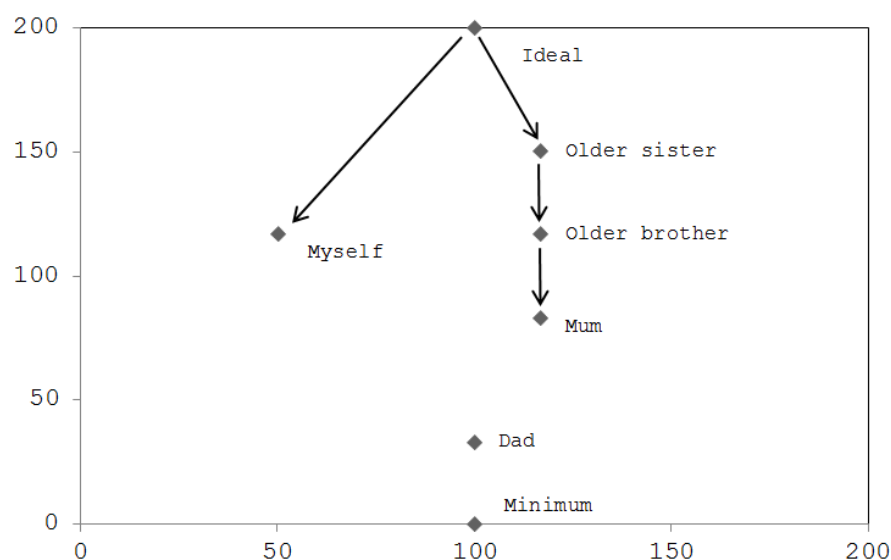


Figure 8.2: *The POSAC representation for Participant 2, Grid 1*

Two independent dependency hierarchies were evident in Participant 2's dependency network. One hierarchy identified that Participant 2 relies on his siblings and mother for similar situations, with his older sister being the most utilised resource. In contrast, 'Myself', although substantially available, was an isolated resource. Inspection of the resources indicated the hierarchy for self-reliance was dominated by managing emotions (e.g., anger, sadness, loneliness), whilst the other hierarchy was used for practical and/or social issues, such as difficulties with homework, problems with friends, or questions about puberty. Participant 2's father was the least relied upon resource; but was specialised in that he was the sole person utilised for questions about puberty.

Participant 3. Participant 3 is a 15 year old male with a diagnosis of Asperger's Syndrome. Observation during the interview and previous independent testing indicated he is of high intelligence. Participant 3 attends a local secondary school and his favourite subjects are science and maths. Participant 3 describes himself as "energetic" and "quiet" and enjoys spending time with friends. Participant 3 adjusted the supplied resources by removing the 'other family' and adding 'Tutor', 'Youth group leader', and 'Professional' (which was a combined resource representing his doctor, counsellor and psychiatrist). During the grid interview, Participant 3 said he was "trying to use logic" to answer some of the questions, for example he thought it would be "illogical" to put 'Leave me alone' with any of the resources that involved obtaining the help of another person. The complex, and sometimes illogical, nature of help seeking was explained to Participant 3 several times throughout the interview. Upon completion of the activity, Participant 3 was concerned whether he had gotten the "answers correct". Figure 8.3 shows the POSAC representation of Participant 3's grid.

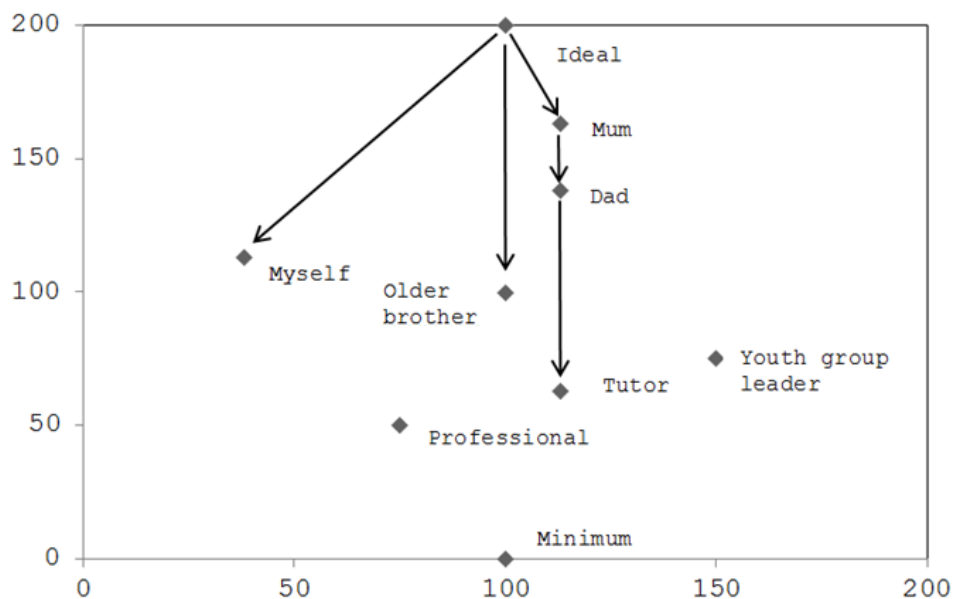


Figure 8.3: *The POSAC representation for Participant 3, Grid 1*

Participant 3's dependency grid depicts various dependency hierarchies, which may reflect a dispersed pattern of dependencies. Alternatively, the dependency pattern may reflect Participant 3's 'logical' approach to dependency allocation rather than his actual distributions. Regardless, the complex dispersion of dependencies depicted in Figure 8.3 corresponds with the comparatively high measures of complexity presented in Table 8.2. Contributing to the complexity of this grid is the larger number of resources ($n=7$) utilised across situations compared to Participants 1 and 2.

Analysis of the resources indicates Participant 3 relies most on his mother, and to a slightly lesser extent, father. Participant 3 also relied heavily on himself and his older brother, but these resources were somewhat independent from each other. More specifically, his older brother was relied on uniquely for problems with bullies, whilst Participant 3 was reliant on himself when feeling bored.

Other independent, yet less utilised, resources were Participant 3's youth group leader and professionals. Inspection of the resources indicated Participant 3 relied

predominantly on the professional resource for questions about puberty and ASD, and relied on his youth group leader for social challenges (e.g., ‘Having difficulties making friends’, ‘Having difficulties with friends’, and ‘Feeling lonely’). It is possible that Participant 3 also utilised his youth group leader for spiritual issues, but these were not captured adequately in the items.

Grid 2: Types of support utilised. Summary measures for Grid 2 are presented in Table 8.3. For all measures, higher scores indicate greater dispersion of dependency.

Table 8.3: *Summary measures of Grid 2*

Participant	Uncertainty index	Dependence total (%)	Cognitive complexity	Breadth index	Depth index	Most utilised resources
1	.83	60 (39%)	.83	.32	.65	‘Explain it to me’ (20%) ‘Sort out problem’ (18%) ‘Help me sort out problem’ (18%)
2	.91	65 (43%)	.86	.43	.57	‘Give me advice’ (26%) ‘Explain it to me’ (17%) ‘Help me sort out problem’ (14%)
3	.92	82 (54%)	.76	.61	.45	‘Listen to me’ (18%) ‘Give me advice’ (18%) ‘Leave me alone’ (18%) ‘Sort out problem’ (18%)

Overall, the Uncertainty Index indicates each grid has high dispersions of dependencies amongst types of support sought. Additionally, based on cognitive complexity measures, each grid has moderate to high differentiation among resources and situations. However, based on the Dependence Total, participants relied on fewer types of support compared to their reliance on people (as presented in Grid 1). This may

mean that generally the participants relied on specific types of support for specific challenges rather than a range of strategies. Overall, the most utilised resources were problem-focused strategies such as ‘Explain it to me’, ‘Sort out the problem’, and ‘Give me advice’, with emotion-focused strategies such as ‘Hug me’ being the least utilised. Grid 2 will be considered for each participant in detail below.

Participant 1. The types of support most sought after by Participant 1 were problem-focused strategies (i.e., ‘Help me sort out problem’, ‘Sort out problem’, ‘Give me advice’ and ‘Explain it me to me’) rather than emotional (e.g., ‘Give me a hug’) or social (e.g., ‘Play with me’) strategies. Additionally, Participant 1 did not endorse ‘Leave me alone’ for any strategy. Together this pattern of dependence may indicate Participant 1 seeks the practical support of others but does not seek emotional or social support. Figure 8.4 shows the POSAC representation of Participant 1’s grid.

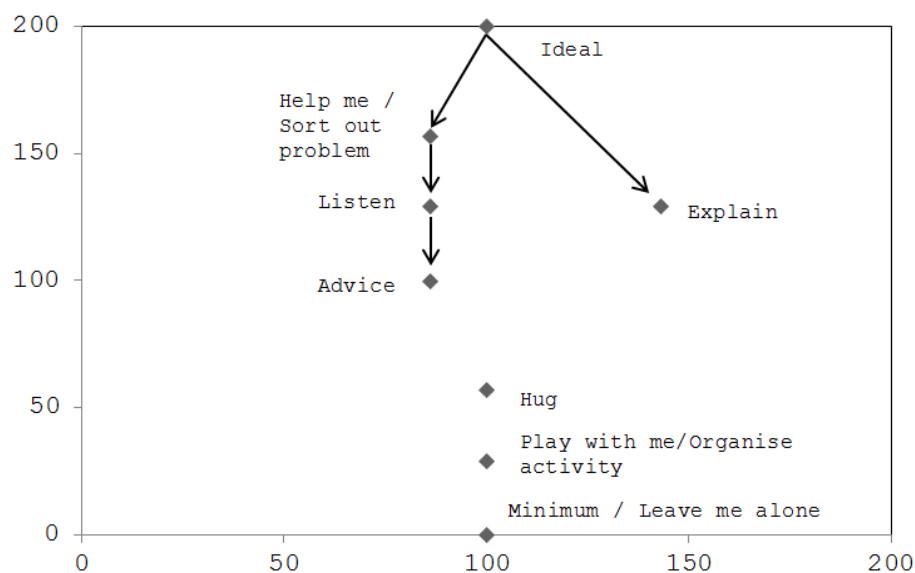


Figure 8.4: The POSAC representation for Participant 1, Grid 2

Participant 2. Similar to Participant 1, the types of support most sought after by Participant 2 were problem-focused strategies (i.e., ‘Give me advice’, ‘Explain it me to

me', 'Help me sort out problem') more so than emotional (e.g., 'Give me a hug') or social (e.g., 'Play with me') strategies. The hierarchy focusing on problem solving strategies suggests a highly organised construct around the types of support utilised in specific situations. It is likely that this hierarchy corresponds with the dominant hierarchy in Grid 1 (Figure 8.2).

Following this, it is possible that the other hierarchy evident in Figure 8.5 corresponds with the 'reliance on self' hierarchy evident in Grid 1 (Figure 8.2), meaning Participant 2 may attempt to manage emotions himself by distraction techniques such as playing games. However, as evident in the POSAC representation, there are no back-up strategies if this type of support is not effective. Figure 8.5 shows the POSAC representation of Participant 2's grid.

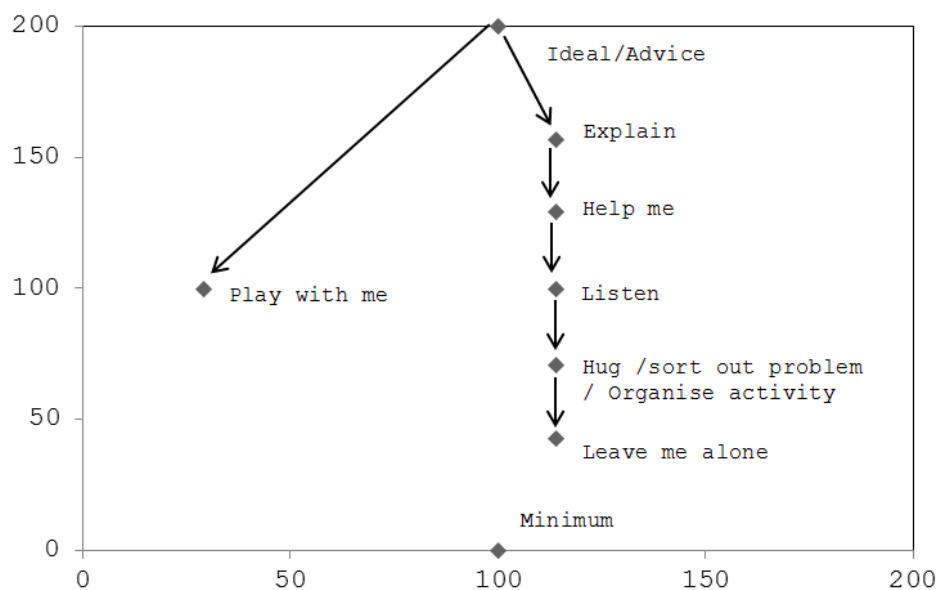


Figure 8.5: The POSAC representation for Participant 2, Grid 2

Participant 3. This POSAC representation shows a very different dispersion pattern from that of Participants 1 and 2, despite comparable Uncertainty Indices. Specifically, Figure 8.6 shows a dependency network dominated by largely independent

support types with few hierarchies. Thus, Participant 3 may see different types of support as unique to different situations but, unlike the preceding grids, has little backup for these support types if they are not effective. This pattern of dependence is considered less cognitively complex, which is echoed in the comparatively low Cognitive Complexity score (see Table 8.3).

Similar to the grids of Participants 1 and 2, there is minimal utilisation of emotional and social support strategies. Of particular interest, Participant 3 elected ‘Hug me’ as strategy sought after in similar situations to ‘Leave me alone’. The conflicting nature of these types of support may be difficult for significant others to understand and therefore fulfil. Figure 8.6 shows the POSAC representation of Participant 3’s grid.

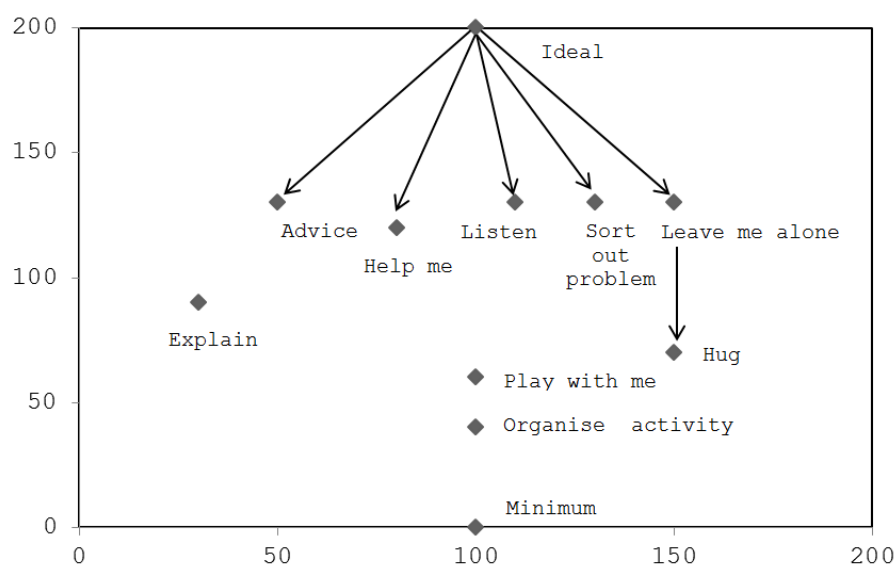


Figure 8.6: *The POSAC representation for Participant 3, Grid 2*

In summary, Study 1 provided a variety of insights into the dependency patterns of the adolescents with ASD. More specifically, the grids depicted the people and types of support the adolescents relied in across a range of challenging situations.

8.4 Study 2: Investigating family awareness of the dependency needs of adolescents with Autism Spectrum Disorder

The primary aim of Study 2 was to investigate family members' awareness of the adolescents' dependency needs. In doing so, we aimed to highlight areas of discrepancy and/or communication issues, thereby increasing family members' ability to understand and address the adolescents' needs.

Repertory grids have been used with families living with ASD previously (Procter, 2000); however, to our knowledge dependency grids have not been used with this population. Therefore, a secondary aim of this study was to determine the utility of conducting Family Dependency Grids with families living with ASD as a means of assessing their awareness of the individual with ASD's distribution of dependency.

8.4.1 Method.

Sample. The sample consisted of the mothers, fathers, and siblings of the adolescents from Study 1. Demographic information is presented in Table 8.1.

Procedure. Family members completed a modified version of the Family Grid (Procter, 1985b). More specifically, family members completed Grids 1 and 2 from Study 1 as to how they perceived the adolescent would complete the grid. The specific instruction for Grid 1 was, 'If this challenging situation happened to your family member right now, and these people were available, who do you think he would turn to for help?' and 'If this challenging situation happened right now, what type of support would your family member use?' for Grid 2. Family members completed the grids by either using the resource cards or directly completing the grids. As the focus was on the adolescents' dependency patterns, family members did not complete grids for their own dependencies.

8.4.2 Results and discussion.

Following similar analysis procedures in Study 1, summary measures were calculated for each family. For all measures, higher scores indicate greater perceived dispersion of dependency.

Family 1: Summary measures for Family 1 are presented in Table 4.

Table 8. 4: *Summary measures for Family 1*

Participant	Uncertainty Index	Dependence Total (%)	Cognitive complexity	Breadth Index	Depth Index	Most utilised resources (%)
<u>Mum</u>						
Grid 1	.92	44 (43%)	.83	.45	.65	Mum (34%) Dad (23%) Self (13%)
Grid 2	.98	72 (47%)	.92	.60	.53	'Listen to me' (15%) 'Help sort out problem' (15%) 'Leave me alone' (14%)
<u>Dad</u>						
Grid 1	.70	29 (28%)	.78	.17	.67	Dad (45%) Mum (35%) Older sister (10%)
Grid 2	.93	56 (37%)	.86	.63	.55	'Explain it to me' (25%) 'Sort out problem' (18%) 'Help sort out problem' (14%)
<u>Older sister</u>						
Grid 1	.69	36 (35%)	.89	.51	.20	Mum (39%) Myself (31%) Dad (25%)
Grid 2	.84	62 (41%)	.83	.39	.78	'Listen to me' (26%) 'Leave me alone' (19%) 'Give me advice' (19%)

Participant 1's family had reasonable awareness of the adolescent's dependency patterns, as evidenced by the various summary measures. However, several points of incongruence were also identified. For example, all family members overestimated the

cognitive complexity of Participant 1's degree of dispersion of resources as measured by Grid 1, whilst the father and sibling underestimated the degree of dispersion of this grid. Further, all family members underestimated the amount of dependency (measured by the Dependence Total) for Grid 1. This finding suggests that the family members were aware of the different types of strategies used by Participant 1 across situations but underestimate the amount of resources utilised.

Regarding the resources relied on most by Participant 1, all family members recognised the mother and father as highly utilised resources. However, the mother and sister did not recognise the extent to which Participant 1 reported that he relied on his sister. This observation could translate to the sister having limited availability for her brother, the sister not being aware of the extent of the support she provides for her brother, and/or the sister receiving limited support from her mother for the support she provides to her brother. Alternatively, the adolescent may have over reported his reliance on his sister.

Regarding the types of support preferred by Participant 1, family member responses reflected the adolescent's preference for problem-focused strategies. However, the mother and sister considered 'Leave me alone' to be a highly utilised strategy by Participant 1, whilst this was his least preferred type of support. Participant 1 may have difficulty communicating his desire for support from other family members, leading to confusion amongst family member as to how support him. Alternatively, the family members may have greater awareness of Participant 1's utilisation of 'alone-time' in challenging situations than the adolescent himself.

Family 2: Summary measures for Family 2 are presented in Table 8.5.

Table 8.5: *Summary measures for Family 2*

Participant	Uncertainty Index	Dependence Total (%)	Cognitive complexity	Breadth Index	Depth Index	Most utilised resources (%)
<u>Mum</u>						
Grid 1	.93	66 (77%)	.80	.33	.00	Mum (26%) Myself (25%) Older sister (24%)
Grid 2	.84	64 (42%)	.84	.53	.46	'Give me advice' (22%) 'Help sort out problem' (20%) 'Leave me alone' (20%)
<u>Dad</u>						
Grid 1	.79	41 (48%)	.93	.32	.51	Mum (32%) Sister (32%) Myself (29%)
Grid 2	.95	62 (41%)	.85	.75	.45	'Leave me alone' (29%) 'Hug me' (13%) 'Listen to me' (13%)
<u>Older sister</u>						
Grid 1	.85	40 (47%)	.93	.49	.53	Mum (40%) Older sister (25%) Dad (22%)
Grid 2	.96	130 (85%)	.86	.33	.00	'Listen to me' (13%) 'Sort out problem' (13%) 'Help sort out problem' (13%) 'Explain it to me' (13%) 'Give me advice' (13%)

Participant 2's family had reasonable awareness of his dependency patterns, as evidenced by the various summary measures. However, several points of incongruence were also identified. For example, all family members overestimated the cognitive complexity of Grid 1. Additionally, Participant 2's mother and sister considered Participant 2 to lack depth of dispersion when distributing his dependency needs. For the mother this finding suggests an overestimation on the amount that her son relied on

her, and for the sister this finding suggests she perceives her brother utilised the same types of support across the majority of situations.

Half of Participant 2's dependencies were distributed amongst his two older siblings (see Table 8.2). However, none of the family members recognised the extent of his reliance on siblings, particularly his older brother. This minimal awareness may mean Participant 2 has difficulty communicating his preference for support from his siblings, the siblings do not meet all of Participant 2's needs, and/or family members did not recognise the amount of support the siblings provide Participant 2.

Regarding the types of support preferred by Participant 2, the mother and father overestimated the degree to which Participant 2 seeks to be left alone. As with Participant 1, this strategy was his least preferred type of support and may mean Participant 2 has difficulty communicating his desire for support from other family members or alternatively family members may have greater awareness of the adolescent's utilisation of 'alone-time' in challenging situations.

Family 3: Summary measures for Family 3 are presented in Table 8.6.

Table 8.6: *Summary measures for Family 3*

Participant	Uncertainty Index	Dependence Total (%)	Cognitive complexity	Breadth Index	Depth Index	Most utilised resources (%)
<u>Mum</u>						
Grid 1	.93	49 (41%)	.82	.40	.59	Mum (33%) Older brother (18%) Dad (10%)
Grid 2	.96	69 (45%)	.77	.71	.41	'Sort out problem' (19%) 'Leave me alone' (15%) 'Give me advice' (13%) 'Play with me' (13%) 'Organise activity' (13%)
<u>Dad</u>						
Grid 1	.86	52 (44%)	.86	.52	.57	Mum (29%) Dad (27%) Myself (17%)
Grid 2	.96	85 (56%)	.69	.71	.41	'Listen to me' (19%) 'Give me advice' (17%) 'Sort out problem' (14%)
<u>Older brother</u>						
Grid 1	.81	41 (35%)	.93	.44	.69	Mum (39%) Dad (22%) Tutor (19%)
Grid 2	.96	79 (52%)	.77	.50	.45	'Sort out problem' (18%) 'Leave me alone' (18%) 'Help sort out problem' (15%)

Participant 3's family had comparatively high awareness of his dependency patterns, as evidenced by congruency amongst the various summary measures. Moreover, the overall similarity between the grids indicates the family members have a comparatively good awareness of Participant 3's dependency needs across a range of situations. Additionally, it may mean Participant 3 has a good ability to communicate his needs to his family.

One point of interest from the grids is that the mother and brother did not recognise the extent to which Participant 3 relied on himself. This could mean the mother and brother underestimate Participant 3's ability to self-manage in challenging situations. Alternatively, it could mean Participant 3 overestimates his coping skills and is not aware of the extent to which he relies on others.

8.5 General Discussion

To our knowledge, this is first the study to explore the use of dependency grids with adolescents with ASD and their families. By involving family members, the study not only investigated the dependency patterns of the adolescents with ASD, but also the level of awareness family members had of the adolescents' dependency preferences.

The dependency grid proved to be a practical and sensitive approach for capturing and presenting the adolescents' unique dependency distribution patterns. Further, similar to repertory grids, the structured nature of the dependency grid interview (and the grid itself) was well suited to the interaction style of individuals with ASD (Hare et al., 1999). Also, the relatively short administration time needed to obtain a significant amount of information about the adolescents' dependency patterns provides support for the use of dependency grids with this population in both research and clinical settings.

The findings indicated several noteworthy issues. First, the adolescents all reported that they relied significantly on their adolescent siblings for support. More specifically, siblings were either in the top three most utilised resources and/or were the preferred sources of support for particular situations for each adolescent. These findings are in line with the literature which indicates siblings provide both significant and unique supporting roles for their sibling with ASD (Benderix, & Sivberg, 2007; Carrillo, 2012; Kaminsky, & Dewey, 2001; McHale, Kim, & Whitman, 2006; Orsmond,

& Seltzer, 2009). It is important that the significant role siblings often provide for the family member with ASD is acknowledged, and that they are provided with adequate support (Smith & Perry, 2005; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Further, it is vital that parents monitor the caregiving responsibilities that siblings undertake to avoid siblings becoming overburdened. Research indicates these issues are of particular importance with adolescent siblings of individuals with ASD, given their heightened awareness of the care-giving demands placed on parents and the siblings' increased capability for undertaking greater responsibilities (Benderix & Sivberg, 2007; Morgan, 1988; Seligman & Darling, 2007).

Another pertinent finding was that emotion-focused strategies were the least sought after type of support identified by the adolescents, with each participant preferring problem-focused strategies. These findings suggest the adolescents perceived greater benefit from solution-focused support such as having someone explain an issue or help 'sort out' a situation rather than support which focused on the emotional aspects of a situation. This type of support is in line with the often practical nature of individuals with ASD. That is, research indicates that these individuals tend to focus on cognitive aspects of a problem over emotional aspects (Altieri & von Kluge, 2009; Bauminger, 2002; Krahn & Fenton, 2012). These findings are important for families, as they may focus on providing emotional support if they perceive their family member with ASD to be struggling with a challenging situation (Bradford, 2010). As an aside, the finding that adolescents with ASD did not identify emotional support as helpful as other strategies does not indicate they do not experience emotional reactions to challenging situations (Bauminger, 2002; Bauminger, Shulman, & Agam, 2003; Cottenceau et al., 2012).

The Family Grids provided insight into the level of awareness family members had of the adolescents' dependency preferences. Overall, the Family Grids showed high levels of communality, which may be indicative of awareness of the adolescents' dependency preferences. Whilst high levels of awareness between grids have been interpreted as a sign of healthy communication between individuals (O'Laughlin, 1989; Ryle & Breen, 1972a), they may also be indicative of family awareness of obvious ineffective dependency distribution patterns. For example, several family members commented on the adolescent's preference for people to 'sort out' challenging situations over collaborative problem solving (which does not encourage active learning). Additionally, whilst the Family Grids showed overall high levels of communality, there were areas of misperception in each family. These findings reflect the real world nature of families, in which there are areas of miscommunication and limited understanding which could be improved on, in even the most positively functioning families (Bowen, 1995). It is also important to consider that the family grids were compared against the adolescents' responses, which were a subjective (rather than objective) assessment of their dependency patterns.

8.6 Limitations

Despite the various benefits of using dependency grids with adolescents with ASD and their families, there are some components of the present studies which should be considered when interpreting findings. First, the use of supplied elements and resources was employed for time efficiency and consistency across participants. The limitations of supplied resources and elements include the possibility of some elements/resources having minimal relevance for some participants and/or participants having varied interpretations of the same elements/resources (Fiske, 1995; Fransella &

Bannister, 2004; Secord & Greenwood, 1995). This issue may be particularly relevant when considering individuals with ASD given their difficulty elaborating on meanings of words due to concrete thinking styles and the possibility of unique uses of words (Attwood, 2007; Cridland et al., 2014b; Gold & Faust, 2012; Koning & Magill-Evans, 2001). Several steps were taken to address this issue. First, the interviewer explained each resource and element to the adolescents prior to the interview and also encouraged participants to clarify any issues they did not understand throughout the interview. Second, participants were encouraged to add elements and resources to increase the relevance of their grid. Additionally, task instructions were presented visually to participants to minimise potential misinterpretation from verbal instructions.

Despite these considerations, it is possible that there were variations in the ways the adolescents interpreted the situations and resources, which should be noted when considering the findings. For example, Participant 3 had difficulty operating in the ‘as if’ mode, as his allocation of resources often focused on whether he had utilised the resources previously. He also made several comments about using ‘logic’ to work out the ‘right’ answer, which was likely to impact on his resource allocation. It is, therefore, important to interpret the findings within their scope; that is, as a case study investigation, which does not claim to be representative of all adolescents with ASD. Following this, the participants were all relatively high functioning, meaning their ability to complete the dependency grids may not be reflected by other adolescents with ASD.

In addition, it is necessary to recognise that the whilst the grids provided a comprehensive representation of the adolescents’ dependency patterns, in reality they only provide a snapshot of how these individuals disperse their dependencies and how they construe the world more generally (Fransella et al., 2004). For efficiency, the

findings were based on the mean POSAC representations, meaning only a general level of analysis was presented. This means it is possible the findings underestimate the complexity of the adolescents' dependency networks.

There are also some issues to consider regarding the Uncertainty Index (Bell, 2001), which was used as a measure of dependency dispersion. As Bell (2009) explains, the Uncertainty Index does not account for the relationship between situations and resources, as it is univariate index. This means the Uncertainty Index treats all circumstances equally, despite the fact that in some circumstances an integrated network of resources is considered healthy, whilst in other situations it may indicate an unhealthy pattern of overdependence (Bell, 2009).

8.7 Recommendations

These studies provide preliminary support for the use of dependency grids with adolescents with ASD and their families in both research and clinical settings. However, further research is needed to clarify their efficacy. Based on the issues raised in this investigation, the following areas warrant further research:

1. Further studies investigating the use of dependency grids with individuals with ASD are needed. Such research may involve children with ASD and/or individuals with lower functioning ASD. Such studies may explore the use of alternate administration approaches, such as pictures or photographs. Additionally, this research may explore the utility of conducting dependency grids with other significant resources for adolescents with ASD such as teachers, health professionals, counsellors, and friends.
2. Research is needed to investigate how adolescents with ASD construe the dependency patterns of family members. Such research may involve having

family members complete their own dependency grids, with the adolescents completing subsequent grids predicting their family members' responses.

3. Future studies may benefit from eliciting individualised rather than prescribed resources and elements to ensure participants have personalised grids. Such research could also investigate the ability of adolescents' with to engage in the process of construct elicitation.
4. Future research may compare the dependency distribution patterns of individuals with ASD with those of neurotypically developing individuals to determine whether there are any differential trends amongst these groups. For example, the adolescents in the current investigation predominantly relied on problem-focused support; however it is unclear whether this is similar to the preferred support of neurotypically developing teens.
5. Future research would benefit from formally investigating adolescents with ASD and their families' experiences of completing dependency grids. Such investigations may help determine the utility of conducting dependency grids with this population and may facilitate the processes of administering the grids.
6. More work is needed to investigate methods of statistically analysing grids which provide relevant and detailed information about the data. In doing so, Likert scales or rating systems could be utilised rather than dichotomous coding to provide further information about dependency distribution patterns.

The studies also provide further rationale for the use of the dependency grids in clinical practice with adolescents with ASD and their families. The following recommendations highlight ways dependency grids could potentially facilitate clinical assessment and/or therapy with this population:

1. Dependency grids could be used in the assessment stages of therapy with individuals with ASD and their families. Such assessment may help identify various components of family functioning such as the roles of different members within the family system and the level of awareness family members have of each other's dependency needs. Additionally, dependency grids may be used to monitor the progress of therapy for individuals with ASD who have undispersed or indiscriminate dependency patterns.
2. Dependency grids may be used to facilitate discussions about the types of support utilised by adolescents with ASD and the efficacy of these supports. From here, informal behavioural experiments testing the efficacy of different types of support could be conducted with the adolescent to facilitate optimal support seeking. For example, an adolescent may use distraction in the form of video games to manage frustration when completing homework assignments. A series of behavioural experiments with the adolescent may help them recognise that problem-solving strategies for managing homework assignments are more efficacious than distraction techniques.
3. Dependency grids may be used to facilitate communication between individuals with ASD and their families in daily interactions. The application of this communication may involve amendments to the grid process, such as the card-sorting approach used in Study 1.

8.8 Conclusion

This investigation provided further support for the value of a personal construct approach in working with individuals with ASD and their families. Conducting dependency grids with the adolescents with ASD and their families proved to be an

efficacious approach for assessing and presenting the dependency distributions of these individuals. Additionally, the approach was helpful for communicating the adolescents' dependency patterns to their family members, which may facilitate their general understanding of the adolescent and how to best support them. It is important we continue to investigate approaches to understand the experiences of adolescents with ASD and develop strategies to assist them in communicating with others.

8.9 References

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CHAPTER 9: SUMMARY AND CONCLUSION

This chapter summarises the major findings from the three phases of research presented in this thesis and discusses the key conceptual and clinical contributions of the thesis. This chapter also discusses the limitations of the research findings and provides suggestions for how these may be addressed in future research.

9.1 Summary

The first Phase of this research explored the application of Family Systems (FS) and Personal Constructivist approaches for understanding adolescents with Autism Spectrum Disorder (ASD). In doing so, the first conceptual paper (Chapter 2) provided an overview of key FS concepts and proposed how FS approaches could be utilised to address some important limitations of existing research in this field. It was recommended that future research should endeavour to utilise a common conceptual framework, such as that provided by FS approaches, to better enable a synthesis of findings and facilitate development of evidence-based clinical approaches for working with families living with ASD.

The second conceptual paper (Chapter 3) elaborated on previous applications of Personal Construct Theory (PCT) for understanding ASD. This elaboration included proposing how key PCT concepts relate to various developmental experiences relevant for adolescents with ASD, including functioning within increasingly complex social situations, identity development, and the increasing importance of flexible processing. The benefits of understanding the experiences of adolescents with ASD based on a personal constructivist understanding include increasing adolescents' awareness of the ways in which their behaviour influences others; encouragement of self-acceptance amongst adolescents with

ASD; and helping families and clinicians acknowledge the challenges individuals with ASD face during adolescence.

The second Phase of this research involved a series of qualitative investigations exploring the experiences of adolescents with ASD and their families. The qualitative approach involved interviews with adolescents with ASD, mothers, fathers, and neurotypically developing (NTD) siblings, which provided a detailed and multifaceted exploration of participants' perspectives. In alignment with the first Phase of the research, the investigations were guided by the conceptual frameworks of FS (Chapter 5, 6, 7, and 8) and personal constructivist approaches (Chapters 4 and 8).

Chapters 4 and 5 presented investigations of the experiences of adolescent boys and girls with ASD respectively. The findings indicated that challenges of adolescence encompassed physical, cognitive, emotional, social, and sexual domains. Some challenges were similar for both adolescent boys and girls with ASD, such as the negative implications of late diagnosis; the challenges of transitioning to and coping with high school; the difficulties of adjusting to increased adolescent hygiene demands; and difficulties socialising with NTD peers. A range of gender specific issues were also identified. For example, management of sex-specific puberty issues and coping with strong emotions in socially appropriate ways were particularly relevant to adolescent boys. In contrast, issues pertinent to the experiences of adolescent girls with ASD included difficulties socialising with NTD girls, sex-specific puberty issues, and sexual vulnerabilities.

Chapter 5 also provided insight into the experiences of parents with an adolescent with ASD, which were then examined in more depth in Chapter 6. Findings indicated parents undertook various parenting roles which may be unique and/or of heightened significance when parenting an adolescent with ASD. The clarity and dispersion of these parenting responsibilities were found to influence the FS in a variety of ways. The main

challenges identified in parenting an adolescent with ASD were behavioural issues associated with puberty, such as managing their child's strong emotions and impulsive self-stimulatory behaviours; and ongoing 'grieving' processes associated with having a child with ASD. The main positive aspects of parenting an adolescent with ASD included experiencing humorous incidents; sharing of affection; and increasingly accepting, and, at times, positive attitudes towards being a parent of a child with ASD. The main coping strategies identified by parents included having time alone, spending time with their partner, confiding with someone, and involvement in ASD support groups.

Chapter 7 investigated various themes emerging from discussions with NTD adolescent sisters and their families about their experiences of having an adolescent brother with ASD. Key findings of this chapter were that the sisters undertook various roles and responsibilities both at school and home that influenced their own wellbeing and family functioning. Further, the sisters reported both positive and negative experiences and emotions related to these roles and responsibilities; ranging from feeling proud and accepting to feeling frustrated and burdened. Strategies and barriers for supporting adolescent siblings in families living with ASD were identified for both formal and informal avenues.

Based on challenges for adolescents with ASD identified in the qualitative investigations in Phase Two, the third Phase of the research investigated the ways adolescents with the condition sought help from their family and the types of support they utilised (Chapter 8). Dependency grids, a personal constructivist tool, were used to capture and present the dependency distribution patterns of three adolescents with ASD. Additionally, the adolescents' family members completed grids focusing on their perceptions of the adolescents' dependency patterns. Therefore, a primary strength of the investigation was the utilisation of a combined personal constructivist and FS framework.

More specifically, the findings offered novel insights into the dependency distributions of the adolescents and the functioning of the families as a whole. Additionally, the combined personal constructivist and FS approach was helpful for communicating the adolescents' perspective, which was likely to facilitate awareness and understanding within each family.

9.2 Conceptual contributions of the thesis

The thesis demonstrates that FS and PCT approaches can be used, both individually and in conjunction, to advance our understanding of adolescents with ASD and their families. Regarding the contributions of FS approaches, the thesis research, informed by this framework, reflects the significant and enduring influence that having a family member with ASD has on the individual and the FS. The research informed by FS approaches investigated family issues at various levels of the FS including systemic, subsystemic, and individual levels. It also utilised an inclusive approach by involving various members of the FS. This inclusive approach provided multifaceted perspectives and experiences, which is a significant strength of the research findings as it did justice to the complexity of the family issues under investigation.

Furthermore, the FS informed research presented in the thesis utilised a range of theoretically grounded concepts to explain issues such as Boundaries, Ambiguous Loss, Traumatic Growth and family roles within the FS. The utilisation of such concepts provided depth to the research findings and will facilitate communication and synthesis of thesis findings within the broader literature. The theoretical concepts utilised also covered positive and negative aspects of family functioning which promoted holistic investigations of family issues. These findings have the potential to inform both problem-focused and strengths-based clinical interventions for individuals and families living with ASD.

The application of PCT for understanding adolescents with ASD and their families has also contributed significantly to current understanding of the experiences and challenges facing these individuals. First, the eloquent and empathetic perspective of ASD provided by PCT makes this approach highly relevant for research and clinical interventions targeting families living with ASD. More specifically, helping adolescents with ASD and their families learn about ASD according to the PCT concepts explored in the thesis may facilitate their awareness of the varying ways people experience the world, explain why individuals with ASD may find social situations to be challenging, and increase understanding and acceptance of/for the individual with ASD (Carrington et al., 2003; Procter, 2001; Stoddart, 1999). Such understanding and acceptance is likely to be particularly pertinent during adolescence given the range of challenges adolescents with ASD and their families encounter during this period (Truneckova & Viney, 2006).

This thesis also demonstrates that personal constructivist methodologies utilised in the thesis have utility for investigating issues for families living with ASD within both a research and clinical context. Predominantly, the personal constructivist methodology of dependency grids was a practical and sensitive approach for capturing, presenting, and communicating the adolescents' dependency distribution patterns.

The integrated application of FS and PCT approaches utilised in the thesis provided a unique perspective for understanding adolescents with ASD and their families. Fundamentally, both approaches emphasise that there are diverse ways in which people perceive themselves and the world, and that these perceptions can be revised, if necessary (Alexander & Neimeyer, 1989; Giblin & Chan, 1995; Puig, Koro-Ljungberg, & Echevarria-Doan, 2008). This capacity to develop more adaptive ways of perceiving oneself and the world is an encouraging approach for considering the challenges adolescents with ASD and their families encounter during this period. Furthermore, the

capacity to change promotes an optimistic outlook for families living with ASD to improve their family functioning and grow individually and systemically.

9.3 Clinical contributions of the thesis

The findings of this thesis also highlight the importance of clinical support targeted at adolescents with ASD and their families. More specifically, while the benefits of clinical support for individuals and families living with ASD, in general, has been well established (Bradford, 2010; Gupta & Singhal, 2005; Guralnick, Hammond, Neville, & Connor, 2008; Heiman & Berger, 2007; Luther, Canham, & Cureton, 2005), the present findings reinforce that adolescence is a unique period of development, meaning clinical support strategies tailored specifically for this period are necessary. Moreover, the issues of importance for children with ASD and their families are likely to be different to those of adolescents with ASD and their families given the range of unique challenges and concerns characteristic of adolescence.

Additionally, the findings highlight the need for clinical support to be targeted at various levels within the FS including systemic, subsystemic and individual levels. Importantly, however, the most effective clinical support interventions are likely to have an integrative approach, allowing for the complex interrelations amongst subsystems within the FS to be recognised (Solomon & Chung, 2012). Additionally, the needs of each FS will be heterogeneous, meaning clinical support strategies individualised for each family are most appropriate.

Clinical support targeted at the family unit considers how family interactions and relationships may be altered to improve functioning of the system (Bowen, 1978, 1995; Bowen & Kerr, 1988). Potential areas of clinical support for families living with ASD indicated by thesis findings include assessment of roles and boundaries within the FS,

facilitating healthy communication between family members, and optimising supports for and within the FS. Systemic approaches may also involve significant others such as extended family, friends, and teachers, who influence the FS. For example, a systemic intervention may involve the parents and adolescent with ASD meeting with teachers to collaboratively address issues at school, which may be indirectly impacting negatively on the home environment.

The present findings also suggest that subsystemic clinical support should target various dyads within the FS, such as parental and sibling relationships. Regarding parents, the findings of the thesis provide many possible directions for clinical services, such as assessment of parental roles and their impact on individual wellbeing and family functioning; psycho-education regarding common adolescent-related challenges; addressing issues of grief or loss associated with having a child with ASD; strengths based programs to facilitate greater recognition of the positive aspects of ASD; discussion of strategies to best support their partner; and awareness raising about the benefits of self-care and ASD social supports. Regarding sibling dyads, thesis findings indicate clinical interventions may include strategies to improve communication, healthy boundary setting strategies, and optimising opportunities to enjoy shared interests.

The importance of family members having the opportunity to access individual clinical support was indicated throughout the thesis. Individual clinical support may focus on challenges an individual experiences within the FS or may be about issues external to the FS (e.g., work-related stress, friendships, financial stressors) that influence wellbeing; thereby indirectly influencing an individual's ability to function positively within the FS. Areas of clinical support for adolescents with ASD indicated by thesis findings include providing developmentally relevant information about ASD and adolescence; developing coping strategies for managing puberty related issues; providing psycho-education and

skill development regarding adolescent relationships; monitoring, and where necessary intervention, for mental health issues; exploration of identity issues; and implementing strategies to increase self-esteem. Areas of clinical support for NTD adolescent siblings indicated here include providing information about ASD; developing strategies to manage challenges and communicate needs; creating opportunities to talk freely about feelings and experiences; encouraging identity development distinct from the FS; and facilitating opportunities to be involved in ASD sibling support groups.

9.4 Limitations and suggestions for future research

The conceptual and qualitative work in each Phase of the thesis provides novel insights into the lived experiences of adolescents with ASD and their families. While much can be learned from the findings, future research is needed to extend on the present findings and address some of the limitations, which are outlined below.

Whilst the qualitative methodology used in the second Phase of the thesis is a strength, given the dearth of literature investigating the direct perspectives of individuals with ASD and their families (Carrington, Templeton, & Papinczak, 2003; Fong, Wilgosh, & Sobsey, 1993; Vliem, 2009), some limitations with qualitative approaches warrant consideration when interpreting the findings. Fundamentally, the reported views and experiences are the subjective perceptions of the participants and cannot be considered representative of the views and experiences of all adolescents with ASD and their families. This issue may be of pertinence as some of the families were involved in more than one of the studies presented in this thesis. Future studies should endeavour to recruit larger samples, so as to improve the generalisability of findings. Further, future studies may investigate issues pertinent to adolescents with ASD using quantitative or mixed-methods approaches in order to further investigate issues raised in the thesis.

The adolescent sample utilised throughout the thesis may be considered relatively homogeneous when compared to previous research in the field (Benderix & Sivberg, 2007; Dew, Balandin, & Llewellyn, 2008). The adolescent-specific findings demonstrated the limitations of extrapolating findings from research with children or adults with ASD. Additionally, the findings highlighted the importance of considering the impact of gender when investigating the experiences of individuals with ASD. Despite these strengths, there are ways in which the sampling could be improved in future investigations. For example, the period of adolescence may be further broken down into early, middle, and late adolescence (Inhelder & Piaget, 1958; Levesque, 2011). Such in-depth investigations of adolescents with ASD are lacking, but are warranted in order to increase our understanding of this developmental period. Such investigations may suit longitudinal designs, as this will permit tracking of pertinent issues for adolescents with ASD and their families over time.

The qualitative studies considered various factors which had the potential to influence family dynamics, such as sibling gender, age, and birth order. However, there are areas in which the homogeneity of the samples may be improved. For example, factors such as cultural background, parental employment and socio-economic status, family cohesiveness, previous ASD interventions, and levels of support from extended family, were not controlled for in the present investigations. Future investigations would benefit from investigating the influences of these factors on research findings.

9.5 Conclusion

This thesis has addressed major conceptual and methodological limitations of existing literature by investigating the lived experiences of adolescents with ASD and their families. The findings significantly contribute to understanding of the complex nature of ASD, for both individuals with the condition, and their families. The qualitative studies

provide numerous directions for future research investigating the experiences of the adolescents with ASD and their families. Additionally, the thesis findings have the potential to directly inform clinical interventions for clinicians working with adolescents with ASD and their families.

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Appendix A: Qualitative research with families living with autism spectrum disorders: Recommendations for conducting semi-structured interviews

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Abstract

This paper draws on the insights and experiences of a research team involved in conducting qualitative research with families living with ASD. The paper provides reflections and recommendations across all stages of the qualitative research process, with particular attention to the stages involved in semi-structured interviews. More specifically, the paper provides reflections and recommendations for issues such as interview guide preparation, participant recruitment, obtaining informed and voluntary consent/assent, conducting effective interviews, accurate analysis and interpretation of data, ways to involve participants in data analysis, effective communication of research findings, and providing feedback to participants. In addition, the paper provides reflections and recommendations regarding researcher health across all stages of the researcher process.

Introduction

Research focusing on the experiences of individuals with Autism Spectrum Disorders (ASD) and their families is on the rise (Bayat, 2007; Bradford, 2010; Hastings, & Taunt, 2002). Reasons for this growing research attention include the increase in individuals being diagnosed with ASD (Boelte, & Poustka, 2000; Duchan, & Patel, 2012; Fombonne, 2002, 2003), and a growing recognition of the importance of understanding the complex impact ASD has on families (Cridland, Jones, Magee, & Caputi, 2013; Morgan, 1988; Seligman, & Darling, 2007). Many of the studies in this area have utilised qualitative methodologies (Cocks, 2008; Mascha, & Boucher, 2006). The benefits of using qualitative approaches when investigating families living with ASD include their capacity to measure the complex issues (such as family dynamics and mixed or ambiguous attitudes) (Cridland et al., 2013; Dew,

Balandin, & Llewellyn, 2008; King, Zwaigenbaum, Baxter, Rosenbaum, & Bates, 2006; Meadon, & Stoner, 2010) and emphasis on presenting rich descriptions rather than on testing a priori hypotheses (Krogh, & Lindsay, 1999). In addition, qualitative approaches are considered an appropriate method when involving children (Dockett, Einarsdottir, & Perry, 2009; Mishna, Antle, & Regehr, 2004) and individuals with disabilities (Barnes, 1992; Cocks, 2008) in research.

Of the range of qualitative methodologies (e.g., unstructured interviews, focus groups, observations, diaries, etc.), semi-structured interviews are one of the most commonly utilised methods in this research area (Krogh, & Lindsay, 1999). Semi-structured interviews involve in-depth conversations between the researcher and interviewee, which have an overall purpose prompted by the research aims, but are strongly guided by the interviewee's perceptions, opinions, and experiences (Carrington, & Graham, 2001; Minichiello, Aroni, Timewell, & Alexander, 1995). The benefits of using semi-structured interviews with families living with ASD include flexibility to focus on issues that are meaningful to participants (Barbour, 2000), permitting diversity of perceptions rather than being inhibited by 'standard' or 'expected' response categories (Mascha, & Boucher, 2006; Petalas, Hastings, Nash, Dowey, & Reilly, 2009a), and minimisation of researcher control over participants' expression of their experiences (Brewin, Renwick, & Fudge Schormans, 2008).

Literature exists for conducting qualitative research with children (Dockett et al., 2009; Mishna et al., 2004) and individuals with learning disabilities (Cocks, 2008; Krogh, & Lindsay, 1999). However, despite the increase of qualitative research in families living with ASD, we were unable to identify guidelines specifically for conducting research with this population. Identification of specific considerations for conducting qualitative research with individuals with ASD and their families is needed as literature based on either neurotypically developing (NTD) children or individuals with other disabilities cannot be directly applied to individuals with ASD. Central to this are the various social and communication impairments, behavioural difficulties, and cognitive processing differences inherent to ASD (Attwood, 2007; Deruelle et al., 2006; Sachse et al., 2013). There are also various unique experiences for family members of individuals with ASD which are worthy of consideration when conducting qualitative research with this population. Such unique experiences include positive and rewarding aspects of having a family member with ASD (Bayat, 2007; Pakenham et al., 2011), ongoing grief responses (O'Brien, 2007), and management of a range of unique intolerances, social misunderstandings, and sudden mood changes exhibited by

their family member with ASD (Attwood, 2007; Heiman, & Berger, 2007; Macks, & Reeve, 2007). These, and other, experiences warrant specific considerations for conducting research with this population.

The reflections and recommendations throughout this paper cover all stages of the qualitative research process. Figure 1 depicts these stages, which include research preparation, data collection, data analysis, and dissemination of research findings. Consideration is also given to the health and well-being of researchers in this area across all stages of the research process.

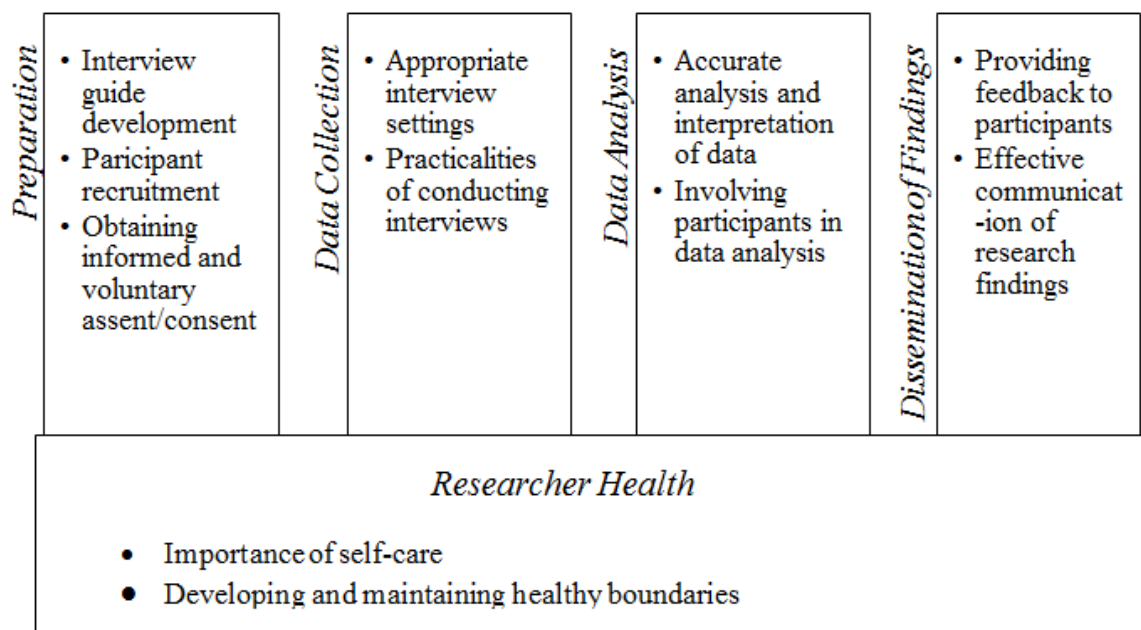


Figure 1: *Stages of qualitative research discussed in paper*

Preparation

Interview guide development.

Preparation is an important aspect of all research (Dickson-Swift, James, Kippen, & Liamputtong, 2007, 2008; Sandelowski, 1995). A critical component of preparation in qualitative research using semi-structured interviews is the development of the interview guide (Minichiello et al., 1995). The interview guide underpins the interview process, and therefore influences subsequent research stages (Minichiello et al., 1995). Given the range of considerations related to interviewing an individual with ASD (such as discomfort discussing certain topics, preference to discuss topics of interest to them), a strong interview guide is

likely to help researchers focus on these aspects rather than on practical components of the interviews (e.g., appropriate wording of interview questions).

Participant recruitment.

Effective recruitment strategies are another critical component of all research studies, as recruitment of an appropriate sample is a founding element to valid research data (Minichiello et al., 1995). Traditionally, recruitment of participants has relied on flyers, posters, and information in community newsletters (Minichiello et al., 1995). However, there may be various barriers to using traditional approaches when recruiting individuals with ASD given that responding to such material requires a willingness to engage socially (usually by phone contact) with the researchers. Social discomfort inherent to such engagement may present as a barrier to some individuals with ASD signing up for the study.

There may also be barriers to utilising such approaches when recruiting families of individuals with ASD. First, families living with ASD may frequently receive invitations to participate in research and, given the impersonal nature of traditional recruitment approaches, they may be less likely to read and respond to them (Krogh, & Lindsay, 1999). Additionally, responding to a study flier is unlikely to be a priority for families living with ASD, given they are busy with the pressures of having a family member with ASD in addition to the usual stressors of family life (Heiman, & Berger, 2007; Macks, & Reeve, 2007; Pakenham, Samios, & Sofronoff, 2005). Further, there is the possibility of recruiting a skewed sample when relying on these approaches as ‘high-functioning’ families may be more likely to respond (Kirkland, 2012).

Obtaining Informed and Voluntary Assent/Consent.

Obtaining informed and voluntary consent is a necessary component of all research (Agre, & Rapkin, 2003). It ensures that individuals understand the study aims, the commitment of being involved in the study, any potential risks and benefits of being involved, and the expected outcomes of the research (Agre, & Rapkin, 2003; van den Hoonaard, 2002). Further, informed consent is an ongoing process, rather than a time-limited event, and it is best sought at all stages of research (van den Hoonaard, 2002)

Whilst parents/carers of individuals with ASD are likely to be the family members who initially show interest in the study, it is important to ensure they do not provide consent on behalf of other members of their family. Individuals with ASD (Cocks, 2008) and children

(e.g., neurotypically developing [NTD] siblings) (Mishna et al., 2004; Potter, & Hepburn, 2005) may be particularly vulnerable to having their consent provided for them (Cocks, 2008). Similarly, while parental/carer consent is generally the primary requirement needed for children to be involved in research, this should not replace obtaining assent from the individuals with ASD and children themselves (Dockett et al., 2009).

Data collection

Appropriate interview settings.

Semi-structured interviews are often conducted within the family home in this research area (Mascha, & Boucher, 2006). Benefits of this approach include avoiding connotations of a clinical assessment; promoting familiarity for participants; and gaining a unique understanding of family dynamics (Mascha, & Boucher, 2006).

The main challenge of conducting interviews within the family home is ensuring interviews are completed in an appropriate private space in order to maintain participant confidentiality (Mascha, & Boucher, 2006). Participants may not recognise the importance of conducting the interviews in a private space; saying their family is ‘open’ with discussing all issues in front of each other (Dockett et al., 2009). If this is the case, it is important to discuss the need for participant confidentiality. Other possible drawbacks of conducting interviews within the family home include safety issues and practicalities of travel for researchers (Minichiello et al., 1995).

Practicalities of conducting interviews.

Numerous practical issues need to be considered when conducting qualitative research with families living with ASD. Such issues include organising interviews at an appropriate time of day for participants; allowing ample time to travel to scheduled interviews; conducting interviews at an appropriate pace; and considering the most appropriate method of recording the interview (e.g., scribing, voice-recording, or video-recording). Consideration of such issues during the planning stages of research will help facilitate effective interviews. Additionally, it may be necessary to reflect on the processes in place during the data collection stages and make appropriate changes if warranted.

The skill base of interviewers is an important consideration in all qualitative research (Brinkmann, 2007). Generally it is recommended that, at a minimum, interviewers are well acquainted with the interview guide and familiar with the interview process (Brinkmann,

2007; Minichiello et al., 1995). Additionally, personality characteristics such as patience, an open and empathetic attitude, and an ability to listen are highly valued (Brinkmann, 2007). In this context, it is also important that researchers have a clear understanding of the characteristics of ASD and how these may present in participants (Cocks, 2008; Krogh, & Lindsay, 1999).

Data analysis

Accurate analysis and interpretation of data.

In qualitative research, data analysis and interpretation are overlapping, yet conceptually different, processes. More specifically, qualitative analysis involves the breaking-down of data, whereas qualitative interpretation illuminates a new way of understanding the data while remaining faithful to the original data (van den Hoonaard, 2002). Importantly, the analysis and interpretation stages of qualitative research are influenced by all other stages of research including preparation, data collection, transcribing, and reading of transcripts (van den Hoonaard, 2002).

Issues to be considered during data analysis and interpretation include considering transcribing as an integral component to the data analysis process; reflecting on what participants discuss as well as issues they do not discuss in interviews; and having multiple researchers involved in the analysis and interpretation of data.

Involving participants in data analysis.

Involving participants in data analysis is a relatively recent concept (Dockett et al., 2009). The rationale behind involving participants in data analysis is to ensure data is accurate (Dockett et al., 2009) and is in line with the process of ongoing informed consent (van den Hoonaard, 2002). There are benefits to including participants in data analysis such as giving participants the opportunity to reflect on their interviews and brainstorm 'themes' emerging from their interviews, and developing an appreciation of the research process (Dockett et al., 2009). Further, some participants may find such involvement to be rewarding and/or therapeutic (Dockett et al., 2009).

One challenge of involving participants in data analysis processes is the possibility that participants may reflect on certain things they had said (particularly discussion of negative aspects of living with ASD) and express a desire for such aspects of the interview to not be included in analysis (Barbour, 2000). Another challenge may be participants asking to read

other family members' transcripts; particularly parents asking to read their children's transcripts. Strategies to manage these challenges include normalising experiences of discomfort when reading transcripts; discussing the use of de-identified data when reporting results; discussing the rights of participants to withdraw consent from the study; and discussing the rationale regarding not allowing participants to read others' transcripts (i.e., participant confidentiality).

Dissemination of findings

Effective communication of research findings.

The communication of qualitative research studies is traditionally confined to academic journal articles and/or conference proceedings (Keen, & Todres, 2007). This can often limit the application of research findings in facilitating positive change for the lives of those impacted by the research - in this case families living with ASD. Put another way, the dissemination of research findings to practice is often seen as a task beyond the research process (Keen, & Todres, 2007). However, we recommend considering the dissemination of research findings as an integral component of the research process (see Figure 1).

The criteria on which dissemination strategies should be based is the intended target audience of the research. Target audiences for research focusing on individuals with ASD include families, clinicians, health practitioners, teachers, policy makers, and so on. Therefore, dissemination strategies may include a range of approaches from presenting at local ASD community groups to presenting to key stakeholders such as governments and other policy makers.

Providing feedback to participants.

Communicating feedback to participants about the results of the study is not considered a necessary component of the research process. However, there may be a range of benefits of doing so. First, feedback provides participants with findings of the study and overall outcomes of the research (e.g., policy changes, publications, funding, etc.) which they may not otherwise have learned. Additionally, families living with ASD who participate in ASD research are likely to have a genuine interest in the research outcomes and therefore appreciate feedback. Feedback also acknowledges the significant commitment of participating in research and may facilitate participants having positive experiences of being involved in qualitative research. Further, providing feedback to participants may help

consolidate research findings for the researcher and highlight the issues of importance for families living with ASD (Keen, & Todres, 2007). Feedback about research findings and outcomes may occur periodically or at the conclusion of the research, depending on the nature of the project.

Researcher health

Importance of self-care.

Self-care involves a range of activities aimed to facilitate physical, emotional and psychological wellbeing, such as exercise, social activities, hobbies, and travelling. The importance of self-care for qualitative researchers investigating emotionally laden topics is recognised, however often overlooked (Killen, 1998; Rager, 2005a, 2005b). Researcher self-care is imperative across all aspects of the research process.

In discussing the potential for emotional effects of conducting qualitative research with families living with ASD, it is not our intention to recommend researchers guard against all emotional reactions to research. On the contrary, we recognise the important role of emotion in qualitative research (Brinkmann, 2007; Rager, 2005a, 2005b), such as the ability to empathetically consider the psychological world of participants. Rather, we recommend that researchers utilise strategies to manage the possible negative emotional impacts of conducting qualitative research. Such strategies include being involved in debriefing sessions, maintaining a journal, and organising interviews with adequate spacing to reduce the intensity of interviewing commitments and allow ample time for reflection between interviews.

Developing and maintaining healthy boundaries.

In qualitative research, it is common for researchers to negotiate multiple roles (such as data collector and empathetic listener) (Lavis, 2010). In fact, these multiple roles are often considered necessary for effective qualitative research whereby the researcher must conduct ethical practices while simultaneously developing authentic relationships with participants (Lavis, 2012). Developing and maintaining healthy boundaries around researcher roles is critical for conducting research in this field, given the potential for role confusion that may result when involving children and/or individuals with disabilities in research (Brinkmann, 2007). Boundary confusion is a bidirectional process whereby misunderstandings from either the researchers or participants can result in inappropriate roles (Brinkmann, 2007). Strategies

to help maintain healthy boundaries include a clear understanding for both researchers and participants about the role of the researcher and limitations to this role, and utilising various monitoring strategies such as other researchers attending the interviews or reading the transcripts.

Table 1 provides detailed recommendations based on the issues discussed above. The recommendations are based on the literature and experiences from the authors' involvement in qualitative research focusing on families living with ASD.

Conclusion

Conducting qualitative research with individuals with ASD and their families is not easy, as highlighted by the range of challenges and considerations discussed throughout this paper. However, with these challenges also comes a multitude of rewards; predominantly the opportunity to meet incredible individuals and hear their stories. Just as we attempt to do justice to the significance of participants' experiences during the write-up of empirical papers, we aim to honour the significance of our research practices by sharing our experiences with other researchers with this paper. We envisage that this paper will contribute to existing knowledge regarding conducting quality qualitative research with individuals with ASD and their families and promote more understanding of ASD in general.

Table 1: Recommendations

	Research stage	Recommendation	General rationale	Rationale for ASD ^a research
1a.	<i>Preparation:</i> Interview guide development	Include an introductory statement.	An introductory statement before commencing the interview can be helpful in reminding participants about the general content of the interview and the expected length of the interview. Including the introductory statement will facilitate a clear and concise introduction and ensure its inclusion in the interview process.	An introductory statement may be particularly relevant for individuals with ASD given their general preference for preparedness (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012).
1b.	<i>Preparation:</i> Interview guide development	Begin interviews with a ‘warm-up’ question.	A ‘warm-up’ question will ‘set the scene’ for the interview whilst simultaneously allowing participants to experience mastery and relax into the interview. Example ‘warm-up’ questions may be ‘Tell me who is in your family’ or ‘What activities do you like doing with your family?’	Initial nervousness may be of particular relevance when interviewing individuals with ASD due to the social and communicative impairments associated with their condition (Cridland, Caputi, Jones, & Magee, 2013a; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012).
1c.	<i>Preparation:</i> Interview guide development	Provide a prelude to challenging questions.	A prelude prepares participants for the upcoming question and normalises any feelings of confusion or discomfort they may have. An example of a prelude is, ‘Some people find the next few questions difficult...’	There are topics that individuals with ASD are likely to find challenging to talk about, such as discussing abstract concepts; social difficulties; emotions; perspective talking; etc. A prelude to challenging questions may help prepare participants with ASD and their families for questions they may find difficult.
1d.	<i>Preparation:</i> Interview guide development	Structure interview guide to have challenging questions followed by easier topics.	Oscillating between challenging and less challenging topics can help reduce the emotional and psychological demands of the interview on participants.	Efficacious ‘easy’ questions should either aim to foster mastery and relate in some way to the research topic (Minichiello et al., 1995). ‘Easy’ questions for individuals with ASD about hobbies or special interests are best avoided as they may lead to lengthy conversations of little relevance to the focus of the study. It may also be difficult to redirect participants back to the interview.
1e.	<i>Preparation:</i> Interview guide development	Develop single-faceted questions	Single-faceted questions are easier for participants to understand and accurately interpret. Examples of single faceted questions are, ‘What are your favourite subjects at school?’ and ‘How do you find homework?’. This is opposed to a multifaceted format; ‘What are your favourite subjects at school and how do you find homework?’.	Single-faceted questions suit the processing style of participants with ASD and facilitate accurate interpretation of the question (Cridland et al., 2013a; Solomon, et al., 2012).

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
1f.	<i>Preparation:</i> Interview guide development	Use both positively and negatively framed questions	Using positively and negatively framed questions facilitates discussion of both rewarding and challenging experiences, attitudes, and feelings, which contributes to a balanced understanding of issues.	It is recognised that living in a family with ASD involves both rewarding and challenging experiences, attitudes and feelings (Cridland, Jones, Magee, & Caputi, 2013b; Davis, & Gavidia-Payne, 2009; Pakenham et al., 2005) and these issues need investigation. In doing so, it may be important to acknowledge that not all participants will share the range of experiences. A prelude such as, ‘Some people find rewarding aspects of living with ASD. Have you experienced this?’ may help normalise discussion of living with ASD and encourage open discussion.
1g.	<i>Preparation:</i> Interview guide development	Avoid using leading questions	All research studies have aims and hypotheses; however it is important that interview questions do not elicit responses solely in support of these hypotheses. An example of a leading question in a study focusing on the challenges of transitioning to high school would be, ‘What have been the hardest parts of transitioning to high school?’. An example of a ‘neutral’ question for investigation of this issue would be, ‘What has been your experience of transitioning to high school?’	When responding to questions, individuals with ASD may be more likely to provide answers that are specific the question posed rather than using that question as a platform to elaborate on, as NTD ^b participants may. Therefore, continuing with the current example, if participants with ASD are asked about the challenges of high school they are likely to only discuss challenges even if they think there are also positive aspects (Cridland et al., 2013a).
1h.	<i>Preparation:</i> Interview guide development	Pilot test the interview guide	Pilot testing the interview guide is helpful in estimating time needed to conduct the interview and promote researcher familiarity with the interview guide.	Pilot testing with an individual with ASD may be useful in identifying questions that may be confusing or open to misinterpretation.
1i.	<i>Preparation:</i> Participant recruitment	Provide multiple methods of contact when advertising the study	Providing multiple methods of contacting the research team gives participants flexibility in response options. Methods of contact may include; text message services, email, or social media such as Facebook.	Some methods of contact (such as emails) may be less socially demanding on individuals with ASD, which may encourage response rates to the study. Additionally, options such as text messages may be less time demanding for family members.
1j.	<i>Preparation:</i> Participant recruitment	Provide clear and detailed information about the study in recruitment information	Providing participants with transparent and detailed information about the study during recruitment may encourage potential participants to respond to the study advertisement. Such information may include study aims, participant requirements, study timeframe (e.g., recruitment cut-off, data collection phases, etc), and expected benefits to participants.	Providing detailed study information when recruiting individuals with ASD may improve response rates. This is likely to be associated with the social and communicative impairments inherent with ASD.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
1k.	<i>Preparation:</i> Participant recruitment	Employ some non-traditional recruitment approaches	Employing some non-traditional recruitment approaches will increase the number of potential participants that the study is advertised to.	Approaches that may be effective when recruiting families living with ASD include attending community ASD support groups; outlining the study to school teachers in order for them to personally provide information to families of students with ASD enrolled in their school; and snowballing from recruited participants.
1l.	<i>Preparation:</i> Participant recruitment	Include information about the expected positive outcomes of being involved in the study	Being involved in qualitative research has been found to be a rewarding and enriching experience for participants (Dickson-Swift et al., 2007, 2008; Dockett et al., 2009; Rager, 2005a, 2005b). Sharing this information with potential participants may increase their interest in being involved in the study.	The positive outcomes of being involved in qualitative research for families living with ASD may include having an opportunity to discuss issues important to them; developing greater awareness and understanding of family member's perspectives, and having an opportunity to 'give back' to the ASD community.
1m	<i>Preparation:</i> Obtaining informed and voluntary assent/consent	Organise a 'preliminary meeting' with potential families to outline the study	A 'preliminary meeting' is useful for providing potential participants with written and verbal information about the study and requirements of participants (e.g., time commitment). It is also useful for answering participant questions, and ensuring research eligibility criteria are satisfied.	During this meeting it may be useful to ask what terminology a family uses to refer to the ASD diagnosis (e.g., Autism, Asperger's, Aspie, etc.) and ensure that all relevant family members have knowledge of the ASD diagnosis.
1n.	<i>Preparation:</i> Obtaining informed and voluntary assent/consent	Obtain informed assent from child participants	While written assent from child participants is not always necessary to fulfil ethical requirements of research (Agre, & Rapkin, 2003; van den Hoonard, 2002), its inclusion is important to ensure all participants are voluntarily participating in the study.	Child participants in this research area include children with ASD and NTD siblings. In utilising assent forms for children with ASD a 'checklist' format may be appropriate as participant requirements can be clearly outlined.
1o.	<i>Preparation:</i> Obtaining informed and voluntary assent/consent	Remind participants of the research aims and participant commitments at each contact	Discussing research aims and participant commitments regularly facilitates informed and voluntary assent/consent. These discussions may involve providing participants with a study information sheet and/or consent form and asking if they would like to continue their involvement in the study.	Ongoing consent is of particular relevance when involving individuals with ASD in research, as they may have additional queries about the study which they may not ask unless overtly given the opportunity.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
1p.	<i>Preparation:</i> Obtaining informed and voluntary assent/consent	When conducting research with families, ensure consent is obtained from individual family members	Whilst parents/carers may be the family members who initially show interest in the study, it is important that they do not provide consent on behalf of other members of their family. Additionally, we advise against requiring all family members to be involved in the study in order for a family to be eligible for study participation. This flexibility will reduce the possibility of some family members feeling pressured to provide consent and also reduce the number of families deemed ineligible for the study.	Individualised consent procedures are equally important in families living with ASD. Further, the literature highlights that individuals with ASD (Cocks, 2008) and children (e.g., NTD siblings) (Mishna, et al., 2004; Potter & Hepburn, 2005) are particularly vulnerable subgroups in having their consent provided for them.
1q.	<i>Preparation:</i> Obtaining informed and voluntary assent/consent	When conducting research with families, clearly outline confidentiality procedures	Clearly outlining confidentiality procedures ensures participants are aware that information provided during interviews will not be shared with other family members (unless the study has an open nature). This awareness may encourage openness during the interviews and prevent participants asking about other family members' responses.	Participants may feel reluctant to speak openly about the challenging aspects of living with ASD if they are uncertain whether their interviews will be shared with other family members. This may result in denial or minimisation of such topics.
2a.	<i>Data Collection:</i> Appropriate interview settings	Ensure home interviews are conducted in an appropriate private space.	Conducting home interviews in an appropriate private space, such as a quiet living area or study, ensures confidentiality of information shared. Additionally, there will be fewer distractions for participants and a quiet environment for clear recording (if utilised).	Conducting home interviews in a private space may facilitate discussion of challenging issues, such as the difficulties of living in a family with ASD, which participants may otherwise feel hindered to discuss openly if they felt family members could overhear.
2b.	<i>Data Collection:</i> Appropriate interview settings	Consider using alternative venue if home interviews are not appropriate	Alternative venues should be considered if there is no appropriate space within the family home (e.g., open plan living, strained family relationships, etc.), or if participants and/or the researcher do not feel comfortable/safe conducting the interview within the home. Suitable venues include a quiet room in the researchers' workplace, or a bookable room in a community building such as a library.	Alternative venues should be considered if interviews involve discussion of difficult topics associated with living with ASD, and the researcher or participant feel it is not appropriate to discuss these issues within the family home. Relevant safety issues include unexpected responses or behavioural reactions. For example, a participant may become highly aroused if feeling confused about a question or feeling uncomfortable about discussing a particular topic. Strategies to promote a safe environment include conducting interviews with two researchers (a primary researcher conducting interview and a second to observe/scribe); and/or ensuring a parent/carer is available but not present.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
2c.	<i>Data Collection:</i> Practicalities of conducting interviews	Schedule interviews at a preferred time for participants	Participants are more likely to be engaged in the interview process if it is conducted at a time suitable for them. In order to conduct interviews at appropriate timeslots, researchers may need to be flexible, which may include conducting interviews outside of business hours (such as weekends).	The engagement of participants with ASD may be particularly influenced by the timing. For example, mornings may be identified as a 'good' time for an interview rather than shortly after school or work when they may be stressed or tired. Additionally, contacting participants with ASD before the interview to check the arranged time is still appropriate is recommended. Rescheduling if needed is important as conducting an interview with an individual with ASD who is not in an appropriate frame of mind, may result in tainted responses (e.g., negatively framed responses or lack of responses).
2d.	<i>Data Collection:</i> Practicalities of conducting interviews	Allow ample time when travelling to interviews to ensure punctuality	Apart from a general sign of courtesy, punctuality portrays a professional attitude towards the research. Arriving on time is also a sign of respect for the participant's time commitment of being involved in the study.	Punctuality may be of particular relevance for interviews with individuals with ASD, as they may become agitated or upset if the researcher is late.
2e.	<i>Data Collection:</i> Practicalities of conducting interviews	Take time to build rapport with participants	The importance of rapport building in qualitative research is well established (Brinkmann, 2007; Lavis, 2010; van den Hoonaard, 2002). However, in building rapport it is important to not just 'do' rapport, where the researcher engages in 'faking friendship' in order to obtain knowledge from the participant (Brinkmann, 2007).	Rapport building is essential in this research area given the highly personal nature of research topics. Rapport with families living with ASD is likely to be established by showing a genuine interest in their experiences; having an open attitude throughout the interview; and regarding the participant as the expert on the interview topic.
2f.	<i>Data Collection:</i> Practicalities of conducting interviews	Be aware of your rate of speech when asking interview questions	Asking interview questions in a measured, slow pace facilitates accurate interpretation.	A slower pace of information presentation has been shown to suit the processing style of individuals with ASD (Deruelle, Rondan, Gepner, & Fagot, 2006; Sachse et al., 2013; Smith Myles, & Simpson, 1998). Related to this, individuals with ASD may require a longer length of time to provide an answer to interview questions (Deruelle et al., 2006) and researchers should allow ample time for a participant to respond before checking-in that they understood the question.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
2g.	<i>Data Collection:</i> Practicalities of conducting interviews	Consider video recording interviews	The benefit of using video-recordings over voice-recordings is the ability to analyse both verbal and visual information (e.g., facial expression, hand gestures, body movements, etc).	Video-recording interviews is an emerging methodological approach in this field (Meirsschaut, Roeyers, & Warreyn, 2011; Mossman-Steiner, 2011; Naber et al., 2008). The benefits of this approach when interviewing participants with ASD includes ability to analyse inconsistencies between verbal responses and body language, individualised uses of hand gestures, and use of eye-contact.
2h.	<i>Data Collection:</i> Practicalities of conducting interviews	Leave recording device going until the interview has come to an absolute conclusion	Participants may continue to speak after the last interview question and useful information may be missed if not recorded.	Participants often continue to share their experiences of living in a family with ASD after the interview.
3a.	<i>Data Analysis:</i> Accurate analysis and interpretation of data	Transcribe interviews rather than utilising scribes	Transcribing has been considered as an integral component of preliminary data analysis (van den Hoonaard, 2002). Transcribing is also an important way to improve interview techniques, such as the wording of questions, smooth transitioning between topics, and beginning and concluding the interview.	Improving interview techniques as a result of the transcribing may be particularly important when interviewing individuals with ASD given the heightened importance of appropriate wording of questions and suitable beginnings and conclusions of interviews with these individuals.
3b.	<i>Data Analysis:</i> Accurate analysis and interpretation of data	Attend to issues that participants do not discuss	There is a focus on what a participant says in qualitative research. However, it is also important to reflect on issues participants do not discuss. Participants may not discuss issues due to legitimate irrelevance of a topic, minimal rapport with the researcher, or a desire to portray a certain image during the interview.	Participants may find it difficult or even taboo to discuss the challenges of living in a family with ASD. Similarly, participants may wish to portray an image of resilience or positivity by focusing on the rewarding aspects of living in a family with ASD.
3c.	<i>Data Analysis:</i> Accurate analysis and interpretation of data	Have multiple researchers code the data	The credibility of qualitative data analysis is improved with multiple researchers coding the data (Barnes, 1992; Braun, & Clarke, 2006). The process of coding with multiple researchers includes a primary researcher conducting, transcribing, and analysing the data, while other members of the research team read, and independently code the data for comparison (Braun, & Clarke, 2006).	Multiple coders is important when conducting research with families living with ASD because it is common for researchers in this field to have strong connections and investment with the research topic (Potter, & Hepburn, 2005) and this background may interfere with objective data analysis. It is important that researchers are aware of their potential for bias (Brinkmann, 2007; van den Hoonaard, 2002).

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
3d.	<i>Data Analysis:</i> Accurate analysis and interpretation of data	Use analytical techniques that model the characteristics of family data.	In using analytical techniques that model the characteristics of family data researchers are able to gain insights into interpersonal relationships within the family, in addition to the perceptions from individual family members.	In researching families living with ASD there may be discrepant perceptions across family members (e.g., a sibling reporting that they take on significant caregiving responsibilities, while parental reports indicate they do not contribute enough). These issues are worthy of investigation.
3e.	<i>Data Analysis:</i> Involving participants in data analysis	Include participants in data analysis	Including participants in data analysis may involve giving participants the opportunity to read their own transcripts (member checks); and encouraging participants to brainstorm ‘themes’ emerging from their interviews. In addition, participants may be invited to read drafts of reports and provide feedback to researchers.	Including individuals with ASD and their families in data analysis is in line with recommendations in the literature (Cocks, 2008; Dockett et al., 2009; Mishna et al., 2004). The benefits of including these participants in data analysis include giving participants the opportunity to reflect on their interviews; and developing ownership of their data and an appreciation of the research process. Further, some participants may find this process rewarding and therapeutic.
4a.	<i>Dissemination of Findings:</i> Effective communication of research findings	Provide feedback about the study’s findings to relevant individuals and community groups	The benefits of providing feedback to relevant individuals and community groups include sharing of research information and fostering networks which may be utilised in future research endeavours.	Relevant individuals and community groups for research focusing on individuals with ASD may include local ASD community groups, ASD research centres, as well as mainstream and ASD specific schools.
4b.	<i>Dissemination of Findings:</i> Effective communication of research findings	Consider target audience when choosing journals to publish research findings	To facilitate effective communication of research findings, it is important to consider the intended target audience of the research when choosing journals to publish in rather than focusing on other research criteria such as the prestige of the journal. Additionally, be prepared that the target audience may change over the course of the research.	Target audiences for research focusing on individuals with ASD may include families, clinicians, health practitioners, teachers, policy makers, etc.
4c.	<i>Dissemination of Findings:</i> Effective communication of research findings	Consider presenting findings to community members.	Academic journals and conferences have their place in disseminating research findings, however it may be efficacious to also pursue other avenues when disseminating findings to the broader community. Such avenues may include community forums, radio stations, and newspapers and/or television news programs.	When disseminating research findings to community members interested in ASD research it may be efficacious to present findings at local ASD community groups, forums, etc. Additionally, when utilising mainstream media avenues, it may be useful to advertise upcoming programs at the local ASD community groups.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
4d.	<i>Dissemination of Findings:</i> Providing feedback to participants	Provide participants with written feedback about the study's findings	Information sheets are an appropriate method for providing feedback to participants because they provide a succinct outline of information, they are a tangible resource for participants to refer to, and they are economical and practical. The main drawback of information sheets is that they may be considered impersonal.	When developing information sheets for individuals with ASD, a structured format (i.e., use of headings, bullet points, etc) may facilitate their understanding of the information. Additionally, it may be useful to provide information about local ASD community groups for participants who are not linked in with support services.
4e.	<i>Dissemination of Findings:</i> Providing feedback to participants	Provide participants with the opportunity to come to a group feedback session	Group feedback sessions are useful for conveying in-depth findings and provide participants with an opportunity ask questions and provide comments. Considerations when conducting feedback sessions for families include running sessions at various times/dates to cater for commitments such as work and after school activities; providing a venue with suitable child minding facilities; and providing written information for participants who were unable to attend.	A secondary benefit of group feedback sessions is an opportunity for participants to interact with other families living with ASD. The social support provided by such feedback sessions may be equally as important to participants as receiving information about the outcomes of the study.
4f.	<i>Dissemination of Findings:</i> Providing feedback to participants	Reflect on the impact of being involved in the study with participants	Reflections from the research team may include professional and/or personal insights, challenges and rewards of conducting the research. Additionally, reflections from the research team acknowledge the significance of participants' sharing their experiences for the research.	Qualitative research investigating the experiences of families living with ASD is likely to involve participants sharing a range of highly personal experiences meaning reflections from research team about their experiences of being involved in the research may be particularly warranted.
5a.	<i>Researcher Health:</i> Importance of self-care	Be involved in debriefing sessions to manage the emotional impact of conducting qualitative research	Debriefing sessions allow researchers to reflect on challenging experiences, discuss ways of improving research processes, and experience moral support. Debriefing personnel may include research team members and/or supervisors. Importantly, debriefing sessions should not replace professional support, which may be necessary if researchers are seriously impacted from the study.	Researchers should not underestimate the emotional impact of conducting interviews with families living with ASD. Reasons for this include listening to difficult experiences, being with participants who are emotional or have behavioural outbursts, and providing a supportive and non-judgemental attitude throughout interviews.
5b.	<i>Researcher Health:</i> Importance of self-care	Maintain a journal to manage the emotional impact of conducting qualitative research	Journal keeping has been shown to help manage the emotional impact of being involved in qualitative research and also promote reflective thinking that facilitates data interpretation (Rager, 2005b).	As outlined in section 5a., managing the emotional impact of conducting interviews with families living with ASD is an important issue in this research area. Journal keeping may be one strategy to assist with this.

	Research Stage	Recommendation	General Rationale	Rationale for ASD research
5c.	<i>Researcher Health:</i> Importance of self-care	Space interviews apart to manage the emotional impact of interviewing	Organising interviews over an extended period may contribute to researcher self-care as it reduces the intensity of conducting the interviews and allows time for reflection between interviews.	Spaced interviews may be particularly warranted when conducting research with families living with ASD given the range of emotionally laded topics that may be inherent to the research topic.
5d.	<i>Researcher Health:</i> Developing and maintaining healthy boundaries	Be aware of the potential for boundary confusions	Boundary confusion can occur when researchers or participants become unclear around the researchers' primary role (which is to collect data rather than being a friend or clinician). The potential for boundary confusion is high in qualitative research due to the personal nature of research topics and the supportive method in which they are conducted. Strategies to minimise boundary confusion include clearly outlining the roles of the researcher prior to interviews, having multiple researchers attend interviews, having transcripts read by other researchers to monitor boundary maintenance, and ongoing debriefing sessions for researchers.	Being aware of the potential for boundary confusion may be particularly important when conducting qualitative research with families living with ASD. Firstly, children and individuals with ASD may find it difficult to understand the unique role of a researcher, particularly when interviews are conducted with a supportive nature and within the family home. Secondly, the emotionally laden topics that are often inherent to this research area may lead participants to become confused about the researchers' role. Additionally, researchers themselves may become confused about their role, particularly if they have personal connection to the research topic and/or professional roles other than a researcher (e.g., counsellor, support worker, teacher, etc.).
5e.	<i>Researcher Health:</i> Developing and maintaining healthy boundaries	Consider the differences in power in the roles of researchers and participants	In most research, there is a power difference between researcher and participant due to the researcher's in-depth knowledge of the particular research area. However, in qualitative research it is acknowledged, and even embraced, that participants are the expert in their own right as it is their personal experiences and opinions that are under investigation (Brinkmann, 2007).	It may be helpful to acknowledge the participants' unique role as 'expert' regarding being an individual/family member living with ASD. Such acknowledgement may facilitate participants' sense of mastery and highlight the value of sharing their experiences in the research.

^a ASD: Autism Spectrum Disorder ^b NTD: Neurotypically Developing

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Appendix B: The 20th International Congress on Personal Construct Psychology

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2013, July). *Understanding high functioning autism during adolescence: A personal construct theory approach*. Paper presented at the 20th International Congress on Personal Construct Psychology, Sydney, Australia.

Abstract

Preliminary research towards applying Personal Construct Theory (PCT) concepts and methodologies to understanding individuals with High Functioning Autism (HFA) have suggested its utility for both research and clinical interventions. The developmental period of adolescence has also been outlined according to PCT. Importantly, however, PCT has not been applied to the more specific subgroup of adolescents with HFA, despite various theoretical tenets suggesting its utility. In addressing this research gap, we consider the following adolescent developmental tasks with particular relation to adolescents with HFA; (i) functioning within the increasingly complex world of adulthood, (ii) identity development, and (iii) development of higher order processing styles (including abstract thinking and flexible processing). These issues are described using PCT concepts. We consider ways to support individuals, and families, living with adolescents with HFA.

Appendix C: Three Minute Thesis Finals Competition Slide

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2013, October). *Puberty blues? The experience of adolescence for individuals with Asperger's syndrome and their families*. Presented at the University of Wollongong Three Minute Thesis Finals Competition, Wollongong, Australia.

'Puberty Blues'?

The Experience of Adolescence for Individuals with Asperger's Syndrome and their Families


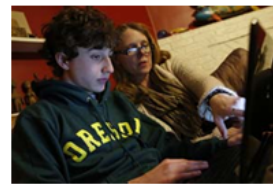
Asperger's Syndrome (AS) is a form of Autism.
Individuals with AS have significant difficulties with communication and social interaction

Significance of research:
First study to explore in-depth experiences of adolescents with AS and their family members

Outcomes of research:
Findings will contribute to strategies for providing clinical support for adolescents with AS and their families.


5 Interesting Findings from my Research


- 1) Adolescence is a complicated time for individuals with AS and their families
- 2) Perceptions differed amongst family members
- 3) There are both positive and negative impacts of living with AS
- 4) Involving girls with AS in the research highlighted both similarities and unique experiences
- 5) A range of researcher issues are involved when conducting research with individuals with AS and their families

Clinical PhD Candidate | Liz Cridland

Supervisors | A/Prof. Peter Caputi | Prof. Sandra Jones | Dr. Christopher Magee





Appendix D: The 49th Australian Psychological Society Annual Conference

Cridland, E.K., Caputi, P., Walker, B., Jones, S.C., & Magee, C.A. (2014, September).

The use of dependency grids when working clinically with families living with autism spectrum disorder. Workshop presented at the 49th Australian Psychological Society Annual Conference, Hobart, Australia.

Abstract

The dependency grid is a clinical tool associated with Personal Construct Psychology used to explore the resources individuals use to cope with challenges. When used with families, dependency grids facilitate exploration of family interactions; roles; boundaries; and general functioning, which are often otherwise difficult to convey. The method of assessing family functioning provided by dependency grids may be particularly useful for clinicians working with families living with Autism Spectrum Disorder (ASD), as individuals with ASD often have difficulty effectively communicating their needs and understanding their roles within the family system. Additionally, the information provided by dependency grids can facilitate treatment planning and evaluation. The aim of this workshop is to provide participants with foundational knowledge about the clinical application of dependency grids when working with families, with particular attention to families living with ASD. In doing so, participants will gain experience in administering and analysing a dependency grid. Family case studies completed by the presenters will also be discussed throughout the workshop to facilitate learning. In addition, feedback from families involved in dependency grid assessment and interventions will be provided. The information and skills offered in this workshop will provide participants with practical tools that they can utilise in their future clinical work with families.

Appendix E: The 22nd Annual PsychDD Conference

Cridland, E.K., Jones, S.C., Caputi, P., & Magee, C.A. (2013, December). *Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence*. Paper presented at the 22nd Annual PsychDD Conference, Homebush, Australia.

Abstract

This study investigates the experiences of adolescent girls with Autism Spectrum Disorders (ASD) during adolescence. Semi-structured interviews were conducted with three mother-daughter dyads and two additional mothers. A range of issues were highlighted covering physical, emotional, social and sexual domains. Some of these issues were similar to those experienced by boys with ASD during adolescence, such as negative implications of late diagnosis, challenges of transitioning to and coping with high school, 'hands-on' role of parents into adolescence, difficulties adjusting to the increased demands of adolescent hygiene routines, and the importance of learning personal boundaries in interactions with others. Other issues discussed were of particular relevance to adolescent girls with ASD, such as difficulties socialising with neurotypically developing girls, sex-specific puberty issues, and sexual vulnerabilities. This study highlights an important research area and is a preliminary step towards understanding the experiences of adolescent girls with ASD and their families.

Appendix F: DSM-V Diagnostic Criteria for Autism Spectrum Disorder

The following diagnostic criteria are from the DSM-V (American Psychiatric Association, 2013).

An individual must meet criteria (a), (b), (c), and (d):

(a) Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.
2. Deficits in nonverbal communicative behaviours used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behaviour to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

(b) Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

(c) Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).

(d) Symptoms together limit and impair everyday functioning.

Appendix G: Subsystems with the Family System

The parental subsystem

The parental subsystem includes the interactions between mothers and fathers and their children. The parental system can be further defined to describe ‘maternal’ (mother and child), ‘paternal’ (father and child) subsystems. The parental subsystem has also been referred to as the ‘executive’ subsystem given the hierarchical structure of most families (Ferrari, & Sussman, 1987). The primary roles of parental figures are to provide leadership and support for their children and the family system (FS) as a whole. The parental roles are predominantly filled by the biological parents of children; however it is increasingly recognised that these roles can be filled or partially filled by other figures such as stepparents, extended family, and even siblings (Ferrari, & Sussman, 1987).

The spousal subsystem

The spousal subsystem refers to the relationship between partners (traditionally the husband and wife) (Herbert, & Harper-Dorton, 2002). In a healthy spousal dyad both partners experience a fulfilling relationship and share intimacy, support, and growth opportunities with each other (Seligman, & Darling, 2007). Inherent to FS approaches, the spousal subsystem is understood to have reciprocal influences on the other subsystems within the system. For example, conflict within the spousal subsystem may cause tension amongst the sibling and/or parental subsystems. Conversely, conflict within sibling or parental subsystems’ is likely to increase spousal stress (Brown, 1999; Hales, & Glasscock, 1998). Importantly, spousal conflict or disagreement does not necessarily equate to poor functioning of the FS.

The sibling subsystem

Sibling dyads are unique relationships; they are ascribed rather than selected relationships, they involve both nurturance and conflict, and are typically the longest and most enduring relationship across the lifespan (Orsmond, & Seltzer, 2007; Seligman, & Darling, 2007; Vliem, 2009). The sibling relationship has a significant impact on child socialization and makes it possible to express feelings and to experience friendships, loyalty, rivalry, and support (Glasberg, 2000; Verte, Roeyers, & Buysse, 2003). The nature of sibling relationships evolves throughout development (Vliem, 2009)

Appendix H: The Fundamental Postulate and 11 Corollaries

The following information is based on Kelly's (1955) seminal work, *The Psychology of Personal Constructs*.

Fundamental Postulate

The Fundamental Postulate describes the anticipatory nature in which a person processes their experiences, feelings, thoughts, and behaviours. In his own words, Kelly (1955) wrote, "A person's processes are psychologically channelized by the ways in which he anticipates events" (Vol 1., p.32). As a result, an individual's sense making of their world is considered to be constructed rather than inherent in events.

Construction Corollary

The Construction Corollary describes the constructive nature by which individuals interpret their world. According to Personal Construct Theory (PCT), individuals are fundamentally conservative in nature, meaning previous experiences are used as templates to anticipate future events and situations. In describing this, Kelly (1955) wrote, "A person anticipates events by construing their replications" (Vol 1., p.35).

The Individuality Corollary

The Individuality Corollary acknowledges the unique and individualised nature of personal constructs. In describing this, Kelly (1955) wrote, "Persons differ from each other in their construction of events" (Vol 1., p.38). That is, the individualised nature of past experiences contribute to the development of unique construct systems, and therefore unique anticipation of future events.

The Organization Corollary

According to PCT, personal constructs are organised into a network system. This organisation is considered to facilitate efficient construing processes. In describing the Organisation Corollary, Kelly (1955) wrote, "Each person characteristically evolves, for his convenience in anticipating events, a construction system embracing ordinal relationships between constructs" (Vol 1., p.38).

The Dichotomy Corollary

Kelly (1955) considered constructs to be dichotomous in nature. This dichotomous structure is important for understanding a constructs meaning; for example, 'short' is only understood in relation to its opposite pole of 'long'.

The Choice Corollary

The Choice Corollary describes the principles by which people use constructs to interpret situations and inform their behaviours. This corollary posits that people generally employ constructs that will expand or elaborate their current construction system, allowing for greater understanding of the world.

The Range Corollary

The Range Corollary describes the relationships between constructs. More specifically, it describes the way in which related constructs are linked in order to facilitate effective construing. The range of constructs are considered to vary from broad or 'comprehensive' to narrow or 'incidental' in their application to other constructs.

The Modulation Corollary

The Modulation Corollary explains that constructs vary in their flexibility or the extent to which they are open to change when applied to different experiences. In describing this, Kelly (1955) wrote, "The variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie". (Vol 1, p.54).

The Fragmentation Corollary

The Fragmentation Corollary acknowledges that people can be inconsistent within themselves. Furthermore, Kelly (1955) considered some degree of logical discontinuity between constructions as a normal. Inconsistency or 'fragmentation' of personal constructs can often result from the various roles undertaken in everyday life such as parent, child, expert, and client.

The Commonality Corollary

The Commonality Corollary acknowledges that, in addition to individuality (as described in the Individuality Corollary), people share some similarity in their personal constructs. In explaining this, Kelly (1955) wrote, “To the extent that one person employs a construction of experience which is similar to that employed by another, his psychological processes are similar to the other person” (Vol 1., p.63).

The Sociality Corollary

The Sociality Corollary accounts for the fact that people are able to relate to and attempt to understand others. That is, people make constructions about how another person may construe situations, people, etc. In describing this, Kelly (1955) wrote, “To the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person” (Vol., p.66). This ‘role playing’ is critical for the functioning of intimate, ongoing relationships.

Appendix I: DSM-IV-TR Diagnostic Criteria for Asperger's Syndrome

The following diagnostic criteria are from the DSM-IV-TR (American Psychiatric Association, 2000).

An individual must meet criteria (I), (II), (III), (IV), (V), and (VI):

(I) Qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- (b) Failure to develop peer relationships appropriate to developmental level.
- (c) A lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
- (d) Lack of social or emotional reciprocity.

(II) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

- (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
- (b) Apparent inflexible adherence to specific, non-functional routines or rituals.
- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
- (d) persistent preoccupation with parts of objects.

(III) The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.

(IV) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

(V) There is no clinically significant delay in cognitive development or in the

development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction) and curiosity about the environment in childhood.

(VI) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Appendix J: DSM-IV-TR Diagnostic Criteria for Autistic Disorder

The following diagnostic criteria is from the DSM-IV-TR (American Psychiatric Association, 2000).

(I) A total of six (or more) items from (a), (b), and (c), with at least two from (a), and one each from (b) and (c)

(a) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
2. Failure to develop peer relationships appropriate to developmental level
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
4. Lack of social or emotional reciprocity (e.g., not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or ‘mechanical’ aids)

(b) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. Stereotyped and repetitive use of language or idiosyncratic language.
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(c) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. Apparently inflexible adherence to specific, non-functional routines or rituals.
3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
4. Persistent preoccupation with parts of objects.

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- (a) Social interaction.
- (b) Language as used in social communication.
- (c) Symbolic or imaginative play.

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Appendix K: DSM-IV-TR Diagnostic Criteria for Pervasive Developmental Disorder Not Otherwise Specified

The following diagnostic criteria is from the DSM-IV-TR (American Psychiatric Association, 2000).

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behaviour, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes atypical autism presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or sub-threshold symptomatology, or all of these.

Appendix L: UOW Human Research Ethics approval



APPROVAL after review

In reply please quote: HE12/186

Further Enquiries Phone: 4221 3386

13 August 2012

Ms Elizabeth Cridland
Centre for Health Initiatives
Building 233 (ITAMS)
Innovation Campus
University of Wollongong NSW 2522

Dear Ms Cridland

Thank you for your letter responding to the HREC review letter. I am pleased to advise that the Human Research Ethics application referred to below has been approved.

Ethics Number:	HE12/186
Project Title:	Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach
Name of Researchers:	Ms Elizabeth Cridland, A/Professor Peter Caputi, Prof Sandra Jones, Dr Christopher Magee
Approval Date:	13 August 2012
Expiry Date:	12 August 2013

The University of Wollongong/ISLHD Health and Medical HREC is constituted and functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research. The HREC has reviewed the research proposal for compliance with the National Statement and approval of this project is conditional upon your continuing compliance with this document.

A condition of approval by the HREC is the submission of a progress report annually and a final report on completion of your project. The progress report template is available at <http://www.uow.edu.au/research/rso/ethics/UOW009385.html>. This report must be completed, signed by the appropriate Head of School and returned to the Research Services Office prior to the expiry date.

As evidence of continuing compliance, the Human Research Ethics Committee also requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforeseen events that might affect continued ethical acceptability of the project.

Please note that approvals are granted for a twelve month period. Further extension will be considered on receipt of a progress report prior to expiry date.

If you have any queries regarding the HREC review process, please contact the Ethics Unit on phone 4221 3386 or email rso-ethics@uow.edu.au.

Yours sincerely

Associate Professor Sarah Ferber
Chair, UOW & ISLHD Health and Medical
Human Research Ethics Committee

Appendix M: Participant Information Sheet

Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach

Researchers: A/Prof Peter Caputi, Miss Elizabeth Cridland, Prof. Sandra Jones, and Dr Christopher Magee.

What is the purpose of the research?

This student research project aims to better understand the experience of Asperger's Syndrome from the perspective of adolescents with Asperger's Syndrome and their family. Participating families will be involved in a series of interviews which will cover both positive and negative experiences of living with Asperger's Syndrome. It is hoped that research findings will help improve support services for adolescent individuals with Asperger's Syndrome and their families.

What will I be doing if I take part in this research?

First, the researcher will have a conversation with interested families to explain the study in detail, to answer any questions, and to determine eligibility for the study. If you have further questions, an additional session can be arranged.

Eligible families who want to participate in the study will then be involved in a discussion with the researcher about your positive and negative experiences of living with Asperger's Syndrome during the adolescent period. You will discuss your experiences with the researcher based on general interview questions.

Your parents will also complete a questionnaire which involves three short questionnaires about their feelings, about being a parent, and about general life events. This research will take place in private settings, such as your home, Northfields Clinic at the University of Wollongong, or the Centre for Health Initiatives at the University of Wollongong. You can choose where you would like to complete your interviews.

How long will it take?

The total time commitment for Phase 1 is estimated to be 1 individual session lasting around 60 minutes.

Can anyone hear what I said, or see what I answered?

Personal information (e.g. names) will not be disclosed in the reporting of the study. Only anonymous, group-based data from this study will be reported, and used to inform academic journal articles.

All interviews will be videotaped so the researchers can transcribe and analyse them. Only the researchers involved in the study will have access to these recordings and transcriptions. Participants within the same family will not be given access to other family member's information (eg; questionnaire answers, or interview transcripts) unless permission is

provided by that family member. Participants from different families will not be given access to other family's information. All information gathered during the study (including recordings) will be stored securely at the university for 5 years.

Can I change my mind?

Participation is entirely voluntary and you can choose to discontinue your involvement before or during the study. You will not be pressured to continue with the study if you do not wish to continue. Please note that you may have to be withdrawn from the study if other family members choose to discontinue their participation in the study.

Will I receive any feedback about the results of the study?

Interested participants will be provided with formal reports about the study's findings.

Are there any potential risks, inconveniences or discomforts from being involved in the study?

Potential risks of participating in the study involve discussion of topics that may upset you (such as negative experiences of living with AS).

Are there any benefits of being involved in the study?

Participants may benefit therapeutically from being involved in the study. That is, discussion is expected to be helpful to participants, by increasing awareness and understanding between family members.

Ethics Review

This study has been reviewed by the Human Research Ethics Committee (Social Science, Humanities and Behavioural Science) of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UoW Ethics Officer on (02) 4221 4457.

If I want to be involved, what do I do?

If you decide you would like to be involved in the study you will sign a form provided by the researcher. Your parent's will also need to sign the form to say it is ok for you to be involved. Your parents can provide their own consent to be involved in the study because they are adults.

If you have any further queries, please do not hesitate to contact Miss Elizabeth Cridland (ekc977@uowmail.edu.au). If you are dissatisfied with any aspect of how this research is conducted you can contact the Secretary of the University of Wollongong Human Research Ethics Committee of 0242 214457. If you are feeling distressed please call Lifeline on 131114 or Northfields Clinic, UOW on 42213747 to arrange an appointment.

Appendix N: Consent Form

Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach

Researchers: A/Prof Peter Caputi, Miss Elizabeth Cridland, Prof. Sandra Jones, and Dr Christopher Magee.

I have read the participant information sheet entitled “*Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach- Phase 1*” and I am interested in participating in the study.

I understand that my participation in the study will involve:

- ☐ completing a short questionnaire
 - ☐ discussing my positive and negative experiences of living with Asperger's Syndrome during the adolescent period with the researcher
 - ☐ a commitment of my time (approximately session lasting around 60 minutes)
 - ☐ being video or audio taped during the research interviews, for the purpose of analysis only.
 - ☐ the results of this study being reported at conferences and academic journal articles.
- I have had the opportunity to ask the researchers any questions I have about the study.
 - I understand that I am free to withdraw my consent at any time during the research.

By signing below I am providing my informed consent to participate in Phase 1 of this research:

Name	Signed	Date
.....

If you have any further queries, please do not hesitate to contact Miss Elizabeth Cridland (ekc977@uowmail.edu.au). If you are dissatisfied with any aspect of how this research is conducted you can contact the Secretary of the University of Wollongong Human Research Ethics Committee on 0242 214457. If you are feeling distressed please call Lifeline on 131114 or Northfields Clinic, UOW on 42213747 to arrange an appointment.

Appendix O: Interview Guide

Please note: This is the interview guide for adolescents with ASD. The interview guides used for other family members have the same content but with wording changes as appropriate (e.g., questions referring to wife, son, and daughter for Fathers).

The first few questions are about you:

- 1) What are your hobbies?
- 2) What words would you use to describe your personality?
- 3) If you could be any type of person who would it be? Why?

The following questions are about you and your family:

- 4) What things about your family do you like the most?
- 5) What things about your family do you dislike?

The next few questions are about you and your Mum:

- 6i) What activities do you like to do with Mum?
- 6ii) How would you describe Mum?
- 6iii) How do you think Mum would describe herself?
- 6iv) How do you think your Mum would describe you?

(Repeat question 6 for each family member)

The next few questions are about Asperger's Syndrome:

- 7) Can you tell me about a time in the last year when you think Mum understood what it was like to have AS?
 - a. How did that make you feel?
 - b. How did that make Mum feel?
- 8) Can you tell me about a time in the last year when you think Mum didn't understand what it was like to have AS?
 - a. How did that make you feel?
 - b. How did that make Mum feel?

(Repeat questions 7 and 8 for each family member)

The next few questions are also about Asperger's Syndrome:

- 9) How would I know that you had AS?
- 10) How would you explain AS to someone who didn't know anything about it (like a teacher or friend)?
- 11) Some people recognise that there are some good things about AS, do you think are some good things about AS?
 - i. (If yes) Can you tell me about a time in the past year where you thought there were some good things about having AS?
- 12) What are some difficulties of having AS?
 - i. Can you tell me about a time in the past year where AS made a situation difficult for you?
 - ii. How did you react to this situation?
 - iii. What strategies did you use to cope in this situation?
 - iv. What would have been unhelpful in this situation?
 - v. Who, in your family, do you find helpful in difficult situations?
 - vi. What do they do to help you?
 - vii. Why do you prefer to go to (*above person*) for help rather than (*another family member*)?
- 13) Do you think being a *teenager* with AS makes you different from other teenagers? If yes, in what ways?
- 14) Is the way you feel about your AS now, different to when you were in primary school?

The last few questions are about household jobs:

- 15) What jobs do you do at home?
- 16) What jobs do other family members do around the home?
- 17) Do you think these jobs are fair?
- 18) Is there anything else that you would like to tell me about your experience of living with AS?

Appendix P: Study Advertisement

Are you, or do you know, a teenager with Asperger's Syndrome or High Functioning Autism? If so, we would love to talk to you!

Researchers at the University of Wollongong are looking for adolescents with Asperger's Syndrome or High Functioning Autism, and their families, to participate in a study aiming to understand the experiences of living on the Autism Spectrum during adolescence.

Participating in the study will involve:

- Discussing your positive and negative experiences during adolescence
- Completing a sorting task with the researcher
- Providing feedback about being involved in the study

This research will be conducted over the next 18 months. Participants will be involved periodically over this time, by completing around 6 interview sessions, lasting approximately 45-60 minutes each.

It is anticipated that research findings will have the potential to inform clinical approaches for working with adolescent individuals with Asperger's Syndrome and High Functioning Autism and their families.

Who can be involved?

To be eligible for the study families must have a family member with Asperger's Syndrome or High Functioning Autism who is:

- In school years 7-10
- Has an older sibling without a formal diagnosis on the Autism Spectrum who lives at home

What should I do if I want more information about this study?

If you would like more information, please contact Elizabeth Cridland via email (ekc977@uowmail.edu.au) or phone (42213693).

If you are dissatisfied with any aspect of how this research is conducted you can contact the Secretary of the University of Wollongong Human Research Ethics Committee on 0242 214457.

Appendix Q: Participant Information Sheet (Dependency Grid)

Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach- Phase 2

Researchers: A/Prof Peter Caputi, Miss Elizabeth Cridland, Prof. Sandra Jones, and Dr Christopher Magee.

What is the purpose of the research?

This student research project aims to better understand the experience of Asperger's Syndrome from the perspective of adolescents with Asperger's Syndrome and their family. It is hoped that research findings will help improve support services for adolescent individuals with Asperger's Syndrome and their families.

What will I be doing if I take part in this research?

In phase 2, you and your family will complete some sorting activities with the researcher. These sorting activities will focus on the ways in which your family helps each other in challenging situations.

The researcher will give you feedback about the sorting activities and will also ask you for general feedback about being involved the study, particularly what it was like to be involved in the sorting activities.

This research will take place in private settings, such as your home, Northfields Clinic at the University of Wollongong, or the Centre for Health Initiatives at the University of Wollongong. You can chose where you would like to complete your interviews.

How long will it take?

The time commitment for Phase 2 involves 1 individual session (lasting approximately 60 minutes) and a family feedback session (lasting approximately 60 minutes).

Can anyone hear what I said, or see what I answered?

Personal information (e.g. names) will not be disclosed in the reporting of the study. Only anonymous, group-based data from this study will be reported, and used to inform academic journal articles.

All interviews will be videotaped so the researchers can transcribe and analyse them. Only the researchers involved in the study will have access to these recorders and transcriptions. Participants within the same family will not be given access to other family member's information (eg; questionnaire answers, interview transcripts, or sorting tasks) unless permission is provided by that family member. Participants from different families will not be given access to other family's information. All information gathered during the study (including recordings) will be stored securely at the university for 5 years.

Can I change my mind?

Participation is entirely voluntary and you can choose to discontinue your involvement before or during the study. You will not be pressured to continue with the study if you do not wish to continue. Please note that you may have to be withdrawn from the study if other family members choose to discontinue their participation in the study.

Will I receive any feedback about the results of the study?

During phase 3, participants will receive feedback about your sorting activities. Interested participants will be provided with formal reports about the study's findings.

Are there any potential risks, inconveniences or discomforts from being involved in the study?

Potential risks of participating in the study involve discussion of topics that may upset you (such as negative experiences of living with AS) during phase 1. However, phases 2 and 3 of the research are anticipated to provide opportunities to address such issues through greater understanding of other family member's perspectives.

Are there any benefits of being involved in the study?

Participants may benefit therapeutically from being involved in the study. That is, discussion of experiences of living with AS in the family (and involvement in phases 2 and 3 of the project) is expected to be helpful to participants, by increasing awareness and understanding between family members.

Ethics Review

This study has been reviewed by the Human Research Ethics Committee (Social Science, Humanities and Behavioural Science) of the University of Wollongong. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the UoW Ethics Officer on (02) 4221 4457.

If I want to be involved, what do I do?

If you decide you would like to be involved in the study you will sign a form provided by the researcher. Your parent's will also need to sign the form to say it is ok for you to be involved. Your parents can provide their own consent to be involved in the study because they are adults.

If you have any further queries, please do not hesitate to contact Miss Elizabeth Cridland (ekc977@uowmail.edu.au). If you are dissatisfied with any aspect of how this research is conducted you can contact the Secretary of the University of Wollongong Human Research Ethics Committee of 0242 214457. If you are feeling distressed please call Lifeline on 131114 or Northfields Clinic, UOW on 42213747 to arrange an appointment.

Appendix R: Consent Form (Dependency Grid)

Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach- Phase 2

Researchers: A/Prof Peter Caputi, Miss Elizabeth Cridland, Prof. Sandra Jones, and Dr Christopher Magee.

I have read the participant information sheet entitled “*Understanding the Experience of Asperger's Syndrome during Adolescence: A Personal Construct Psychology and Family Systems Approach: Phase 2*” and I am interested in participating in the study.

I understand that my participation in Phase 2 of the study will involve:

- ☐ completing a short questionnaire
 - ☐ completing two sorting tasks with the researcher
 - ☐ receiving feedback about the sorting tasks from the researcher
 - ☐ providing feedback to the researcher about my experience of being involved the study
 - ☐ a commitment of my time (approximately 2 sessions lasting 45-60 minutes each)
 - ☐ being video or audio taped during the research interviews, for the purpose of analysis only.
 - ☐ the results of this study being reported at conferences and academic journal articles.
- I have had the opportunity to ask the researchers any questions I have about the study.
 - I understand that I am free to withdraw my consent at any time during the research.

By signing below I am providing my informed consent to participate in phase 2 of this research:

Name

Signed

Date

.....

.....

.....

If you have any further queries, please do not hesitate to contact Miss Elizabeth Cridland (ekc977@uowmail.edu.au). If you are dissatisfied with any aspect of how this research is conducted you can contact the Secretary of the University of Wollongong Human Research Ethics Committee of 0242 214457. If you are feeling distressed please call Lifeline on 131114 or Northfields Clinic, UOW on 42213747 to arrange an appointment.

Appendix S: Supplied Situations and Resources

Situations	Feeling sad
	Feeling overwhelmed
	Feeling frustrated
	Feeling bored
	Feeling anxious
	Feeling lonely
	Problems with Mum
	Problems with Dad
	Problems with sibling
	Have questions about ASD ^a
	Have questions about puberty
	Having difficulty with homework
	Having difficulty making friends
	Having difficulty with friends
	Having difficulty understanding a social situation
	Being bullied
Resources grid 1: People	Mum
	Dad
	Sibling
	Other family member
	Myself
	Someone outside the family
Resources grid 2: Types of support	Someone who can give me a hug
	Someone who listens to me
	Someone who can sort out the problem
	Someone who can help me sort out the problem
	Someone who can explain it to me
	Someone who will give me advice
	Someone who can play/hang out with me
	Someone who can organise an activity for me
	I want to be left alone

Note: ^a Autism Spectrum Disorder

Appendix T: Dependency Grid Templates

	Mum	Dad	Sibling	Other	Myself	Someone outside family	Other.....	Other.....
Feeling angry								
Feeling sad								
Feeling overwhelmed								
Feeling frustrated								
Feeling bored								
Feeling anxious								
Feeling lonely								
Problems with Mum								
Problems with Dad								
Problems with sibling/s								
Have questions about ASD								
Have questions about puberty								
Difficulty with homework								
Difficulty making friends								
Difficulty with friends								
Difficulty understanding a social situation								
Are being bullied								

	Someone who can give me a hug	Someone who listens to me	Someone who can sort out the problem	Someone who can help me sort out problem	Someone who can explain it to me	Someone who will give me advice	Someone who can play with me	Someone who can organise an activity	I want to be left alone	Other.....
Feeling angry										
Feeling sad										
Feeling overwhelmed										
Feeling frustrated										
Feeling bored										
Feeling anxious										
Feeling lonely										
Problems with Mum										
Problems with Dad										
Problems with sibling/s										
Have questions about ASD										
Have questions about puberty										
Difficulty with homework										
Difficulty making friends										
Difficulty with friends										
Difficulty understanding a social situation										
Are being bullied										

Appendix U: Resource-Card Sorting Mat

‘If this challenging situation happened right now, and these people were available, who would you turn to for help?’

Challenging situation

I would
turn to this person for help

I would not
turn to this person for help

Appendix V: Thesis Revisions

Section 1: Revised wording of Chapter 4 research aims (Page 90, paragraph 1)

The aim of this study was to determine whether the issues discussed by adolescents with ASD and their families would be consistent with the issues highlighted in the previous application of PCT for understanding adolescents with ASD (see Table 4.2). The study also aimed to determine if there were additional issues pertinent to the experience of being an adolescent/having an adolescent family member with ASD raised by participants that were not highlighted in Cridland et al. (2013a).

Section 2: Elaboration of data analysis procedures in Chapter 4 (Page 94, Paragraph 1)

Data were initially coded based on the themes discussed in Cridland et al (2013a), with additional themes generated from remaining data. No major changes to the themes identified by the first author were identified as being necessary by either co-authors or the independent checker. Following the analysis procedure outlined by Braun and Clarke (2006), a final consultation with the authors followed to discuss specific theme descriptions and selection of most relevant quotes.

Credibility of data analysis was facilitated by a systematic record of how data were collected, maintained, and prepared for analysis. Other strategies employed to enhance the integrity of data analysis included the first author having prolonged engagement with the data (including interview administration and transcription) (van den Hoonaard, 2002) and the three methods of bracketing outlined in Tufford and Newman (2012). Specifically, the bracketing methods included keeping memos during data collection and analysis as a means of examining and reflecting on their engagement with the data, engaging in discussions with an outside source to bring awareness to preconceptions and potential biases, and keeping a reflexive journal during all stages of the research process to sustain a reflexive stance (Tufford & Newman, 2012).

A formal measure of inter-rater agreement was not employed. Rather the process involved one of the co-authors and one independent checker reading all transcripts with the potential themes identified by the first author. This method of ‘investigator triangulation’ (Guion, Diehl, & McDonald, 2011) was employed over traditional member checking for various reasons. More specifically, there were concerns that, despite de-identification of transcripts, individuals involved in member checking may be able to identify other participants based on experiences discussed in the interviews. This issue was particularly pertinent in recognizing other family members’ transcripts. However, this issue was also relevant for recognition of other participants given the local community within which the sample was recruited. Associated with this, participant

anonymity was important in obtaining accurate data, whereby participants may have felt reluctant to speak openly in interviews if there were concerns about being identified through member checking processes.

As this was an exploratory study using a sample of convenience, data saturation of themes was not a specific aim. The limitations of the small sample are elaborated on in further detail in the discussion. Having said that, themes were generated from the frequency of topics discussed by participants, meaning data saturation was satisfied for each theme. In regards to positionality, the co-authors and independent checker had various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences. Such varying experiences were important in minimising potential biases in data interpretation (Whittemore, Chase, & Mandle, 2001).

Section 3: Elaboration of data analysis procedures in Chapter 5 (Page 132, Paragraph 2)

Data analysis followed the inductive coding process outlined by Braun and Clarke (2006), which involves familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final definition of themes (Braun & Clarke, 2006). Credibility of data analysis was facilitated by a systematic record of how data were collected, maintained, and prepared for analysis. Credibility checks involved the research team reviewing all transcripts together with the potential themes identified by the first author. No major changes to the themes identified by the first author resulted. This consultation process is recognised as an important process in IPA, given that the analysis of the interview material is inevitably influenced by the researchers' characteristics. The research team consisted of four researchers with various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences.

This method of credibility checking, also referred to as 'investigator triangulation' (Guion, Diehl, & McDonald, 2011), was employed over traditional member checking for various reasons. Primarily, there were concerns that, despite de-identification of transcripts, individuals involved in member checking may be able to identify other participants based on experiences discussed in the interviews. This issue was particularly pertinent in recognizing other family members' transcripts. However, this issue was also relevant for recognition of other participants given the local community within which the sample was recruited. Associated with this, participant anonymity was important in obtaining accurate data, whereby participants may have felt reluctant to speak openly in interviews if there were concerns about being identified through member checking processes.

Other strategies employed to enhance the integrity of data analysis included the first author having prolonged engagement with the data (including interview administration and transcription) (van den Hoonaard, 2002) and the three methods of bracketing outlined in Tufford and Newman (2012). Specifically, the bracketing methods included the first author keeping memos during data collection and analysis as a means of examining and reflecting on their engagement with the data, the first author engaging in discussions with an outside source to bring awareness to preconceptions and potential biases, and the first author keeping a reflexive journal during all stages of the research process to sustain a reflexive stance (Tufford & Newman, 2012).

Section 4: Revised wording of Chapter 7 research aims (Page 201, paragraph 2)

The present study investigates the experiences of adolescent girls with a younger, adolescent brother with ASD. Specifically, the study aims to explore the roles and responsibilities undertaken by the sisters at school and in the home contexts, and further how these roles interact. The study investigates these issues from the perspectives of the adolescent sisters and their family members. In doing so, the study aims to gain a multifaceted and holistic understanding of family functioning.

Section 5: Elaboration of data analysis procedures in Chapter 7 (Page 208, Paragraph 3)

The data were analysed following the inductive coding process outlined by Braun and Clarke (2006). This process included familiarization with the data (the primary researcher conducted and transcribed all interviews), generation of initial codes, collation of codes into potential themes with corresponding quotes, review of themes with credibility checks, and final coding of themes (Braun & Clarke, 2006). Credibility of data analysis was facilitated by a systematic record of how data were collected, maintained, and prepared for analysis.

A formal measure of inter-rater agreement was not employed. Rather the process involved one member of the research team and one independent checker reading all transcripts with the potential themes identified by the first author. This method of credibility checking, also referred to as ‘investigator triangulation’ (Guion, Diehl, & McDonald, 2011), was employed over traditional member checking for various reasons. Primarily, there were concerns that, despite de-identification of transcripts, individuals involved in member checking may be able to identify other participants based on experiences discussed in the interviews. This issue was particularly pertinent in recognizing other family members’ transcripts. However, this issue was also relevant for recognition of other participants given the local community within which the sample was recruited. Associated with this, participant anonymity was important in obtaining accurate data, whereby

participants may have felt reluctant to speak openly in interviews if there were concerns about being identified through member checking processes.

No major changes to the themes identified by the primary researcher were identified as being necessary by either member check. Following the procedure outlined by Braun and Clarke (2006), a final consultation with the research team followed to discuss specific theme descriptions and selection of most relevant quotes

Other strategies employed to enhance the integrity of data analysis included having prolonged engagement with the data (including interview administration and transcription) (van den Hoonaard, 2002) and the three methods of bracketing outlined in Tufford and Newman (2012). Specifically, the bracketing methods included keeping memos during data collection and analysis as a means of examining and reflecting on their engagement with the data, engaging in discussions with an outside source to bring awareness to preconceptions and potential biases, and keeping a reflexive journal during all stages of the research process to sustain a reflexive stance (Tufford & Newman, 2012).

Further, in regards to positionality, the co-authors and independent checker had various backgrounds of involvement with adolescents with ASD including research, clinical, and familial experiences. Such varying experiences were important in minimising potential biases in data interpretation (Whittemore, Chase, & Mandle, 2001). As this was an exploratory study, it was not the aim to achieve data saturation of all themes. In order to convey the strength of themes, the number of participants who discussed each point is presented.

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