Raising a preschooler with an Autism Spectrum Disorder: The impact on parent and family wellbeing, and the role of the home learning environment

Faculty of Health, Arts, and Design
Swinburne University of Technology
Hawthorn, Victoria, Australia

Rachel Jellett

A thesis submitted in partial fulfillment for the degree of
Doctor of Psychology (Clinical)
February 2016
Abstract

Family involvement is a key principle of good practice for early intervention in Autism Spectrum Disorders (ASDs) according to the Australian guidelines. To inform the provision of family centered care, more information is needed regarding the strengths and needs of families of preschoolers with ASDs. A key objective of this research was to examine parents’ perceptions of the impact raising a preschooler with an ASD had on their wellbeing, parenting, and family functioning. A further objective was to investigate the ways in which parents provided support to their preschooler with an ASD through the provision of a home learning environment. To meet these objectives, two studies were conducted. The aim of Study 1 was to investigate relationships between children’s behaviour problems, parents’ wellbeing, parenting practices, and family functioning. Participating included 97 parents of preschoolers with an ASD. Findings indicated that children’s behaviour problems were associated with increased levels of stress, depression, and fatigue. Depressive symptoms, in turn, were associated with family functioning. Furthermore, depressive symptoms were directly associated with reduced parental warmth and higher hostility, and indirectly associated with parental involvement via family functioning. Home visits were then conducted with 21 different families of preschoolers with ASDs for Study 2. Parents’ experiences were drawn upon to identify themes that captured various aspects of family life. The qualitative analysis resulted in four themes. The parents showed extensive knowledge of their children’s qualities, abilities, and challenges (Theme 1: Knowing the Child). The parents described the way providing intervention to their child was an integral part of their home activities (Theme 2: Therapy in Daily Life). They were emotionally affected by raising a child with an ASD (Theme 3: Emotional Impact on Parents). Raising a preschooler with an ASD also had an impact on daily family routines and family relationships (Theme 4: ASD as a Family Priority). It was concluded that further support is needed to address the wellbeing and family functioning difficulties associated with raising a preschooler with an ASD. Supporting parents to adjust to raising a preschooler with an ASD, and building on their skills and knowledge, are other avenues for early intervention. There are parents who show a high degree of resilience and have the capacity to provide intensive support in the home. These findings may assist clinicians to better understand the strengths and needs of these families, and also highlight the importance of considering family ecology in clinical practice.
Acknowledgements

I was fortunate to work with a highly supportive supervisory team over the course of this research project. Dr Katie Wood and Dr Rebecca Giallo provided me with consistent guidance, wisdom, and encouragement. They were generous with their time, resources, and knowledge, and encouraged me to fully participate in the broader research community. Without their support I would not have been able to complete a practical and clinically based project in an area I am passionate about. I am grateful to Dr Simone Buzwell for her invaluable feedback while drafting the document. I would also like to acknowledge the contribution of Dr Kerry Bull who shared her expertise on the administration and interpretation of the Psychoeducational Profile and provided practical assistance on my first administration of this measure.

Thanks to Monique Seymour and Lauren Rawlings for sharing an interest in this area of research and making the entire process of conducting this study more enjoyable. Sincere thanks also to Angelika Radeka for the hours she volunteered to assist with home visits for this research project. My partner, family, friends, and fellow students at Swinburne have all been incredibly supportive and understanding while I have been preoccupied with this task, for which I am sincerely appreciative.

It would not have been possible to conduct this research without the support of the organisations that assisted by sharing information about the study with potential participants. Finally, I am so grateful to the parents who so generously gave their time to shed light on this area of research, not only because they made this project possible, but for teaching and inspiring me along the way.
Declaration

I declare that this dissertation contains no material that has been accepted for the award of any other degree or diploma. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person except where due reference is made in the text.

I further declare that the ethical principles and procedures specified in the Swinburne University of Technology Human Research Ethics Committee documentation have been adhered to in the process of conducting this research.

A subsection of Study 1 of this thesis formed a joint publication (Jellett, Wood, Giallo, & Seymour, 2015). The co-authors assisted with the formation and design of the study, as well as with editing the published paper, of which, parts have been incorporated in to this thesis. Ms. Seymour assisted with data collection. Dr. Giallo provided guidance on the data analysis. The copyright requirements of the publishers have been observed.

------------------------
Rachel Jellett
19th June 2015
# Table of Contents

Abstract............................................................................................................................ ii  
Acknowledgements........................................................................................................ iii 
Declaration...................................................................................................................... iv  
Table of Contents ............................................................................................................ v  
List of Tables ................................................................................................................. vii  
List of Figures ................................................................................................................. ix  
List of Abbreviations ...................................................................................................... x  

Chapter 1. General Introduction .................................................................................. 1  

Chapter 2. Overview of Autism Spectrum Disorders .................................................. 4  
   Historical Origins of ASDs ........................................................................................... 4  
   Diagnosis of ASDs ........................................................................................................ 5  
   Epidemiology ............................................................................................................... 7  
   Aetiology ....................................................................................................................... 8  
   Comorbidity ................................................................................................................ 11  
   Emotional and Behavioural Problems ........................................................................ 11  
   Prognosis ..................................................................................................................... 14  
   Early Intervention for Preschoolers with ASDs .......................................................... 15  
   Summary ..................................................................................................................... 22  

Chapter 3. Impact of Raising a Child with an ASD on Family Functioning, Parental Wellbeing, and Parenting Practices ......................... 23  
   Historical Context of Parenting and ASDs................................................................. 23  
   Demands of Parenting a Preschooler with an ASD ..................................................... 25  
   Impact of ASDs on Family Functioning ..................................................................... 26  
   Impact of ASDs on Parental Wellbeing ..................................................................... 29  
   Impact of ASDs on Parenting Practices ..................................................................... 35  
   Relationship between Child, Parent, and Family Factors ......................................... 38  
   Lived Experience of Raising a Child with an ASD ..................................................... 43  
   Summary ..................................................................................................................... 46  

Chapter 4. The Role of Families in Early Intervention for ASDs ............................... 47  
   Australian Guidelines for Good Practice ................................................................. 48  
   Costs to Families Raising a Preschooler with an ASD ............................................. 49
The Helping Children with Autism (HCWA) Package ............................................... 51
The Gap between Evidence and Practice ................................................................. 53
The Family Environment ......................................................................................... 55
The Home Learning Environment .......................................................................... 57
Summary .................................................................................................................. 61

Chapter 5. Theoretical Basis for the Current Research ............................................ 63
  Bioecological and Transactional Models .................................................................. 64
  Developmental Theory and ASDs ........................................................................... 66
  Purpose Statement and Study Design ..................................................................... 67
  Research Aims ......................................................................................................... 68

Chapter 6. Study 1: An Investigation of the Pathways between Child Behaviour
            Problems, Parental Wellbeing, Family Functioning, and Parenting Practices ...... 71
  Method .................................................................................................................... 72
  Participants ............................................................................................................. 72
  Measures ............................................................................................................... 75
  Procedure ............................................................................................................... 80
  Results ..................................................................................................................... 80
  Overview of Data Analysis Procedure .................................................................. 80
  Preliminary Data Analysis ..................................................................................... 81
  Describing the Sample Relative to Published Norms ............................................. 83
  Testing the Hypothesised Models ......................................................................... 86
  Summary of the Findings ....................................................................................... 92

Chapter 7. Study 2: A Qualitative Exploration of the Family Environments for
            Preschoolers with ASDs .................................................................................... 94
  Study Design .......................................................................................................... 95
  Personal Statement ................................................................................................. 95
  Method .................................................................................................................... 97
  Participants ............................................................................................................. 97
  Questionnaire Measures ....................................................................................... 100
  Qualitative Interview Measures ........................................................................... 104
  Procedure ............................................................................................................... 106
  Data Analysis Procedure ....................................................................................... 107
Results ................................................................................................................................. 110
  Quantitative Results ........................................................................................................ 110
  Qualitative Results ......................................................................................................... 117
    Theme 1: Knowing the Child: .................................................................................. 121
    Theme 2: Therapy in Daily Life ................................................................................. 124
    Theme 3: Emotional Impact on Parents .................................................................. 132
    Theme 4: ASD as a family priority ......................................................................... 135
Summary of the Findings ............................................................................................... 140

Chapter 8. General Discussion ...................................................................................... 142
  Overview and Summary of the Findings ...................................................................... 142
  Impact of Raising a Child with an ASD on Family Functioning, Parental
  Wellbeing, and Parenting Practices ........................................................................... 146
  Adapting Parenting and the Home Learning Environment for Preschoolers
  with ASDs ...................................................................................................................... 154
  Theoretical Implications of the Current Findings .................................................... 157
  Limitations and Directions for Future Research ...................................................... 159
  Implications for Clinical Practice .............................................................................. 167
  Conclusion ..................................................................................................................... 169

References ...................................................................................................................... 171

Appendices ...................................................................................................................... 210
  Appendix A. Study 1 Measures .................................................................................. 210
  Appendix B. Study 1 Ethics Clearance ...................................................................... 219
  Appendix C. Study 1 Advertising Flyer ................................................................. 223
  Appendix D. Study 1 Plain Language Statement ...................................................... 224
  Appendix E. Study 2 Measures .................................................................................. 227
  Appendix F. HOME Inventory Interview Guide ...................................................... 228
  Appendix G. Study 2 Ethics Clearance ...................................................................... 229
  Appendix H. Study 2 Advertising Flyer ................................................................. 232
  Appendix I. Study 2 Plain Language Statement ...................................................... 233
  Appendix J. Study 2 Consent Forms .......................................................................... 236
List of Tables

Table 1. Overview of Qualitative Studies Describing the Impact of Raising a Child with an ASD on Parents and Families ......................................................... 43

Table 2. Demographic Characteristics of the Sample ................................................ 73

Table 3. Demographic characteristics of the Focus Child ......................................... 75

Table 4. Norms, Means, Standard Deviations, and Ranges for Questionnaire Measures ...................................................................................................... 84

Table 5. Correlations among the Study Variables and Covariates............................. 87

Table 6. Demographic Characteristics of the Parents ................................................ 97

Table 7. Demographic Characteristics of the Families .............................................. 98

Table 8. Demographic Characteristics of the Focus Children ................................... 99

Table 9. Means, Standard Deviations and Ranges for Questionnaire Measures ...... 111

Table 10. Mean Percentile Ranks for Measures of Adaptive Functioning and Developmental Skills ................................................................................... 112

Table 11. Descriptive statistics and comparisons to normative data for mothers’ and fathers’ wellbeing and parenting warmth ................................................. 114

Table 12. Means, Standard Deviations, Ranges and Normative Comparisons for Measures of Family Functioning and the Home Environment ............. 116

Table 13. Summary of Participant Age, Focus Child Age, and Time Since Diagnosis ............................................................................................................. 118

Table 14. Summary of Themes and Subthemes Identified through Thematic Analysis ............................................................................................................. 120

Table 15. Summary of Research Findings from Studies 1 and 2 ................................. 144
List of Figures

Figure 1. Hastings’ transactional model of the relationship between child behaviour problems, parenting stress and parent behaviour........................................ 66

Figure 2. Model for the indirect effects of child behaviour problems on family functioning via parent stress, depression, and fatigue ................................. 89

Figure 3. Model for the indirect effect of parental depressive symptoms on warmth, hostility, and involvement, with family functioning as a mediator ............. 90

Figure 4. Model for the direct effect of parent depressive symptoms on warmth and hostility, and the indirect effect of parental depressive symptoms on involvement, with family functioning as a mediator.............................. 91

Figure 5. Summary of qualitative data analysis process............................................. 108
List of Abbreviations

a-FAS .......... Adapted Fatigue Assessment Scale
ABA .......... Applied Behaviour Analysis
ABS .......... Australian Bureau of Statistics
ADHD .......... Attention Deficit Hyperactivity Disorder
APA .......... American Psychiatric Association
ASD .......... Autism Spectrum Disorder
CFI .......... Comparative Fit Index
DASS-21 ......... Depression Anxiety and Stress Scales
DBC ........ Developmental Behaviour Checklist
DBC-P24 ....... Developmental Behaviour Checklist – Short Form
DIR/Floortime .... Developmental Individual-Difference Relationship-Based Floortime
DSM-III .......... Diagnostic and Statistical Manual of Mental Disorders, Third Edition
DSM-IV .......... Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSM-IV-TR ....... Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
DSM-5 .......... Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EIBI .......... Early Intensive Behavioural Intervention
FAD .......... Family Assessment Device
FAD-GF ....... Family Assessment Device – General Functioning Scale
FaHCSIA .......... The department of Families, Housing, Community Services, and Indigenous Affairs
HCWA .......... Helping Children with Autism
HOME .......... Home Observation for the Measurement of the Environment
ICD-10 ..........International Statistical Classification of Diseases and Related Health Problems
IQ .................Intelligence Quotient
LSAC ..........Longitudinal Study of Australian Children
MLM ..............Maximum Likelihood Mean-adjusted
MLR ..............Maximum Likelihood Estimation with Robust Standard Errors
PDDNOS ..........Pervasive Developmental Disorder – Not Otherwise Specified
PECS ..........Picture Exchange Communication System
PEP-3 .............Psycho-educational Profile, Third Edition
RDI ..............Relationship Development Intervention
RMSEA ..........Root Mean Square Error of Approximation
SEIFA ..........Socio-Economic Index For Areas
SPSS-22 ..........Statistical Package for the Social Sciences, version 22
SRMR ..............Standardised Root Mean Square Residual
SSTP ..........Stepping Stones Triple-P Positive Parenting Program
TABC ..........Total Adaptive Behaviour Composite
TAFE ..........Technical and Further Education
TD ..........Typically Developing
TEACCH ..........Treatment and Education of Autistic and related Communication-Handicapped Children
TLI ..........Tucker-Lewis Index
UN ..........United Nations
Vineland-II ........Vineland Adaptive Behaviour Scales, Version-II, Parent/Caregiver Rating Form
WHA ..........World Health Assembly
WHO ..........World Health Organisation

xi
Chapter 1. General Introduction

The preschool years are considered a critical window of development for children with Autism Spectrum Disorders (ASDs; Boyd, Odom, Humphreys, & Sam, 2010; Dawson, 2008). Intervention can be most beneficial at this time as there are opportunities to promote skills and positive behaviours, which can enhance development and increase the child’s capacity for future learning (Eldevik et al., 2009; Lovaas, 1987). Intervention tends to be more effective when started early (Harris & Handleman, 2000). However, not all children with ASDs are diagnosed at a young age, and not all of those who are diagnosed early receive recommended interventions. The gap between recommendations for intervention and clinical practice is concerning (Dillenburger, McKerr, & Jordan, 2014; Szatmari, Charman, & Constantino, 2012). As a result, parents of children with ASDs take on much of the responsibility for supporting and managing their child’s condition (Drapela & Baker, 2014; Matson & Williams, 2015; Valentine, 2010).

Best practice guidelines recommend preschoolers with ASDs receive between 15 and 25 hours per week of early intervention (Prior & Roberts, 2006; 2012). The high time intensity poses significant costs to families who can access limited funding. As a result, families might make a number of accommodations to support their child (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Keogh, Garnier, Bernheimer & Gallimore, 2000). Therapeutic approaches are often integrated into home life due to financial and time constraints of parents as well as the advantages of working with the child in a familiar setting (Reed & Osborne, 2014). However, further work is necessary to ensure therapeutic strategies are embedded well within families’ home routines, and to enhance partnerships between service providers and families (Bernheimer & Weisner, 2007; Valentine, Rajkovic, Dinning, & Thompson, 2010). Innovative practice is needed to meet children’s needs without over-extending families (Karst & Van Hecke, 2012).

Although the person with an ASD is often the focus of early intervention, this condition also affects parents and families. Transactional and bio-ecological theories explain that just as the family environment influences children, children have an influence on others around them, and can elicit different interactions from other people (Bronfenbrenner, 2005; Sameroff, 2009). Raising a child with an ASD is often
distressing for parents, who are at risk of experiencing elevated symptoms of depression, stress, and fatigue (Dumas, Wolf, Fisman, & Culligan, 1991; Hayes & Watson, 2013; Seymour, Wood, Giallo, & Jellett, 2013). Importantly, behaviour problems in children with ASDs have been identified as a stressor for parents (Estes et al., 2009). Parents tend to find behaviour problems more stressful than autism symptomatology or adaptive skills (Estes et al., 2013; Jones, Totsika, Hastings, & Petalas, 2013; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013). When parents are negatively affected by behaviour problems there are likely to be implications for the family system. This further complicates the picture when parents and families are depended on as a key source of support for the child.

Prior to attending school, the family environment provides the primary developmental context for children, and incorporates the home learning environment, family relationships, and parenting practices. This environment is being used increasingly as a setting for early intervention (Schreibman et al., 2015). Current knowledge of the family environment emanates from families of typically developing (TD) children (e.g., Mullan & Higgins, 2014). For TD children, the family environment influences the attainment of numeracy and literacy skills, as well as children’s social and emotional development (Bradley, Corwyn, Burchinal, McAdoo, & Coll, 2001; Leerkes, Blankson, O’Brien, Calkins, & Marcovitch, 2011; Mullan & Higgins, 2014). Given the potential for the family environment to positively influence children and the key role that parents play in early intervention, understanding the factors that shape this environment is an important direction for ASD research. This would provide a basis to inform policies and interventions that build upon, and accommodate, the strengths and needs of parents and families of children with ASDs.

The aim of the current study was to explore the family environments of preschoolers with ASDs from multiple perspectives. The study was conducted in two phases, using a mixed-methodology. The first study extended the literature identifying a link between children’s behaviour problems and parental distress by determining whether this had consequences for family functioning and aspects of parenting. The second study involved an in-depth investigation of the family environment using predominantly interview methods. The impact of raising a preschooler with an ASD on families, as well as the adjustments and accommodations parents make to meet the needs of their preschooler, were a focus of this program of research.
This thesis contains eight chapters, including this current overview (Chapter 1). The literature review is presented in Chapters 2 to 5, beginning with a description of ASDs (Chapter 2). Literature on the impact raising a child with an ASD has on parents and families is reviewed in Chapter 3. In Chapter 4, the importance of the home learning environment is described within the context of recommendations for early intervention. This is followed by an explanation of the theoretical orientation of this thesis in Chapter 5. The literature review provides a basis for the two research studies presented in this thesis. The first is a cross-sectional study investigating the relationships between child behaviour problems, parent mental health, and family functioning/parenting practices (Chapter 6). The second is a qualitative exploration of the family environment (Chapter 7). The results of the two studies are summarised in turn, followed by a general discussion (Chapter 8) of the significance, research and clinical implications of this thesis.
Chapter 2. Overview of Autism Spectrum Disorders

People with ASDs are a heterogeneous group, with unique profiles of strengths and difficulties (Attwood, 2006; Gillberg, 1990). This means that the symptom profile and severity is very different from one person to the next. Individuals with ASDs have been described as having a *diffability* rather than a *disability*, reflecting a different, but not defective, way of understanding and relating to the world (Attwood, 2006; Lawson, 2008). This difficulty relating to the social world (Volkmar, Chawarska, & Klin, 2005; Wing, Gould, & Gillberg, 2011) or lacking “social instinct” (Wing et al., 2011, p. 769) is unique to individuals with ASDs. Even individuals with ASDs who have average or above average intelligence and verbal skills find this challenging, although they may be able to compensate, to an extent, with their intellect (Asperger, 1944/1991; Helt et al., 2008; Schaefer-Whitby, Ogilvie, & Mancil, 2012). Due to their lack of social understanding, difficulties with communication, and atypical behaviours, an individual with an ASD might be described as someone who “perceives and thinks about the world differently to other people” (Attwood, 2006, p.12).

**Historical Origins of ASDs**

Autism stems from the Greek word *autos* meaning *self* (Wing, 1997). As a psychiatric term, autism originates from Bleuler’s work on schizophrenia in 1910; he used this term to describe withdrawal from reality (Kuhn, 2004). Psychiatrist Leo Kanner (1943) and paediatrician Hans Asperger (1944/1991) were the first to use the word “autistic” diagnostically, and historical accounts of ASDs usually begin with their work. Descriptions of what would now be called an ASD can also be found in folklore, factual history, and psychiatric case studies predating the 1940s (Ssucharewa, 1926/1996; Wing, 1997). In the 1920s, terms such as schizoid character and detached idealism were used to describe children who would most likely have met modern criteria for an ASD (see Gillberg, 1998, for a review).

In the 1940s, Kanner (1943) working in Baltimore, and Asperger (1944/1991) in Vienna, published case studies of children with a similar profile of abilities. The children manifested “fascinating peculiarities,” in particular, a detachment from their social environment (Kanner, 1943, p. 217). Whereas Kanner used the term “Early Infantile Autism,” Asperger used “Autistic Psychopathy” with psychopathy in this
context translating more closely to personality (Attwood, 2006; Frith, 1991; Wing, 1981a). The children described by Kanner were more severely impaired than those described by Asperger, although it is of note that Asperger was writing in Europe at a time when Nazi occupancy threatened the welfare of those considered disabled (Frith, 1991). The differences in abilities meant that the syndromes described by Kanner and Asperger were thought by some, including Asperger, to delineate into two distinct conditions (van Krevelen, 1971; Wing, 1997).

Wing and Gould (1979) hypothesised that Kanner (1943) and Asperger (1944/1991) were describing conditions that belonged on a continuum. They introduced a triad of impairments that captured the difficulties experienced across the spectrum, these being impairment of social relatedness, social communication, and imagination (Wing, 1981b; Wing & Gould, 1979). Wing (1981a) introduced the term “Asperger’s Syndrome” as a subtype of autism to help communicate the needs of children with more subtle impairments, and facilitate appropriate treatment for them. At this time, Infantile Autism had entered the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; American Psychiatric Association, [APA], 1980). Asperger’s Syndrome was entered first in the International Statistical Classification of Diseases and Related Health Problems (ICD-10; World Health Organisation [WHO], 1993) and became a diagnostic category in the DSM-IV the following year (APA, 1994; Volkmar et al., 1994).

Diagnosis of ASDs

The DSM-IV-Text Revision (DSM-IV-TR; APA, 2000) was current at the time of this research. To meet diagnostic criteria for Autistic Disorder, two examples of impairment in social interaction were needed (e.g., “failure to develop peer relationships appropriate to developmental level”) along with impairment in social communication (e.g., “stereotyped and repetitive use of language or idiosyncratic language”) and restricted behaviours, interests, and activities (e.g., “apparently inflexible adherence to specific, non-functional routines or rituals;” APA, 2000, p. 75). Delays must have been noticeable prior to the age of 3 years (APA, 2000). Asperger’s Disorder was differentiated from Autistic Disorder in that there was no criterion for impairment in social communication, and there must not have been a delay in language, cognitive development, or adaptive skills (APA, 2000). Children with significant difficulties in
social interaction, who also showed either communication anomalies or stereotypic
behaviour, not meeting criteria for Autistic Disorder or Asperger’s Disorder, could be
diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified
(PDDNOS).

A number of researchers investigated whether Autistic Disorder and Asperger’s
Disorder provided valid and clinically useful diagnostic categories (e.g., Eisenmajer et
al., 1998; Mayes, Calhoun, & Crites, 2001; Prior et al., 1998). It was consistently
demonstrated that children diagnosed with Asperger’s Disorder conclusively met
criteria for Autistic Disorder when evaluated against the DSM-IV (Eisenmajer et al.,
1996; Mayes et al., 2001; Tryon, Mayes, Rhodes, & Waldo, 2006). Usually, these
children had delays in social communication with onset prior to the age of 3 years
(Mayes et al., 2001). Even Asperger’s (1944/1991) original case studies met criteria for
Autistic Disorder under DSM-IV (Miller & Ozonoff, 1997).

Although Asperger’s Disorder was not supported as a valid categorical diagnosis
in research, Eisenmajer et al. (1996) found this label had practical applications.
Clinicians tended to diagnose Asperger’s Disorder, rather than Autistic Disorder, in
children who were interested in developing friendships, had better play skills, and
engaged in pedantic, one-sided communication. As anticipated by Wing (1981a),
clinicians used the term Asperger’s Syndrome to describe individuals who did not fit
the “aloof” or “in their own world” image associated with Autism (Eisenmajer et al.,
children diagnosed with Autistic Disorder, Asperger’s Disorder, or PDDNOS were
related to their degree of cognitive and social impairment rather than any specific
defining features. These findings supported the idea that Autistic Disorder, Asperger’s
Disorder, and PDDNOS were best conceptualised as existing on a continuum, the
Autism Spectrum.

A more dimensional approach to diagnosing ASDs has been incorporated into
DSM-5, which introduced Autism Spectrum Disorder (APA, 2013). The criteria now
comprise symptoms in two domains: restricted and repetitive behaviours, and deficits in
social interaction/communication (APA, 2013). To meet criteria, an individual must
show three examples of impairment in social interaction and social communication
(e.g., deficits in social-emotional reciprocity) and two restricted behaviours (e.g.,
excessive adherence to routines). In addition, they must have shown signs of the
disorder in early childhood. A severity level is also assigned ranging from Level 1 “requiring support” to Level 3 “requiring very substantial support” (APA, 2013, p. 52).

Changing the diagnostic criteria for DSM-5 has had implications for both research and practice. Diagnostic specificity seems to have improved, as those who were excluded from a diagnosis of an ASD under DSM-IV continue to be excluded based on the DSM-5 revisions (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012; Huerta, Bishop, Duncan, Has, & Lord, 2015; McPartland, Reichow, & Volkmar, 2012). Children with ASDs were more reliably distinguished from children with Attention Deficit Hyperactivity Disorder (ADHD), intellectual disability, language disorders, or anxiety disorders when clinicians used the DSM-5, rather than DSM-IV criteria (Huerta et al., 2015). The changes have also affected the diagnostic sensitivity whereby a subgroup of children diagnosed with an ASD based on DSM-IV criteria, might not reach the diagnostic threshold under DSM-5, particularly those previously diagnosed with PPDNOS (Gibbs et al., 2012; McPartland et al., 2012). The clinical implications of these changes are of primary concern, as this group of children and families might not be eligible for services that are allocated only to those with a confirmed diagnosis. In addition, these changes in the criteria will affect the ability to draw comparisons between studies conducted across different eras (Fung & Hardan, 2014; McPartland et al., 2012; Skuse, 2012).

**Epidemiology**

Autism, as it was defined in the 1960s and 1970s was considered to be a rare condition, with most children affected having comorbid intellectual disability (Lotter, 1966; Prior, Gajzago, & Knox, 1976; Treffert, 1970; Wing, Yeates, Brierley, & Gould, 1976). Early studies conducted in the United Kingdom found that Autism affected less than 5 per 10,000 children (Lotter, 1966; Wing et al., 1976). However, the clinical picture has changed over time, and it has become apparent that ASDs are more common than once thought, with some referring to an “autism epidemic” (Leonard et al., 2010). Fombonne (1999) reviewed all epidemiological studies conducted between 1967 and 1998, and calculated that 18.7 per 10,000 people had an ASD. Fombonne updated his review as new studies were published, and tracked the increasing prevalence estimates over time (2003, 2005, 2009; French, Bertone, Hyde, & Fombonne, 2013). The
prevalence estimate grew from 27.5 per 10,000 individuals in 2003, to 60 per 10,000 in 2005, 60-70 per 10,000 in 2009, and most recently, 74 per 10,000 individuals in 2013.

Other epidemiological studies of ASDs provide prevalence rates of 1% if not higher (Baird et al., 2006; Baron-Cohen et al., 2009; Kim et al., 2011). In the United States, the Centers for Disease Control and Prevention (2014) reported that ASDs affected one in 68 children, after monitoring 8 year olds living across 11 states in 2010. Estimates are lower in Australia with the most recent Australian Bureau of Statistics (ABS) data suggesting ASDs affect 0.5% of individuals. This figure is based on survey data from 2012 and shows a 79% increase since the previous estimate in 2009 (ABS, 2009, 2012). The prevalence rate varied across geographical regions, with the highest rates of ASDs in Victoria and the lowest rates in the Australian Capital Territory. The ABS survey method may have underestimated the prevalence of ASDs, as it was not designed solely for this purpose, but rather screened general health symptoms or learning difficulties (ABS, 2012). There is uncertainty about whether changes in prevalence estimates over time reflect an increase in incidence, growing public awareness, or differences in the way ASDs are diagnosed and counted (Charman, 2011; Elsabbagh et al., 2012; French et al., 2013; Leonard et al., 2010). It has been proposed that the changes for DSM-5 will lead to a reduction in the number of individuals diagnosed with an ASD (Fung & Hardan, 2014).

There is no evidence that the incidence of ASDs differs depending on nationality, geography, or socio-economic status, although availability of resources and diagnostic services does differ based on these factors (Elsabbagh et al., 2012; Fombonne, 1999). More males than females are diagnosed with ASDs at a ratio of at least 3:1 (Muhle, Trentacoste, & Rapin, 2004). These conditions often go unrecognised in women, who commonly have a different clinical presentation, potentially contributing to this gender difference (see Kirkovski, Enticott, & Fitzgerald, 2013, for a review).

Aetiology

The causes of ASDs are currently unknown. Some ASD advocates object to the medical model and the search for a cause or cure for these conditions. Instead they embrace ASDs as an important part of a persons’ identity. Under the neurodiversity movement, ASDs are conceptualised as a natural human variation, and the notion of
needing to be cured is rejected (Bagatell, 2010; Jaarsma & Welin, 2012; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Others seek to find a cause for ASDs, to move toward prevention and advance treatments, and along these lines genetics, environmental factors, and neurobiology have been explored (Dawson, 2008; Walsh, Elsabbagh, Bolton, & Singh, 2011).

**Genetics.** The results of twin and sibling studies indicate that the influence of genetics on the development of ASDs is moderate to strong (see Muhle et al., 2004, for a review). There is increased risk for ASDs in younger siblings of a diagnosed child, with one prospective study finding that of 664 infant siblings, 18.7% were later diagnosed with an ASD (Ozonoff et al., 2011). Furthermore, outcomes from twin studies have shown that there is a higher diagnostic concordance rate for monozygotic (69% concordance) as compared to dizygotic twin pairs (0-5% concordance; Bailey et al., 1995; Rutter, 2005). Although providing evidence of a genetic component to ASDs, these results also indicate that genetics are not the only causal factor (Bailey et al., 1995; Hallmayer et al., 2011). Twin studies might over estimate genetic influences, as the intra-uterine environment, or perinatal difficulties such as hypoxia, might also contribute to the development of ASDs (Froehlich-Santino et al., 2014; Hallmayer et al., 2011).

**Environment.** Numerous environmental factors have been explored as potentially triggering ASDs in genetically susceptible individuals (see Muhle et al., 2004, for a review). Environmental factors that may increase the risk of ASDs include early immune activation (Depino, 2013), maternal age, paternal age, and vitamin D deficiency (Kocovska, Fernell, Billstedt, Minnis, & Gillberg, 2012). A meta-analysis by Gardener, Spiegelman, and Buka (2011) identified more than 60 different neonatal and perinatal risk factors that have been explored in the aetiology of ASDs, suggesting the scope of this research continues to be very broad. It is unlikely that a single environmental trigger will be identified as the cause of ASDs, and genetic-environmental interactions continue to be explored (Kim & Leventhal, 2015).

**Neurobiology.** Structural and neuropathic processes differentiate individuals with ASDs from those who are TD, which might be related to the ASD symptom profile
When controlling for brain size, a larger amygdala develops prior to the age of 3 years in children with ASDs as compared to TD children (Schumann et al., 2009). A larger amygdala is associated with more severe social and communication impairments in boys with ASDs. However, in girls the amygdala enlargement seems more pronounced, and might not be related to symptom severity (Schumann et al., 2009). Interestingly, by adolescence and adulthood, individuals with ASDs have significantly lower amygdala volume than their TD peers indicative of underlying neuropathic processes in these brain structures (Schumann et al., 2004).

Preschoolers (aged 2 to 4 years) with ASDs have almost twice as many prefrontal cortex neurons than is seen in a TD brain, and yet by adulthood this number is greatly reduced (Courchesne et al., 2014; Courchesne et al., 2011). This suggests that during early development, either excess neurons are produced, or less are removed during prenatal apoptosis (cell death). Courchesne and colleagues (2014) theorised that increased neuron numbers and excessive connectivity are neurological causes of ASDs. From a neuropsychological standpoint, early intervention is essential and might reduce the amount of maladaptive connectivity in the brain. These factors, along with the greater neuroplasticity seen in very young children, indicate that theoretically, better outcomes are obtained when intervention begins early in life (Courchesne et al., 2014; Dawson & Bernier, 2013).

Further complicating the picture is the likelihood that ASDs are the phenotypic presentation of a range of underlying neurological variations (Fernell, Eriksson, & Gillberg, 2013; Waterhouse & Gillberg, 2014). Waterhouse and Gillberg proposed that in order to understand the neurobiology of ASDs, the condition should be “taken apart” (2014, p. 1788). By this statement, they meant that within neurobiological research, a unitary model is unlikely to capture the heterogeneity seen across individuals with ASDs. As an alternative, working with subgroups of individuals with ASDs who share common neurological profiles might elucidate further information about different aetiologies, and inform more specific treatments for the “Autisms” (Waterhouse & Gillberg, 2014).
Comorbidity

Individuals with ASDs are vulnerable to a number of comorbid symptoms and conditions. For instance, they show higher rates of anxiety and depression than individuals in the general population (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). Risk for comorbid conditions is apparent in preschoolers with ASDs, who show elevated scores on parent or teacher rated measures of ADHD, and both mood and anxiety disorders (Gadow, DeVincent, Pomeroy, & Azizian, 2004; Hayashida, Anderson, Paparella, Freeman, & Forness, 2010). Concurrent diagnoses of conditions such as Oppositional Defiant Disorder, ADHD, mood, and anxiety disorders contribute to the complex support needs of children with ASDs and their families (Levy et al., 2010).

A small proportion of children with ASDs also have an intellectual disability. Widely discrepant estimates of the prevalence of this co-occurrence have been reported in the literature (Matson & Shoemaker, 2009). Findings from a study conducted in the Barwon region of Victoria suggested that 47% of children with ASDs also had an Intelligence Quotient (IQ) below 70 (Icasiano, Hewson, Cooper, & Marshall, 2004). Larger review studies suggest intellectual disability occurs in 15 to 20% of people with ASDs (Fernell et al., 2013). For individuals with an ASD and an intellectual disability, the challenges with adaptive functioning, language, and social skills, contribute to a poor prognosis (Matson & Shoemaker, 2009).

Emotional and Behavioural Problems

In their daily lives, children with ASDs exhibit emotional and behavioural problems beyond the core features of their diagnosed condition (Georgiades et al., 2011). Emotional and behavioural problems are those that are socially inappropriate, occur excessively in either frequency or intensity, and are challenging for caregivers to manage (Fodstad, Rojahn, & Matson, 2012; Mudford et al., 2011). Such behaviours are often disruptive or destructive and can impact upon the individual’s safety, learning, or community involvement (Emerson et al., 2001; Fodstad et al., 2012; Mudford et al., 2011). People with ASDs show both internalising (e.g., being withdrawn, emotionally reactive, anxious) and externalising (e.g., temper tantrums, being aggressive, hyperactive, non-compliant, and/or self-injurious) behaviour problems (Bearss, Johnson, Handen, Smith, & Scahill, 2013; Geier, Kern, & Geier, 2012; Hartley, Sikora,
& McCoy, 2008; Maskey, Warnell, Parr, Le Couteur, & McConachie, 2013). Eating and sleeping difficulties are also common in this group (Gadow et al., 2004; Geier et al., 2012; Richdale & Schreck, 2009). Behaviour problems occur in a majority of individuals with ASDs (Icasiano et al., 2004; Mudford et al., 2011; Murphy, Healy, & Leader, 2009). It is more common for people with ASDs to show multiple co-occurring problem behaviours than to have one isolated concern (Hartley et al., 2008; Maskey et al., 2013, Murphy et al., 2009).

The rate and severity of problematic behaviours is higher in children with ASDs as compared to TD children or those with other developmental concerns (Bauminger, Solomon, & Rogers, 2010; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2013; Fodstad et al., 2012). For example, a large cohort of Australian parents reported that their child or adolescent with an ASD ($n=367$) showed higher levels of problematic behaviours than young people with an intellectual disability uncomplicated by ASD ($n=550$; Brereton, Tonge, & Einfeld, 2006). The children with ASDs showed more severe disruptive, self-absorbed, and anxious symptoms than the comparison group, as measured by the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 2002). The range of symptoms indicated emotional and behavioural problems in children and adolescents with ASDs were multifaceted. Brereton et al. (2006) suggested that challenging behaviours might have been a result of neurobiological factors associated with the diagnosis of an ASD.

Behavioural and emotional problems are usually conceptualised as being comorbid with symptoms of ASDs. However, recent findings suggest that for preschoolers, emotional and behavioural problems form part of the ASD phenotype (Georgiades et al., 2011). Using Principal Components Analysis, Georgiades et al. (2011) demonstrated that behaviour problems underlie both social communication deficits and restricted and repetitive behaviours. Behaviour problems did not form a separate third cluster providing preliminary evidence that these difficulties are integrated within the disorder. Furthermore, behaviour problems were not associated with the language, intellectual, or adaptive skills of the children. Thus, children with a broad range of abilities across the Autism Spectrum are likely to exhibit behaviour problems.
Emergence of emotional and behavioural problems. In the mid-2000s, findings from several studies demonstrated that preschool-aged children with ASDs showed more severe parent-reported behaviour problems than TD children, and children with other conditions such as intellectual disability or Down syndrome (Eisenhower et al., 2005; Gadow et al., 2004; Herring et al., 2006). More recently, researchers have identified that this divergence in behavioural trajectories emerges very early in development (Estes et al., 2013; Fodstad et al., 2012; Kozlowski & Matson, 2012). Estes et al. (2013) detected a discrepancy in behaviour problems between groups of children aged 18 to 30 months. Toddlers with ASDs had higher levels of problem behaviours than toddlers who were TD or had a non-ASD developmental delay. Toddlers with ASDs aged between 12 and 39 months (Fodstad et al., 2012) or between 17 and 36 months (Kozlowski & Matson, 2012) have also been found to show more frequent and severe aggressive/destructive, stereotyped, and self-injurious behaviour than aged-matched peers with non-ASD developmental delays.

Behaviour problems seem to persist across the preschool years for children with ASDs. By dividing participant data into four age groups (i.e., 12-18 months; 19-25 months; 26-32 months), Fodstad et al. (2012) found that older children with ASDs tended to show higher rates of aggressive and destructive behaviours than younger children. There were also non-significant trends suggesting self-injurious and stereotyped behaviours were worse for the older children. These findings needed to be interpreted with caution, due to the cross-sectional, rather than longitudinal study design, meaning a different cohort of children with ASDs represented each age range. Hartley et al. (2008) failed to find a correlation between age and externalising behaviour problems in their sample of preschoolers with Autistic Disorder. However, internalising problems correlated with age, suggesting that as preschoolers with ASDs approached 4 years of age, they were more likely to show withdrawn behaviours and somatic complaints (Hartley et al., 2008). A longitudinal study by Eisenhower et al. (2005) suggested that scores on Achenbach’s (2000) Child Behavior Checklist remained elevated for children with ASDs assessed at ages 3, 4, then 5 years. Overall, findings from these studies indicate that behavioural problems unfold early in individuals with ASDs, and can remain elevated or even become progressively worse across the preschool years. These difficulties may continue through to adulthood (Billstedt, Gillberg, & Gillberg, 2005).
Behaviour problems are often a primary target of treatment and a key reason for referring children with ASDs to mental and/or allied health services (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Mudford et al., 2011). Emotional and behavioural problems occur for a multitude of reasons in children with ASDs, which can be unclear for parents and professionals alike (Attwood, 2006). In addition to considering the functionality of behaviour problems (e.g., attempts to avoid aversive stimuli, access an object, or communicate) other biopsychosocial factors can contribute to behaviours presenting more frequently and severely. These include sensory sensitivity, cognitive impairment, and interpersonal processes (Chuang, Tseng, Lu, & Shieh, 2012; Hartley et al., 2008; O'Donnell, Deitz, Kartin, Nalty, & Dawson, 2012). Managing challenging behaviours is important to keep children safe, provide them with opportunities for learning and social participation, and to help caregivers manage daily life with their child (Mudford et al., 2011). Parents consistently report finding their children’s behaviour problems distressing (e.g., Eisenhower et al., 2005). Such problems also have negative consequences for family functioning, as will be described in the next chapter of this thesis.

**Prognosis**

ASDs are considered to be lifelong disorders, although some authors claim that individuals can achieve optimal outcomes, and move off the Autism Spectrum (Fein et al., 2013; Sutera et al., 2007). Children with a prior diagnosis of an ASD may later be comparable to TD children on a range of measures (e.g., cognitive, adaptive functioning, language, and processing facial expressions) although it is unclear as to whether more subtle differences in their social functioning remain (Fein et al., 2013). For example, they might show less insight into friendships and social relationships when compared to TD peers (Orinstein et al., 2015).

Using longitudinal designs, researchers have identified three different developmental trajectories for individuals with ASDs: persistent, worsening, or improving (Gotham, Pickles, & Lord, 2012; Lord, Luyster, Guthrie, & Pickles, 2012). These categories reflect the pattern seen in the core features of ASDs over time, as measured by the Autism Diagnostic Observation Schedule (Lord et al., 2000). Based on the findings from a small sample of toddlers who were followed up longitudinally from age 18 months to 36 months, roughly equal numbers of children followed each of these
three developmental trajectories (Lord et al., 2012). It is unclear whether biological or external factors such as the level of intervention received, or a combination of these elements, influenced their developmental course. Further work is needed to determine whether these different profiles continue across the lifespan, and how the trajectory of a young person with an ASD can be improved.

Outcomes for adults with ASDs seem to be well predicted by their childhood cognitive and language abilities (Howlin & Moss, 2012; Magiati, Tey, & Howlin, 2014). A series of studies were conducted where 60 individuals with ASDs who were initially assessed as children (mean age = 6 years) were then followed up as adults (mean age = 44 years). Findings indicated the participants’ cognitive abilities were quite stable across the two time points, whereas their ASD symptoms and language skills improved (Howlin, Moss, Savage, & Rutter, 2013; Howlin, Savage, Moss, Tempier, & Rutter, 2014). The majority of these adults had poor outcomes overall. Despite having non-verbal intelligence in the average range as children, their social inclusion, employment, and independent living skills were impaired as adults (Howlin et al., 2013). Very few participants were in paid employment ($n=17$), or had sustained friendships or relationships ($n=4$). The participants in the study were diagnosed in the 1960s or 1970s and so did not have the same access to services as children with ASDs do today. Advancements in intervention strategies for children with ASDs could potentially improve their outcomes as adults in the future (Howlin et al., 2013; Magiati et al., 2014).

**Early Intervention for Preschoolers with ASDs**

Due to their impairment in connecting with others socially, infants and young children with ASDs have difficulty learning through processes like joint attention, imitation, and play (Jordan, 2003; Kasari, Gulsrud, Freeman, Paparella, & Helleman, 2012; Matson & Fodstad, 2010; Schreibman et al., 2015). Missing out on these early experiences means children lose opportunities to practice and develop their cognitive, social, language, and emotional skills. This serves to widen the gap between their abilities and those of TD peers (Jordan, 2003; Matson & Fodstad, 2010). Early intervention is considered vital for improving the chances of altering the trajectory of ASDs (Dawson, 2008; Prior & Roberts, 2012).
Early intervention approaches are available to assist children with ASDs to develop skills and abilities. This common goal is approached from various theoretical orientations and philosophies, such as behavioural, developmental, and biomedical. Below is a selected (but not exhaustive) summary of intervention strategies that are currently implemented for preschoolers with ASDs.

**Behavioural approaches.** Early Intensive Behavioural Interventions (EIBIs) use Applied Behavioural Analysis (ABA) procedures to target a range of developmental skills and behaviours in young children with ASDs. This model is based on operant conditioning principles that outline the way behaviours are reinforced by the child attaining something pleasant (i.e., positive reinforcement) or via removal of an aversive stimulus (i.e., negative reinforcement; Ferster, 1961; Lovaas, 1987). Children’s abilities are extended using techniques such as shaping, which involves setting incremental goals and providing reinforcement (Matson & Neal, 2009). By teaching children to communicate their needs more adaptively, teaching others to respond differently to the child, and minimising environmental precipitants, a reduction in problem behaviours often occurs (Mudford et al., 2011).

EIBIs are typically conducted for between 20 and 40 hours per week and may be home-based or school/centre based (Eldevik et al., 2009; Matson & Neal, 2009; Reichow, Barton, Boyd, & Hume, 2012). Parents are often involved as co-therapists in the provision of EIBIs (Eldevik et al., 2009) consistent with the early studies in this field (Lovaas, Schreibman, & Koegal, 1974). Outcomes from a recent Cochrane review indicated that EIBIs led to improvements in children’s IQ, adaptive functioning, communication, daily living skills, and socialisation in many, but not all, young children with ASDs (Reichow et al., 2012). Further research is needed to identify factors related to heterogeneity in treatment responses (Reichow et al., 2012). Reichow et al. (2012) suggested that the evidence base for EIBIs continues to be of low quality due to the small number of rigorous Randomised Control Trials (n=1) or Clinical Control Trials (n=4) that have been conducted to date. As such, it is currently recommended that in clinical practice, decisions about using EIBIs be made on a case-by-case basis taking family preferences and resources into consideration (Prior & Roberts, 2012; Reichow et al., 2012).
Despite the potentially positive outcomes reported for children receiving EIBIs, there continue to be children with ASDs who do not respond to the treatment, or do not make substantial gains. This could be related to the extent to which interventions are implemented correctly. For some ABA teaching techniques, such as pivotal response training, higher treatment fidelity is associated with greater cognitive gains for children with ASDs (Pellecchia et al., 2015). Child, parent, and family factors could also affect treatment efficacy (Fava & Strauss, 2014; Osborne, McHugh, Saunders, & Reid, 2008a; Reichow et al., 2012; Strauss et al., 2012). Training parents to assist with implementing interventions can facilitate children’s gains (Strauss, Mancini, & Fava, 2013). However, when parental stress levels are high, children tend to make fewer gains in treatment (Osborne et al., 2008a; Strauss et al., 2012). Parental stress may have a more pronounced effect when the treatment is highly time intensive (Osborne et al., 2008a). This is problematic as children can potentially make the greatest gains when intensity is high (Osborne et al., 2008a).

Despite having the soundest empirical backing, EIBIs tend to be accessed by small numbers of families. Some families are hesitant to implement EIBIs because of the highly structured teaching approach, and the associated costs of these programs (Klintwall, Gillberg, Bölte, & Fernell, 2012). Generally EIBIs are expensive, as well as being time and labour intensive (Kornack, Persicke, Cervantes, Jang, & Dixon, 2014; Matson & Williams, 2015). Although many parents report positive experiences of EIBIs, coordinating and implementing an intensive intervention program can be stressful and intrusive on family life (Hastings et al., 2005; Remington et al., 2007; Schwichtenberg & Poehlmann, 2007). To address these barriers, efforts have been, and continue to be, directed toward applying these principles more naturalistically within children’s daily activities (see Schreibman et al., 2015, for a review).

**Developmental interventions.** Developmental interventions use interactions between children with ASDs and their caregivers to build social-communication, and emotion-regulation skills. Some example intervention types are the Relationship Development Intervention (RDI; Gutstein, Burgess, & Montfort, 2007) and the Developmental Individual-Difference Relationship-Based Floortime Model (DIR/Floortime; Greenspan & Wieder, 2009). Both of these approaches encourage
caregivers to integrate therapeutic techniques into daily routines and activities and so are considered high in time intensity.

The RDI is designed to increase experience-sharing behaviours (e.g., joint attention, pretend play) in children with ASDs (Gutstein et al., 2007). Some of the RDI goals include improving parental self-efficacy, teaching children to use the caregiver as a point of reference, and altering parental communication styles (Gutstein, 2009). To implement the RDI, caregivers attend a six-day training program where they are taught the theory and practice of this approach. They also meet frequently with a consultant, who reviews videotapes of them working with their child (Gutstein et al., 2007). The RDI may result in improved social relatedness and reciprocal communication in children, and improved flexibility in parents (Gutstein et al., 2007).

The DIR/Floortime is a play-based approach that involves purposefully following the interests of the child with an ASD. The therapist tries to join the child in their world and then guide them towards shared experiences (Greenspan & Wieder, 2009). For example, if the child with ASD is wandering around the room then the adult will join them in this activity, and find opportunities to interact with them with warmth (Greenspan & Wieder, 2009). Throughout this child-directed play, challenges are introduced that aim to boost the child’s skills, such as shared attention, engagement with the caregiver, communication, and symbolic play (Batejan & Spritz, 2013).

The evidence base for the RDI and DIR/Floortime is limited by a lack of randomised controlled trials, and a lack of research conducted independently of the pioneers of each approach. Both the RDI and DIR/Floortime are currently rated as interventions that show promise with emerging evidence, but require further research to support their efficacy (Prior & Roberts, 2012; Prior, Roberts, Rodger, & Williams, 2011). Some parents choose these approaches as they feel that they are more in line with their parenting style, and so feel comfortable interacting with their children in this way (Hebert, 2014).

**Structured teaching.** The Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) approach is a therapy model designed to build on strengths in the learning profile of individuals with ASDs (Mesibov & Shea, 2010). Essential components of the TEACCH intervention include structuring the environment, using strengths in visual processing to help overcome areas
of weakness, using special interests to engage children in learning, and supporting efforts toward meaningful communication (Mesibov & Shea, 2010). Providing a structured environment has been shown to result in more affect regulation, relatedness, and on-task behaviour in children with ASDs (Mesibov & Shea, 2010). This ecological method has received empirical support through a review of single-subject designs (Bodfish, 2004; Odom et al., 2003). However, further research is required to thoroughly evaluate the TEACCH approach. Although TEACCH is used in the United States it is not currently available in Australia; however, concepts of structured teaching are incorporated in to other interventions.

**Communication and language interventions.** Interventions to assist with communication skills are used for children with ASDs across a range of severity levels. For children with limited speech, augmentative and alternative communication approaches are required. This is necessary for non-verbal children but can also be used to expand a speaking child’s vocabulary or social-communication abilities. An example approach aimed at improving children’s functional communication skills is the Picture Exchange Communication System (PECS; Bondy & Frost, 2001).

The PECS is implemented following a protocol based on principles of ABA to teach spontaneous, functional communication to children with a range of disabilities (Bondy & Frost, 2001). Within the PECS protocol, children are taught to make requests by handing a picture to another person in exchange for a desired item (Bondy & Frost, 2001). Gradually, PECS users are taught to construct sentences with their pictures, and to engage in social commenting. In many cases, PECS users develop spoken language and may transition off the system (Sulzer-Azaroff, Hoffman, Horton, Bondy, & Frost, 2009).

Case studies evaluating the PECS with small numbers of participants have suggested children can learn to use the system quickly, and that it enhances their communication skills and may also reduce behaviour problems (Charlop-Christy, Carpenter, Le, LeBlanc, & Kellett, 2002). A randomised controlled trial conducted in the United Kingdom found that when teachers were trained in the PECS and supported by a consultant, children in their classes initiated communication more frequently than before the intervention. Although, further research is needed to determine how well students can generalise their PECS use, how often children move on to develop spoken
language, and whether the treatment effects are maintained over time (Howlin, Gordon, Pasco, Wade, & Charman, 2007).

**Family-based interventions.** Family based interventions aim to provide parents with information and teaching strategies to support their child with an ASD. An example family-based approach is the Hanen More Than Words Program (Sussman, 2012). To learn to implement the Hanen program, parents attend eight weekly group sessions, where they learn skills to help them interact with their children in ways that are hypothesised to promote communication development (e.g., providing cues, using repetition). Parents also receive three home visits where their implementation of the Hanen program is supported and reviewed by a professional (e.g., a speech pathologist). Findings from a randomised controlled trial indicated that although parents improved in their responsivity overall, changes in the children’s communication skills were inconsistent (Carter et al., 2011). Differences in children’s communication outcomes were partially explained by their initial abilities prior to receiving the intervention. Children with low levels of object interest at baseline (i.e., the children did not engage in functional play with toys) showed the most improvement over the course of the intervention (Carter et al., 2011). These results exemplified the heterogeneity seen in treatment responses amongst children with ASDs (Carter et al., 2011; Vivanti, Prior, Williams, & Dissanayake, 2014).

**Parenting programs.** Parent training approaches are designed to help parents address problematic behaviours in their child, and respond to them in a way that minimises reoccurrence. Parent training approaches have shown promise in reducing non-compliance, and increasing adaptive skills in verbal preschoolers with ASDs (Bearss et al., 2013). Additionally, parent training can lead to a reduction in stereotyped behaviour patterns in children with ASDs (Boyd, McDonough, Rupp, Khan, & Bodfish, 2011). However, the research in this area is limited by small sample sizes, and a lack of control or comparison groups.

Stepping Stones Triple-P Positive Parenting Program (SSTP; Sanders, Mazzucchelli, & Studman, 2004) is an intervention aimed at reducing behaviour problems in children with disabilities that is used internationally. This program follows a public health model and has five levels of intervention that aim to teach parents
strategies to manage developmental and behavioural problems. At the broadest level, information about parenting is provided through the media. Level two involves a short consultation with parents or giving seminars on parenting topics. At level three, a brief program is offered to target a discrete behavioural or developmental concern. Level four interventions provide eight to ten sessions to assist families with managing severe behaviour problems and at level five, family systems concerns such as parental mood management, and partner supports are also addressed (Sanders et al., 2004).

A recent meta-analysis indicated that the SSTP intervention resulted in positive outcomes for children with disabilities, including ASDs, and their parents (Tellegen & Sanders, 2013). Improvements in child problems showed a medium effect size, which increased with intervention intensity across the different levels. A large effect size was found for improvements in parenting styles. Level three and four interventions were associated with improved parent adjustment (medium effect size), but no change was found at levels two and five, despite level five directly targeting these issues. This low-intensity public health approach has the potential to provide information and support to improve outcomes for children with ASDs and their families.

**Psychotropic medication.** Psychotropic medications are prescribed to some infants, toddlers (Fodstad et al., 2012; Horovitz, Matson, & Barker, 2012), and children with ASDs (Tureck, Matson, Turygin, & Macmillan, 2013). These medications do not treat the core features of the condition, but assist with associated emotional and behavioural problems, such as hyperactivity, anxiety, or aggression (Tureck et al., 2013). Medications prescribed for this purpose come from various classes including stimulants, selective serotonin reuptake inhibitors, antipsychotics, or anticonvulsants (Witwer & Lecavalier, 2005). Children with comorbid diagnoses such as ADHD, depression, or anxiety are more likely to be prescribed medications, than those with a sole diagnosis of an ASD (Coury et al., 2012; Spencer et al., 2013). Children with ASDs exhibiting more severe externalising behaviours are more likely to be prescribed psychotropic medication than those with low levels of such behaviours (Tureck et al., 2013; Witwer & Lecavalier, 2005). In fact, based on his review of the research, Matson (2009) suggested that medications were often used as the first line of treatment for behavioural problems in children with ASDs. Medications involve the risk of side
effects, and there is uncertainty about the impact psychotropic medications have on the developing brain (Gleason et al., 2007).

**Complementary and alternative medicines.** Numerous complementary and alternative medicine approaches are used to treat children with ASDs (see Whitehouse, 2013, for a review). The number of complementary and alternative approaches marketed to families of children with ASDs is extensive. Examples include the use of gluten and/or casein free diets, melatonin, and hyperbaric oxygen therapy. Melatonin has been shown to improve sleep-onset for individuals with ASDs and may be considered a low-risk and potentially beneficial approach (Rossignol & Frye, 2011; Whitehouse, 2013). Currently, there is insufficient evidence to support dietary changes as a treatment for ASDs (Williams et al., 2014). Despite being popular and commonly used, most complementary and alternative medicine approaches lack empirical support, and some approaches are harmful (Whitehouse, 2013).

**Summary**

Over the last 70 years, the conceptualisation and diagnosis of ASDs has evolved substantially, from descriptions of a small number of case studies, to subcategories of this disorder, and the recent introduction of the *DSM-5* criteria (Volkmar & McPartland, 2014). The changing nature of the way ASDs are conceptualised is linked to the likelihood of multiple aetiologies, the changing epidemiology, and the heterogeneity seen in the qualities, abilities, and trajectory of severity across individuals. Young children with ASDs tend to have complex needs with one study suggesting behaviour problems may be inextricable from the core symptoms of these conditions (Georgiades et al., 2011). This diversity and complexity contributes to the difficulty providing appropriate support to individuals with ASDs and their families. Behaviour problems, in particular, have a negative impact on the families of children diagnosed with ASDs, as will be described in the next chapter.
Chapter 3. Impact of Raising a Child with an ASD on Family Functioning, Parental Wellbeing, and Parenting Practices

An overview of the difficulties preschoolers with ASDs face across a range of domains, including social functioning, restricted interests, and emotional and behavioural problems, was presented in the previous chapter. In addition to affecting the person with an ASD, these impairments affect caregivers and family members immensely (Karst & Van Hecke, 2012). The influence of children with ASDs on their parents and families is relatively under-researched, although literature in this area has expanded over the last decade. It has been proposed that the sparseness in parenting and family research for ASDs is linked to the controversial history in this field (Reed & Osborne, 2014).

Chapter 3 will begin with a brief description of the potentially damaging beliefs and traditions that have contributed to a reluctance to research family processes in the ASD field (Reed & Osborne, 2014). Then, the demands and challenges associated with raising a preschooler with an ASD will be described. Subsequently, literature outlining the impact raising a child with an ASD has on parents and families will be reviewed. Although the impact of children’s behaviour problems on either parental wellbeing or family functioning has been investigated in a number of studies, further work is needed to integrate these areas. Clarifying the processes that occur within these families during a critical window for development and intervention (i.e., the preschool years) is likely to assist with informing treatment so as to improve outcomes for children with ASDs and their parents. This approach also reflects an ongoing push to include the family system in the assessment and treatment of ASDs (Baker, Seltzer, & Greenberg, 2011; Karst & Van Hecke, 2012; Prior & Roberts, 2012).

Historical Context of Parenting and ASDs

In the early stages of the identification of children with Early Infantile Autism psychodynamic theories were prominent. Interpersonal processes within the family of origin were believed to contribute to the aetiology of ASDs, in particular, unconscious rejection of the child by his/her mother (see Campbell, Schopler, Cueva, & Hallin, 1996, for a review). Terms such as “emotional refrigeration” were used to describe supposed parental shortcomings (Kanner & Eisenberg, 1956, p. 562). Based on this
assumption, separating the child from his/her family environment was an accepted treatment approach (Bettelheim, 1967; Feinstein, 2010). Children were often institutionalised with little hope for improvement (Wolff, 2004).

The belief that ASDs had psychogenic origins persisted among some circles for decades, and some parents still feel as though they are blamed for their child’s ASD (Bultas & Pohlman, 2014; Feinstein, 2010; Neely-Barnes, Hall, Roberts, & Graff, 2011). As a result of these theories, many parents in the 1950s and 1960s sought professional help, feeling distraught and believing they had unknowingly caused their child’s condition (Baker, 2010; Feinstein, 2010; Kysar, 1968; Wing, 1997). In addition, parents felt responsible for unsuccessful psychodynamic treatment attempts (Gillberg, 1984; Kysar, 1968; Mesibov, Adams, & Schopler, 2000; Schopler & Reichler, 1971; Wing, 1997). This perspective and treatment model contributed to feelings of parental guilt and disempowerment (Gillberg, 1984).

A number of practitioners disagreed with the psychodynamic approach to ASDs, and went on to develop the first educational and behavioural treatments as an alternative (Fenichel, 1974; Lovaas et al., 1974; Rutter, 1968; Schopler, 1971; Schopler & Reichler, 1971). Parents became involved in therapy as treatment partners (Fenichel, 1974; Schopler & Reichler, 1971). Rather than being critiqued for being obsessive and fastidious, parents began to be recognised as having expert knowledge of their children (Fenichel, 1974; Schopler & Reichler, 1971). This change was accomplished, in part, due to the self-advocacy of groups of parents of children with ASDs (Wing, 1997; Wolff, 2004).

Much has changed since the era of blaming parents for causing ASDs and viewing the family environment as pathological. However, this history continues to exert some influence on the research, in that there is a reluctance to investigate parenting and ASDs for fear of attributing blame (Reed & Osborne, 2014). Although it is now understood that parents do not cause ASDs, learning about the role that parents have in their child’s prognosis and development is important. Part of this involves understanding the unique challenges and demands parents experience in their daily lives (Gallimore, Bernheimer, & Weisner, 1999). Parents often spend more time with their children than anyone else and have the most comprehensive knowledge of their child’s characteristics and abilities. It therefore makes sense that in addition to being affected
by their child’s characteristics, they influence their child’s development immensely (Reed & Osborne, 2014).

**Demands of Parenting a Preschooler with an ASD**

Despite parents having unique knowledge and perspectives about their children with ASDs and being in a good position to assist with interventions, they also face ongoing challenges related to managing their child’s complex needs. The toddler and preschool years can be particularly demanding, as parents must process the diagnosis, while simultaneously noticing and managing the emergence of skill deficits and behavioural problems (Davis & Carter, 2008). Parents are usually responsible for initiating the diagnostic assessment process for their child and might have their concerns dismissed (Sansosti, Lavik, & Sansosti, 2012; Turygin, Matson, Williams, & Belva, 2014; Zuckerman, Lindly, & Sinche, 2015). Most parents recognise signs of an ASD before their child’s second birthday (Chawarska et al., 2007; De Giacomo & Fombonne, 1998; Howlin & Asgharian, 1999; Zwaigenbaum, Bryson, & Garon, 2013) yet on average, children are diagnosed with ASDs at 5 years of age, or later for milder presentations (Baio & Rice, 2006; Shattuck et al., 2009). Waiting lists for diagnostic services in Australia can be long, and the process often requires input from numerous allied health professionals meaning a number of separate appointments might be needed (Valentine et al., 2010; Williams et al., 2014). Therefore, a substantial amount of time usually elapses between parents’ first concerns and a confirmed diagnosis of an ASD, during which parents are likely to struggle to understand and manage their child’s difficulties.

After a child is diagnosed with an ASD, parents often report moving in to a “crisis period” (Bloch & Weinstein, 2009; Davis & Carter, 2008; White, McMorris, Weiss, & Lunsky, 2012). At this time, parents grieve and begin to adjust their expectations for their own and their child’s future (Altiere & von Kluge, 2009; Bloch & Weinstein, 2009). Coinciding with this adjustment, parents must navigate available treatment programs for the first time. Parents often feel compelled to begin this process urgently, because clinically it is recommended that interventions begin as soon as possible (Karp & Kuo, 2015). During the preschool years, parents often feel under pressure to begin implementing interventions quickly, and might feel guilty about the prospect of not having chosen the most suitable intervention for their child (Karp &
Kuo, 2015; Roberts & Prior, 2006). Amongst these responsibilities, parents might not have time to adjust and process their emotions about their child’s diagnosis (Wachtel & Carter, 2008).

The demands of caregiving often result in sacrifices being made in other areas of family life (Altiere & von Kluge, 2009). Caring for a child with an ASD is time intensive, with one study suggesting mothers spent an average of 6.6 hours ($SD = 2.8$ hours) per day caring for their school-aged child with an ASD (Sawyer et al., 2010). Caring for a younger child is likely to be even more time intensive. As a result, families have less time available for recreational activities and parents might be unable to return to work. In response to managing their child’s difficult behaviours, many parents of children with ASDs report feeling “stretched beyond their limits” (Sharpley, Bitsika, & Efremidis, 1997, p. 23).

Parents might find that they need to take on a number of extra roles to support their children with ASDs, including carer, advocate, coach, teacher, and therapist (Benson, Karlof, & Siperstein, 2008; Rogers, 1998). Taking on these roles can alter the relationship with their child (Karp & Kuo, 2015). Although many parents are motivated to support their children in these ways, and are rewarded by seeing their child’s progress, they may take on these roles as a necessity due to their children having unmet educational or healthcare needs (Kogan et al., 2008; Sansosti et al., 2012; Sharpley et al., 1997). Other parents do not believe that they can parent their child effectively, and so have a reduced sense of parenting self-efficacy, which is associated with negative emotions (Kuhn & Carter, 2006). The demands apparent in the preschool years, when a child is recently diagnosed, are therefore multifaceted and unique to this condition. In addition to affecting the wellbeing of parents, these challenges also infiltrate into other domains of family life, such as family relationships, as parents are often preoccupied with supporting and caring for their child with an ASD (Hoogsteen & Woodgate, 2013). This can make it difficult to maintain a well functioning family system.

**Impact of ASDs on Family Functioning**

A family is a system of interrelated parts, including individuals and subsystems (Miller, Ryan, Keitner, Bishop, & Epstein, 2000). Family functioning refers to the extent to which family members communicate effectively, manage daily life, and foster positive relationships (Miller et al., 2000; Zubrick, Williams, Silburn, & Vimpani, 2000). Amongst these responsibilities, parents might not have time to adjust and process their emotions about their child’s diagnosis (Wachtel & Carter, 2008).
Being able to resolve problems, fulfil roles and responsibilities, and share and respond to emotional experiences together, are further indicators of family functioning (Miller et al., 2000). The way a family system operates influences the behaviour of individual family members (Miller et al., 2000). A well-functioning family system provides support for family members and is associated with positive child and parent outcomes (Renzaho, Mellor, McCabe, & Powell, 2013).

Parents of children with ASDs tend to report less effective family functioning on questionnaire measures than parents of TD children (Gau et al., 2012; Higgins, Bailey, & Pearce, 2005; Sivberg, 2002), children with Down syndrome (Sanders & Morgan, 1997), and children with intellectual disabilities (Weiss, 2002). Although in some studies (e.g., Manning, Wainwright, & Bennett, 2011) this difference was not supported. For example, Manning et al. (2011) found that compared to normative data from parents of TD children, parents of school-aged children with ASDs reported significantly higher levels of family cohesion, and similar levels of emotional expressiveness and conflict. These findings suggested the family members were highly supportive of one another, perhaps facilitated by the parents’ capacity to positively reframe their experiences of raising a child with an ASD (Manning et al., 2011). High levels of cohesion can be interpreted as an indication of enmeshment, where family members lack personal boundaries. However, in families of children with ASDs, a high level of cohesion has been found to be a protective factor, associated with parents implementing adaptive coping strategies (Altiere & von Kluge, 2008).

Most prior research findings highlight a significant difference in family functioning between families of children with ASDs or developmental delay (e.g., Herring et al., 2006), and families of TD children. This has been reported across cultures in Sweden (Sivberg, 2002), Taiwan (Gau et al., 2012; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008), Israel (Manor-Binyamini, 2011), Jordan, and Ireland (McConkey et al., 2008). Parents in the study by McConkey et al. (2008) had children with intellectual disabilities, and a range of other conditions, and so the findings were not representative of families of children with ASDs. Sivberg (2002) compared family functioning as reported by Swedish parents (n=66) of children with ASDs from 37 families to a control group (n=66; 37 families) closely matched for family composition. Findings suggested that parents of children with ASDs were more likely to blame family problems on a particular child, lack shared activities, and report
chaos and intrusiveness, than families in the control group. Difficulty coping with distress contributed to less effective family functioning (Sivberg, 2002). These studies (Gau et al., 2012; Manor-Binyamini, 2011; McConkey et al., 2008; Sivberg, 2002) included families of children across a broad age range, so differences associated with particular life-stages were not established. Participants in a study by Gray (2002) reported that their parent and family stress related to parenting a child with an ASD declined over time. However, recent findings from a questionnaire study indicate stress and family difficulties are fairly constant for parents of children with ASDs from the preschool through to the adolescent years (McStay, Trembath, & Dissanayake, 2014).

Across studies exploring the impact of a child with an ASD on families, indicators of family functioning have differed, ranging from family adaptability and cohesion (Gau et al., 2012; Higgins et al., 2005) to family hardiness, a quality associated with being able to remain a sense of control in response to stressors (Weiss, 2002). Oftentimes, measures of parent stress are used as indicators of family functioning, without researchers directly assessing broader impact of raising a child with an ASD on the family system (see Tint & Weiss, 2015, for a review). Overall, these comparative cross-sectional studies indicate that families raising a child with an ASD are under strain, although these studies do not explain how or why these difficulties arise.

Family functioning might be influenced by a number of individual, intra-familial, and social factors (see Tint & Weiss, 2015, for a review). For example, limited social support (Bromley, Hare, Davison, & Emerson, 2004; McConnell, Savage, & Breitkreuz, 2014; Weiss et al., 2013), socioeconomic disadvantage, poor individual wellbeing (Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008), and maladaptive parental coping (Khanna et al., 2011) are all factors that can make it difficult for families to function optimally. Characteristics of children with ASDs, particularly their behaviour problems, have also been found to contribute to family distress (Khanna et al., 2011). When the child with an ASD is perceived as having a strong negative impact on the family, parents are more likely to view the condition as severe (Zablotsky, Bramlett, & Blunberg, 2015). The way severity is conceptualised in clinical practice might not necessarily reflect parents’ experiences. Parents might interpret severity in terms of the impact on their lifestyle rather than the nature of their child’s symptoms.
When parents are faring poorly, while also being confronted with persistent problem behaviours, this might also contribute to family hardship.

**Impact of ASDs on Parental Wellbeing**

Given that the demands of raising a child with an ASD are extensive, and multifaceted, it is not surprising that these parents tend to experience reduced psychological wellbeing. A number of studies have investigated the experience of stress amongst parents of children with ASDs, with results showing that these parents experience stress to a greater degree than parents of TD children (see Hayes & Watson, 2013 for a review). These parents are also at risk of experiencing elevated depressive symptoms and fatigue, as will be described below.

**Stress.** Studies have consistently shown that parents of children with ASDs report higher levels of stress than parents of TD children, or parents of children with other conditions, for example, Down syndrome (Dumas et al., 1991; Pisula, 2007; Sanders & Morgan, 1997); non-specific developmental delay (Estes et al., 2009); Cystic Fibrosis (Bouma & Schweitzer, 1990); and intellectual disability (Eisenhower et al., 2005). This discrepancy in parenting stress is apparent early on, when children are preschool aged (Eisenhower et al., 2005; Estes et al., 2009) and has been reported cross-culturally (e.g., Samadi & McConkey, 2014; Wang et al., 2013). Sometimes parents manage their stress by reframing their experiences, seeking social support, and problem solving (Pottie & Ingram, 2008). Less effective ways of managing stress include withdrawing, blaming others, and feeling hopeless (Pottie & Ingram, 2008). Difficulty managing stress can contribute to poor physical health in parents of children with ASDs.

The long-term stress associated with raising a child with an ASD affects parents’ cortisol levels and cortisol response patterns (De Andrés-García, Moya-Albiol, & Gonzáles-Bono, 2012). Parents of children with ASDs often have blunted cortisol production, which is associated with poor physical health (Dykens & Lambert, 2013; Lovell, Moss, & Wetherell, 2015). Showing a pattern of blunted cortisol production has been found to be more common amongst parents of children with ASDs than parents of children with other disabilities (Dykens & Lambert, 2013). These findings suggest that
In addition to being evident in self-report data, the high degree of stress experienced by these parents is apparent according to objective physiological measures.

In their meta-analysis of 10 studies published between 1989 and 2009 comparing stress levels of parents of children with ASDs to parents of TD children, Hayes and Watson (2013) established that parents in the ASD groups consistently reported significantly higher levels of stress. A large effect-size was established suggesting the significant findings across these studies were indicative of a true difference in parental stress levels in the population. The authors also analysed 12 studies that showed higher stress in parents of children with ASDs than parents of children with other disabilities (i.e., Down syndrome, Cystic Fibrosis, ADHD, Cerebral Palsy, Fragile X syndrome, and Foetal Alcohol syndrome). Again, a large effect size was established, where parents of children with ASDs showed higher levels of stress than parents of children with other disabilities. The majority of studies assessed stress particularly related to the parenting role rather than general life stress, which usually involved asking parents how they responded to their child’s difficult behaviours. This approach would not necessarily capture the stress parents experience in other domains of their lives, outside of their interactions with their child with an ASD, particularly because these children show a high incidence and severity of difficult behaviours (Eisenhower et al., 2005; Fodstad et al., 2012). Overall, the results of the meta-analysis by Hayes and Watson (2013) indicated that comparing stress in parents of children with ASDs to other groups would continue to result in significant findings. The authors recommended that future research should be directed toward developing a better understanding of the experiences within families, to help explain why this difference might come about, and more importantly, how to effectively intervene to improve the wellbeing of parents (Hayes & Watson, 2013).

**Depression.** Parents of children with ASDs are at risk of experiencing depressive symptoms (Dumas et al., 1991; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Lai, Goh, Oei, & Sung, 2015; Kuhn & Carter, 2006; Xu, Neece, & Parker, 2014). These parents have been shown to report higher levels of depressive symptoms on the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erlbaugh, 1961) than parents of children with Down syndrome, or parents of TD children (Dumas et al., 1991). The findings of Dumas et al. (1991) have been replicated in more recent studies
using different measures of depression. For example, Hamlyn-Wright et al. (2007) found that parents of children with ASDs \((n=265)\) reported higher levels of depression than parents of children with Down syndrome \((n=223)\) or parents of TD children \((n=131)\) using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Within the ASD group, the mean depression score approached the clinical cut-off for this measure. Lai et al. (2015) found mothers of children with ASDs reported elevated depressive symptoms relative to parents of TD children using the Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995). The higher level of depressive symptoms reported by parents of children with ASDs as compared to parents of TD children, on a range of measures, suggests this difficulty is likely to be widespread. The majority of participants in these studies have been mothers, meaning the experiences of fathers were not well represented. This is a common difficulty in family research, yet addressing the experiences of fathers is also important (McStay et al., 2014).

It has been suggested that raising a child with an ASD affects the wellbeing of mothers to a greater extent than fathers. Hastings et al. (2005) conducted a study where both mothers and fathers of 48 preschoolers with ASDs completed questionnaires to describe their child’s behaviour, and their mental health. Within this study, fathers \((n=41)\) reported lower levels of depression than mothers \((n=48)\); which has been reported in other studies (e.g., Davis & Carter, 2008). The severity of depression reported by participants was related to the level of stress reported by their spouse. Davis and Carter (2008) found that although there was a significant difference in depression scores between mothers and fathers, their stress and anxiety were similar.

When compared to mothers of children with ASDs, fathers tend to show lower levels of depression (Davis & Carter, 2008). However, they may experience wellbeing difficulties to a greater extent than men who are not raising a child with a disability. A recent study indicated Australian fathers of children with intellectual disabilities \((N=315)\) reported elevated stress and depression relative to men in the population (Giallo et al., 2015). Of the sample, close to half (44.8%) were fathers of a child with comorbid intellectual disability and ASD. Their depression was predicted by child behaviour problems, parenting stress, and dissatisfaction in their parenting role. Unlike the findings of Hastings et al., (2005), partner mental health did not predict fathers’ depression scores. Therefore, raising a child with an ASD, and stressful parenting experiences, might also impact on the wellbeing of fathers.
Carter, Martinez-Pedraza and Gray (2009) assessed mothers of toddlers with ASDs (n=177) annually for the three years following their child’s diagnosis. The mothers had moderately elevated depression scores, and as a group, their average levels of depression did not change over time. Closer inspection of the data suggested that although there were no group differences over time, there was a pattern whereby the depressive symptoms experienced by some mothers improved whereas others worsened. Characteristics of the child with an ASD, including their sleep, behaviour problems, and competence were associated with mothers’ concurrent depressive symptoms but did not predict changes over time. Maternal self-efficacy and anxiety scores predicted changes in depressive symptoms over time, although the interpretation was not straightforward. Higher maternal efficacy was associated with lower depression initially, but then predicted increases in depressive symptoms over time. Higher anxiety symptoms were associated with a reduction in depressive symptoms over time, which was also counter-intuitive. The authors proposed that having unrealistic expectations about parenting might have lead parents to feel helpless. This study highlights the potential chronicity of parental depression in the preschool years, and challenges the idea that parents naturally adapt to raising a preschooler with an ASD over time.

It is possible that the mental health difficulties experienced by parents of children with ASDs reflect pre-existing psychopathology, which may be a genetic or antenatal risk factor for having a child with ASD. Alternatively, the elevated mental health difficulties experienced by this group of parents might be in response to the stress of parenting a child with additional needs (Fairthorne, de Klerk, & Leonard, 2015). To address this, a series of studies were conducted by analysing public health records from mothers in Western Australia who had a child between 1983 and 2005 (Fairthorne, de Klerk et al., 2015). In one part of the study, data from 213,656 women who had a child between 1983 and 1999 were analysed (Fairthorne, Hammond, Bourke, de Klerk, & Leonard, 2016). Of these women, 9,341 had been in contact with psychiatric outpatient services prior to having their child. These mothers were more than twice as likely to have a child with an ASD compared to mothers with no psychiatric history (Fairthorne et al., 2016).

In another part of their study, Fairthorne and colleagues (Fairthorne, Jacoby, Bourke, de Klerk, & Leonard, 2015) used the data from Western Australian birth records between 1983 to 2005 but excluded women who had accessed public health
services for a mental health condition prior to having their child. The sample comprised 272,947 mothers with no prior report of a psychiatric diagnosis. The results showed that mothers of children with ASDs (without comorbid intellectual disability) had the highest rates of public health service access for their own affective (e.g., depression, bipolar disorder) and anxiety disorders when compared to mothers of TD children or mothers of children with ASD and intellectual disability. Mothers of children with comorbid ASD and intellectual disability had similar rates of a psychiatric diagnosis when compared to mothers of TD children. These findings suggest that raising a child with an ASD without intellectual disability could be a trigger for the onset of mental health issues in mothers. It is possible that these mothers had children with higher-functioning ASD, which might have meant that the diagnosis was made later than for the children in the ASD and intellectual disability group. As such, the mothers in the ASD only group might have been subject to more stigma associated with their child’s difficulties as well as having less access to services/supports, both of which might have added to their burden of care, stress, and mental health (Fairthorne, Jacoby et al., 2015). A limitation of the study was that only public mental health records were available to the researchers meaning that women accessing private facilities were not included in the clinical group. Furthermore, the severity of the mental health symptoms was not evaluated. Nonetheless, these studies highlight that women with mental health concerns are at higher risk for having a child with an ASD, potentially due to genetics, or antenatal factors such as medication use during pregnancy (Fairthorne et al., 2016). For other women, having a child with an ASD seemed to be a trigger for the onset of mental health issues (Fairthorne, de Klerk et al., 2015). Regardless of the direction of effects, it remains clear that the demands of parenting a child with an ASD and the receipt of insufficient support places mothers at risk of poor mental health (Fairthorne de Klerk et al., 2015; Fairthorne, Jacoby et al., 2015).

**Fatigue.** Fatigue refers to ongoing exhaustion that is not relieved despite opportunities for rest, and is a subjective experience (Ream & Richardson, 1996). Fatigue differs from tiredness, as tiredness is considered temporary and can be alleviated by rest (Ream & Richardson, 1996). Fatigue can impair physical and mental competence and can result in irritability, forgetfulness, decreased energy, and impaired concentration (McQueen & Mander, 2003; Ream & Richardson, 1996). Although
fatigue is a symptom of a major depressive episode (APA, 2013), confirmatory factor analysis with a large sample of parents in the community established that fatigue and depression are distinct constructs (Giallo, Wade, Cooklin, & Rose, 2011). It is relatively common for parents to report differing levels of fatigue and depressive symptoms (e.g., moderate depression and low fatigue) and there can be a risk of exhausted parents being mistaken for depressed parents (Wade, Giallo, & Cooklin, 2012).

Until recently, fatigue was framed as an issue that only affected mothers in the post-partum period. A series of studies conducted in Victoria, Australia, indicated that fatigue is of concern for many parents and that parental fatigue extends into their child’s preschool years (Cooklin, Giallo, & Rose, 2011; Giallo, Rose, Cooklin, & McCormack, 2013). A large community sample of Australian parents with a child aged 5 years or younger (N=1276) completed a questionnaire reporting on various aspects of parenting. Within this study, a majority of parents (62%) agreed with the statement “tiredness gets in the way of being the parent I would like to be” (Cooklin et al., 2011, p. 5). Higher levels of fatigue were associated with feeling less competent as a parent, engaging in hostile parenting, and feeling stressed (Cooklin et al., 2011).

When compared to the aforementioned community sample (Cooklin et al., 2011), Australian mothers of preschoolers with ASDs were reported to experience significantly higher levels of fatigue (Giallo, Wood, Jellett, & Porter, 2013). These mothers (N=50) had a child (aged 2-5 years) diagnosed with an ASD. Their children had been diagnosed, on average, 12 months prior to participating in the study. Parental fatigue was associated with child (e.g., behaviour problems), parent (e.g., education, quality of diet, sleep, and exercise) and social (e.g., social support) factors. The association between behaviour problems in preschoolers with ASDs and maternal fatigue has since been replicated and extended with a sample of 65 mothers (Seymour et al., 2013). Structural equation modelling indicated that fatigue mediated the relationship between child behaviour problems and maternal stress. Furthermore, higher levels of fatigue were associated with greater use of maladaptive coping strategies. The authors highlighted the potential for behaviour problems and fatigue to have bidirectional influences, whereby fatigued parents may have more difficulty managing behaviour problems, which may then escalate (Seymour et al., 2013).
When asked about raising a child with an ASD or other chronic conditions, fatigue emerges as a concern for a number of parents (Benderix, Nordström, & Sivberg, 2007; Vickers, Parris, & Bailey, 2004). In one study, Iranian parents of children with ASDs were interviewed about their health, stress, and family communication. Several parents referred to a lack of energy, making statements such as: “we have no energy to waste upon family issues” and “I think that I have lost my energy and I need some type of medications” (Samadi & McConkey, 2014, p. 248-249). Working mothers caring for children with ongoing or chronic conditions (i.e., Leukaemia, Down syndrome, ASD) described having a strong sense of responsibility for the functioning of their family and their child’s development, which they perceived as exhausting (Vickers, et al., 2004). Parental exhaustion also emerged as a factor that contributed to parents’ decisions to place their child with an ASD and extreme behaviours in a group home facility (Benderix et al., 2006). These qualitative studies indicate raising a child with an ASD can be fatiguing for parents, which also affects their contribution to family life.

**Impact of ASDs on Parenting Practices**

Parenting practices refer to the typical parenting behaviours mothers and fathers engage in with their children. These are distinct from parenting styles, which are multifaceted parenting patterns (Lucas, Nicholson, & Maguire, 2010). Warm parenting includes showing affection to the child, as well as being attentive to their activities and interests, whereas hostility entails the parent losing their temper and feeling angry with their child (Nicholson, Sanson, Ungerer, Wilson, & Zubrick, 2002). Involvement refers to including the child in everyday activities, such as reading books or playing games (Giallo, Treyvaud, Cooklin, & Wade, 2013). Parenting practices of warmth, hostility, and involvement are associated with social and behavioural outcomes for TD children (Giallo, Treyvaud et al., 2013). In the Australian population, parents tend to report a high degree of warmth and low hostility (Lucas et al., 2010).

Findings from families of TD children indicate parental wellbeing is implicated in the ability to parent sensitively. In particular, parental depression is associated with less warm and more hostile parenting in both mothers and fathers (Edwards & Maguire, 2011). Parents experiencing depression might have difficulty showing their children affection, and might view their interactions with their children negatively (see Lovejoy, Graczyk, O’Hare, & Neuman, 2000 for a review). Parental mental health difficulties
may also contribute to reduced confidence in parenting, and less parental involvement (Giallo, Treyvaud, et al., 2013).

Parenting practices when there is a child with an ASD have received less research attention. However, it has been proposed that these factors might be even more important in families of children with additional needs (Totsika, Hastings, Vagenas, & Emerson, 2014). These children are usually more reliant on parents to meet their needs for an extended period of time (Totsika et al., 2014). Both similarities and differences in the approaches taken to parenting a child with an intellectual or developmental disability, as compared to a TD child, have been reported in the literature. Findings from a large, nationally representative sample from the United Kingdom indicated that parents of preschoolers with intellectual disability (n=516, of which 7% had an ASD) tended to report using inappropriate discipline (e.g., shouting, smacking) less frequently than parents of TD preschoolers (n=14,730), but they reported having more conflict and less closeness in their relationships with their children (Totsika et al., 2014). Closeness and conflict were measured in relation to the parent-child dyad, rather than as particular parenting practices. Longitudinally, closeness in the parent-child relationship was associated with less current and future behaviour problems, whereas conflict in the parent-child relationship was associated with worse current and future behaviour problems for children with intellectual disabilities. The authors suggested intervening at the level of the parent-child relationship could be effective for parents of children with disabilities, to help reduce problem behaviours.

When looking specifically at parenting for children with ASDs, research findings suggest parents tend to report setting limits and encouraging independent skills in their children at similar rates to parents in the community (Beurkens, Hobson, & Hobson, 2013; Osborne & Reed, 2010). Parents of children with ASDs tend to report having more difficulty involving their children in shared activities than parents in the general population (Osborne & Reed, 2010). Parents of younger children report having difficulty communicating effectively with their children with ASDs (Osborne & Reed, 2010). Such communication difficulties might be strongly influenced by children with ASDs having impaired social communication skills. When children have poor receptive and expressive communication skills, parents are likely to have difficulty talking and getting through to them, highlighting the transactional nature of these parent-child
factors. Parents’ abilities to set limits for their child with an ASD seem to be more closely related to their children’s future behaviour problems than involvement, encouraging independent skills, or communication (Osborne, McHugh, Saunders, & Reed, 2008b). However, the parenting practices that best support children and promote skill development in other areas, such as improving their adaptive skills, and communication, are unknown.

Some researchers have used practical tasks to attempt to more objectively rate parenting practices when there is a child with an ASD (e.g., Beurkens et al., 2013). During a free play activity in a clinic setting mothers and their child with an ASD were rated as having difficulty relating to one another during play. Increased severity of ASD symptoms seemed to make it more difficult for parents to relate to their child. Difficulties experienced by children with this diagnosis do have an impact on how they relate to their caregivers, which in turn, may affect parenting behaviours. In contrast to the video task, parent-reports suggested that the parent-child relationship was not correlated with ASD severity. This discrepancy suggested that parents might perceive and experience their relationship with their children differently to the way clinicians rate them. Furthermore, although parents were instructed to behave as they would at home, this may not be feasible when being video-recorded in clinic rooms.

Elements of parenting might need to be considered as transient constructs, rather than a quality or style of a particular parent (Blacher, Baker, & Kaladjian, 2013; Griffith, Hastings, Petalas, & Lloyd, 2014). For example, the same parent may take a different approach with siblings, whereby parenting is influenced by the relationship the mother or father has with that particular child (Griffith et al., 2014). Parenting practices can change over the course of time and different developmental stages. To test this, a group of 143 mothers were asked to speak freely about their child with an ASD and the TD sibling closest in age, for five minutes uninterrupted. Coding the speech samples revealed that parents expressed more criticism and less warmth toward their child with an ASD, than toward their TD sibling, highlighting the relational element of these parenting constructs (Griffith et al., 2014).

Parenting practices can also change depending on the context of the interactions with their children. Parents may relate to their child differently in free play as compared to structured tasks where demands are placed on their child (Blacher et al., 2014). For example, parents of children with a range of disabilities (ASD, Cerebral
Palsy, Down syndrome, developmental delay) were found to show more negative parenting (e.g., intrusiveness, hostility) in structured tasks, and more positive parenting (e.g., stimulation, sensitivity) during unstructured tasks. This is particularly concerning for parents of children with ASDs who are often asked to carry out structured tasks with their children as part of their child’s therapy. As a whole, the parents of children with disabilities were generally more negative than parents of TD children. The authors suggested behaviour problems in children with disabilities during structured tasks might have been related to these difficult parent-child interactions.

It has been proposed that when behaviour problems lead to distress in parents of children with developmental disabilities, parents are likely to respond with ineffective parenting behaviours (Hastings, 2002). These parenting behaviours are then theorised to contribute to future behaviour problems creating a cycle of difficulties. The associations between parental mental health and parenting practices when raising a child with an ASD have received little research attention. Findings from one known longitudinal study indicated that parenting stress could lead to less involvement and trouble communicating with a young child with an ASD (Osborne & Reed, 2010). In the TD literature, depression emerges as a predictor of parenting difficulties but has received little attention as a risk factor for less effective parenting practices when there is a child with an ASD. In addition to the transactions between parents and their children with ASDs that might influence elements of parenting, other factors such as the wellbeing of parents and whether they feel supported by their family system may affect the extent to which they are able to implement effective parenting practices.

**Relationship between Child, Parent, and Family Factors**

The research reviewed thus far has described parent and family wellbeing difficulties associated with raising a child with an ASD, and has largely focussed on comparisons between parents of children with ASDs and parents of children with other conditions. However, there has been a lack of synthesis in findings at the level of the child, parent, and family system (Mullan & Higgins, 2014). Evidence suggests that families of children with ASDs are at risk of experiencing reduced functioning and parental wellbeing when compared to families of children who do not have an ASD. Families might not be receiving the support required to reduce their risk of widespread challenges. Findings from studies that have investigated the interrelatedness of
children’s behaviour problems, parent wellbeing, and family difficulties when raising a child with an ASD are presented in this section.

Although family strain cannot be entirely attributed to an individual child with an ASD, findings from a number of studies have shown an association between behaviour problems in children with ASDs and family functioning (Herring et al., 2006; Khanna et al., 2011; McConkey et al., 2008; McStay et al., 2014; Paynter, Riley, Beamish, Davies, & Milford, 2013; Sikora et al., 2013). For example, correlational analysis based on a sample of Australian parents (N=43) of preschoolers with ASDs indicated challenging behaviours, but not ASD symptomatology, were associated with family distress (Paynter et al., 2013). Studies using path analysis have also indicated children’s behaviour problems are associated with family difficulties (Khanna et al., 2011; McConnell et al., 2014).

Externalising, as opposed to internalising, behaviours might be particularly difficult for families to manage (Sikora et al., 2013). Sikora et al. (2013) had 136 parents of a child (aged < 18 years) with an ASD rate their child’s behaviour problems, and the impact their child had on their family. Participant data were split into groups based on whether or not the child was rated as having clinically significant internalising/externalising behaviours. Analysis of variance indicated participants differed significantly on a family functioning measure when split according to externalising, but not internalising, behaviour scores, suggesting behaviours such as noncompliance had a great impact on the family system than the child showing anxious or depressive symptoms. Splitting the sample according to a score on a continuous variable introduces difficulties, as varying severities of behaviour problems are treated equally (i.e., behaviour problems or no behaviour problems). A regression-based approach may have provided further information about the strength of the relationship between children’s behaviour problems and family difficulties.

Sikora et al. (2013) suggested that managing externalising behaviours might have led to chronic hyper-vigilance on the part of caregivers, exacerbating stressors and limiting the family’s ability to function healthily. However, this (mediation) interpretation is yet to be tested empirically and would need to involve the assessment of parent factors. A clearer understanding of the relationship between these child, parent and family factors is needed to most effectively support children with an ASD in
the context of a family system. This is of particular importance given that these difficulties can be long standing.

Longitudinal research by Herring et al. (2006) showed that behaviour problems in preschoolers with ASDs were associated with higher maternal stress and lower levels of family functioning. Parent ratings on these variables taken one year apart were moderately to strongly correlated, suggesting difficulties were maintained over time rather than resolved. This difficulty adjusting during the preschool years highlights the need for better understanding and support (Karst & Van Hecke, 2012). Behaviour problems can impact on the family system in several ways and one likely pathway is via the well-established negative effects of child behaviour problems on parental wellbeing (Hayes & Watson, 2013).

In families of children with ASDs, one of the most consistent predictors of parental wellbeing is the severity of children’s behaviour problems. Challenging behaviours are more strongly associated with parenting stress than autism symptomatology or adaptive skills (Estes et al., 2009; Hastings et al., 2005; Jones et al., 2013; Lecavalier, Leone, & Wiltz, 2006; McStay et al., 2013; Peters-Scheffer et al., 2012). Research findings have shown that behaviour problems are associated with parenting stress (Baker et al., 2003; Estes et al., 2009, 2013; Herring et al., 2006; Tomanik et al., 2004) and fatigue (Seymour et al., 2013) in families of young children and toddlers with ASDs and other developmental delays. In line with a transactional approach, bidirectional effects are evident, whereby parenting stress can also escalate behaviour problems (Bauminger et al., 2010; Osborne et al., 2008b; Zaidman-Zait et al., 2014). Parental wellbeing is also associated with the overall functioning of the family system (Baker et al., 2011; Khanna et al., 2011).

Longitudinal research indicates that families of preschoolers with an ASD may have difficulty adjusting and adapting to the challenges of this developmental stage (Carter et al., 2009; Herring et al., 2006). Baker et al. (2011) measured child behaviour problems, maternal depression, the mother-child relationship, and family adaptability in families of adolescents or adults with ASD. These measures were administered at baseline and again at follow-up three years later. Findings from this study suggested that lower levels of family adaptability at time one predicted behaviour problems and maternal depression at time two. The authors of this study highlighted the transactional nature of these variables, stating that children with ASD both acted upon and were
influenced by the family system. These studies suggested that the difficulties faced by many families of individuals with ASD are maintained over time, rather than resolved, and highlight the need for further work to better understand and support parents and families.

Using a longitudinal research design, Osborne and colleagues (2008b; see also Osborne & Reed, 2009) demonstrated that parenting stress at baseline predicted child behaviours at follow-up (9-10 months later) in families of children with ASDs. Parenting stress was a stronger predictor of future behaviour problems than the reverse in this study (Osborne & Reed, 2009) although the opposite has been found in other research (Eisenhower, Baker, & Blacher, 2009). The effect of parental stress on child behaviour might be explained by changes in parenting practices, which then has implications for the child (Hastings, 2002; Osborne et al., 2008b). It seems intuitive that caregivers may be limited in their ability to provide effective care when their wellbeing is compromised (Sawyer et al., 2010). The relationship between parent stress and future behaviour problems was fully mediated by the parenting practice of limit setting (Osborne et al., 2008b). This is one of few studies available demonstrating the associations between parental wellbeing, parenting practices, and child behaviour in families of children with ASDs.

Findings from correlational (Johnson, Frenn, Feetham, & Simpson, 2011; Khanna et al. 2011) and longitudinal (Baker et al. 2011) studies indicate there is a relationship between parental wellbeing and family functioning in families where there is a child or young adult with an ASD. However, this has not been investigated in the preschool years. Furthermore, reduced parental wellbeing is often conceptualised as an outcome of poor family functioning (e.g., Baker et al. 2011; Renzaho et al. 2013). For example, a recent population based study of families in Victoria suggested poor family functioning was a risk factor for parent psychological distress and a range of emotional and behaviour problems in children (Renzaho et al. 2013). It has also been shown that a larger discrepancy between the actual and desired family functioning is associated with poorer mental health outcomes for parents of children with ASD (Johnson et al. 2011). Similarly, in families of children with ASD, a more adaptive family system has been linked to reductions in parental depression and child behaviour problems over time (Baker et al. 2011). Less is known about the way child and parent factors contribute to family functioning, particularly in the preschool years. No known studies have tied
together these experiences in a child-driven model. This is an important area of investigation to better understand family processes that may maintain family difficulties in the preschool years.

The influence of child characteristics on the family system is theorised to be transactional in nature, suggesting that if behaviour problems influence families, then families will influence behaviour problems. One known prior study has been conducted to investigate the impact of family interactions on children (aged 6 to 16 years) with ASDs (Kelly, Garnett, Attwood, & Peterson, 2008). The findings indicated that family conflict was associated with increased anxiety/depression, which then predicted the severity of autism symptomatology. When the path model was reversed, the model showed poor fit, giving preliminary evidence that family interactions predicted ASD symptomatology more strongly than the reverse (Kelly et al., 2008). Family cohesion was also found to indirectly predict symptomatology but this became non-significant when family conflict was accounted for. This study highlighted the detrimental effect of family conflict on wellbeing of children with ASDs.

In some cases, families seem to manage well despite experiencing the stressors associated with raising a child with a disability (McConnell et al., 2014). Families who experience a high degree of social support, along with low levels of financial hardship seem to be resilient to the impact of behaviour problems on their families (McConnell et al., 2014). These families show a higher rate of family-life congruence, a construct reflecting the extent to which families are living in line with their values. The findings of McConnell et al. (2014) were based on data from parents of children aged between 4 and 18 years with a range of disabilities and so may not be directly applied to families of children with ASDs. However, the findings from this study suggest that the impact of behaviour problems on the family system may be mediated or moderated by socio-ecological factors, and that social support can ameliorate some of the influence of behaviour problems on families. Furthermore, the authors highlighted that when interventions solely focus on children’s behaviour problems, there may not necessarily be benefits for the rest of the family unless family resilience factors also improve. The investigation of resilience in families of children with ASDs is an emerging area of research (Bayat, 2007). Studies reporting on the lived experiences of parents provide further insight into the ways in which caring for a child with an ASD affects parents and families.
**Lived Experience of Raising a Child with an ASD**

Bölte (2014) recently published an editorial in the journal *Autism* highlighting the importance of qualitative research in the ASD field. In comparison to the large number of quantitative studies, the number of qualitative studies published in peer-reviewed journals is negligible (Bölte, 2014). Table 1 outlines a selection of qualitative studies that have been conducted to explore the experiences of parents and families of children with ASD. Table 1 is a variation on that presented by Reed and Osborne (2014, p. 189) and the themes are listed using the names allocated by the respective study authors. Studies incorporating parents of children with other disabilities were excluded from this summary (e.g., King et al., 2006; Resch et al., 2010).

Table 1  
**Overview of Qualitative Studies Describing the Impact of Raising a Child with an ASD on Parents and Families**

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Method</th>
<th>Impact on Family</th>
<th>Impact on Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altiere &amp; von Kluge* (2009)</td>
<td>52</td>
<td>Semi-structured interview</td>
<td>Loss of support</td>
<td>Questioning</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Personal struggles</td>
<td>Devastation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Family benefits</td>
<td>Solutions</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Growth</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Personal benefits</td>
</tr>
<tr>
<td>DeGrace (2004)</td>
<td>5 family units</td>
<td>In-depth interview</td>
<td>Whole family life revolves around autism</td>
<td>Finding a balance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Feeling robbed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fleeting moments</td>
<td></td>
</tr>
<tr>
<td>Hoogsteen &amp; Woodgate (2013)</td>
<td>28</td>
<td>Semi-structured interview</td>
<td>Centering autism within the family (i.e., family life revolves around the child with an ASD)</td>
<td>Intense focus on the child’s needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Multiple Roles</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Multiple Roles</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Finding a balance</td>
<td></td>
</tr>
<tr>
<td>Hutton &amp; Caron* (2005)</td>
<td>21</td>
<td>Semi-structured interview</td>
<td>Little time for fun activities</td>
<td>Stressful parenting experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Need to plan ahead</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Stress on marriage</td>
<td></td>
</tr>
<tr>
<td>Lutz, Patterson, &amp; Klein (2012)*</td>
<td>16</td>
<td>In-depth interview</td>
<td>Dis-ease and relationship strain</td>
<td>Guilt and anger</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Adaptation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Grief and anger</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Disappointment and sacrifice</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Appreciating and defining life and multiple roles</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Study Year</td>
<td>Method</td>
<td>Themes</td>
<td>Implications</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------</td>
<td>--------------------</td>
<td>----------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Meirsschaut, Roeyers, &amp; Warreyn</td>
<td>2010</td>
<td>In-depth interview</td>
<td>It affects our whole life, Lack of understanding, Inaccessible care-giving system</td>
<td>Coping strategies, Concerns and questions</td>
</tr>
<tr>
<td>Myers, Mackintosh, &amp; Goin-Kochel</td>
<td>2009</td>
<td>Open-ended questionnaire</td>
<td>Stress, Impact on family as a whole, Social isolation</td>
<td>Parents’ personal wellbeing, work lives and marital relationships, Child’s behaviour and demands of care and therapy</td>
</tr>
<tr>
<td>Phelps, Hodgson, McCammon, &amp; Lamson</td>
<td>2009</td>
<td>Open-ended questionnaire</td>
<td>Familial Implications, Economic Implications, Social Impact</td>
<td>Psychological Implications</td>
</tr>
<tr>
<td>Safe, Joosten, &amp; Molineux</td>
<td>2012</td>
<td>Semi-structured interviews</td>
<td>Something’s got to give (the mothers were having difficulty meeting family roles and expectations)</td>
<td>Paradox of emotions, Frustration of finding the right support, Mother as therapist</td>
</tr>
<tr>
<td>Schaaf, Toth-Cohen, Johnson, Outten &amp; Benevides</td>
<td>2011</td>
<td>Semi-structured interviews</td>
<td>Flexibility, Familiar vs. unfamiliar space, Difficulty completing family activities, Impact on siblings</td>
<td>Constant monitoring</td>
</tr>
<tr>
<td>Woodgate, Ateah, &amp; Secco</td>
<td>2008</td>
<td>Interviews</td>
<td>Isolation</td>
<td>Vigilant parenting, Sustaining the self and family, Fighting all the way</td>
</tr>
</tbody>
</table>

Note. *Additional themes were identified in the study that do not directly relate to the impact of ASDs on parents and families.

As shown in Table 1, when parents reflect on their experience of raising a child with an ASD, some similar themes emerge. Firstly, ASDs have an all-encompassing effect on family life, and the affected child often becomes the focal point within the family (DeGrace, 2004; Hoogsteen & Woodgate, 2013; Meirsschaut, Warreyn, & Roeyers, 2011; Myers, Mackintosh, & Goin-Kochel, 2009; Nealy, O’Hare, Powers, &
Swick, 2012). This can mean that parents have difficulty distributing their time to other family members, including their partner (Nealy et al., 2012; Phelps, Hodgson, McCammon, & Lamson, 2009). Secondly, raising a child with an ASD has a substantial emotional impact on parents, who may struggle to balance the caregiving demands with self-care, and feel socially isolated (Altiere & von Kluge, 2009; Hutton & Caron, 2005; Lutz, Patterson, & Klein, 2012; Myers et al., 2009; Nealy et al., 2012; Phelps et al., 2009; Safe, Joosten, & Molineux, 2012). Thirdly, parents take on multiple roles to support their child, such as advocate, caregiver and teacher/therapist (Altiere & von Kluge, 2009; Hoogsteen & Woodgate, 2013; Lutz et al., 2012; Safe et al., 2012). In addition to these themes highlighting areas of difficulty, participants in some studies described positive gains, and personal growth as a result of raising a child with an ASD (e.g., Altiere & von Kluge, 2009).

Findings from the majority of the studies shown in Table 1 are based on the accounts of small numbers of parents. Yet, together these studies provide preliminary evidence of common family difficulties. One study achieved a large sample size ($N=493$) by having parents respond online to the prompt: “How has your child in the autism spectrum affected your life and your family’s life?” (Myers et al., 2009, p. 672). Parents from the United States (77% of sample) and other countries (i.e., Australia, New Zealand, England, Ireland, and Canada; 18%) participated. Five key themes emerged, as shown in Table 1. The overall tone of each response was also coded, showing that 237 parents carried a negative tone, 194 parents responded with a mixed tone, and 46 parents provided an overall positive tone in their response. This large-scale study provides further evidence for the multifaceted and widespread impact a child with ASD has on the family system. The findings suggested most parents perceived their experiences of raising a child with an ASD negatively, and positive outcomes, such as personal growth were less common amongst parents (Myers et al., 2009). None of the aforementioned qualitative studies have focussed on the family impact of a child with ASD during the preschool years, a stage that comes with unique challenges for families (Davis & Carter, 2008; White et al., 2012). The distress some parents experience during this period when their child is recently diagnosed, and when they are beginning a process of learning about the condition and how to support their child, is likely to contribute to family difficulties.
Summary

Controversial historical beliefs about the aetiology of ASDs have contributed to a reluctance to investigate family processes amongst families of children with ASDs (Reed & Osborne, 2014). Consequently, information about parent and family experiences related to raising a child with an ASD has emerged relatively recently (Reed & Osborne, 2014). The majority of this research has focussed on the impact of raising a child with an ASD on parental stress (Hayes & Watson, 2013; Tint & Weiss, 2015). Raising a child with an ASD tends to be associated with poor parental wellbeing and reduced family functioning (Hayes & Watson, 2013). Findings from qualitative research indicate this might be related to the intense focus on the needs of the child with an ASD within families (e.g., Hoogsteen & Woodgate, 2013).

Parents of children with ASDs are faced with additional demands that put them at risk for reduced wellbeing. The preschool period in particular comes with challenges that may test parents’ resilience and place them under duress. Gallimore and colleagues (1999) explained that stress, difficulties, and crises are not the only experiences that characterise raising a child with a disability. They proposed that gaining a more comprehensive understanding of the daily routines of families, and whether they are sustainable, is an important direction for research. This approach might help inform the provision of family-centered care in early intervention (Gallimore et al., 1999; Karst & Van Hecke, 2012; Stahmer & Pellecchia, 2015), which is valued as a principle of good practice (Prior & Roberts, 2012).
Chapter 4. The Role of Families in Early Intervention for ASDs

Early intervention is important for children with ASDs to improve their future outcomes (Prior & Roberts, 2012). Whereas studies have been conducted to identify effective methods of intervention for preschoolers with ASDs, a serious misalignment exists between recommendations for good practice, and the interventions being chosen and implemented by families (Szatmari et al., 2012). Barriers such as costs, time commitments, proximity to available services, and difficulty making treatment decisions prevent families from accessing interventions of the recommended type or intensity for their child (Johnston, Tracey, Mahmic, & Papps, 2013; Siller et al., 2014). Oftentimes it seems as though “it’s up to the parents” to meet their child’s intervention needs and this happens at a time when family members and carers are vulnerable to distress (Valentine, 2010, p. 954).

A number of researchers advocate for a family-centered approach to early intervention for children with disabilities (e.g., Dempsey & Keen, 2008; Gallimore et al., 1999; Karst & Van Hecke, 2012). A family-centered approach, involves parents and professionals working in partnership to achieve both child and family goals (Gallimore et al., 1999; Karst & Van Hecke, 2012; Keen, 2007). Supporting the family system can lead to positive outcomes for children with ASDs, as well as their parents and other family members (Karst & Van Hecke, 2012; Keen, 2007). However, in practice, intervention approaches for children with ASDs tend to focus on improving the skills and abilities of the child. Outcomes for parents and families are often overlooked, regardless of their level of involvement in the intervention (Karst & Van Hecke, 2012).

This chapter presents an overview of the Australian guidelines for good practice in early intervention for ASDs (Prior & Roberts, 2012). Government funding models designed to help families to access these services are then described, along with the barriers that make it difficult for families to access and implement recommended interventions. This information provides a basis for the argument that the current service delivery model takes a child-focussed approach that does not necessarily meet the needs of parents and families. This is partly because further insight is needed to better understand parents’ experiences of raising a preschooler with an ASD. Family centred care can be difficult to implement without strong foundation knowledge of the
experiences of families and the accommodations families make to support their child with an ASD in the home and community.

**Australian Guidelines for Good Practice**

Australian guidelines for good practice highlight that a “one size fits all” approach is not applicable in early intervention for ASDs (Prior & Roberts, 2006, 2012). Although intensive therapies based on behavioural principles (i.e., ABA) have the strongest evidence base, these methods will not suit every child and family; and other approaches show promise despite not having as many rigorous controlled trials to support their efficacy (Prior & Roberts, 2012; Vivanti et al., 2014). Rather than recommending any one particular approach, the guidelines give an overview of strategies that have consensus as being important components of any early intervention program for children with ASDs (Prior & Roberts, 2012; Roberts & Prior, 2006; Valentine et al., 2010).

The guidelines stipulate that in order to best meet the needs of a child with an ASD, intervention should begin as early as possible. After a thorough assessment of the child, an individualised education plan must be formulated and regularly reviewed (Prior & Roberts, 2012). This plan takes into consideration the strengths and needs of the child, and documents a strategy for achieving goals. The 2006 guidelines advised that early intervention programs should be highly time intensive (at least 20 hours per week) and should continue for at least two years. The more recent update suggested that although 15 to 25 hours are generally recommended, the quality of the intervention, and the ability to engage the child, are as important as the number of hours provided (Prior et al., 2011; Roberts & Prior, 2012). Multidisciplinary collaboration is usually needed involving teamwork from professionals such as teachers, speech therapists, and psychologists. The content of the intervention should address skill deficits associated with ASDs (e.g., social engagement) and be taught in supportive environments then generalised to other settings.

Family involvement is emphasised as one of the principles of good practice, whereby families are encouraged to play a role in the planning and implementation of interventions (Prior et al., 2011). Within the guidelines, family involvement includes professionals teaching and empowering families to use strategies with their child at home, being sensitive to the stresses encountered by parents and families, and offering
parents emotional support and respite care to alleviate their stress (Prior & Roberts, 2006, 2012). Outlining family involvement as a principle of good practice is a strength of the Australian guidelines. However, a true partnership between families and professionals involves viewing the family system as the client rather than the person with ASD, and having a better understanding of the way interventions are positioned within family life (Keen, 2007). This approach reflects a position of shared-decision making between parents and professionals, and prevents professionals from making recommendations that are not feasible for families (Bernheimer & Weisner, 2007).

Accommodations made within the family system often involve trade-offs. For example, attending frequent appointments to support the child with an ASD increases the workload for parents, and is associated with expenses affecting the family budget (Bernheimer & Weisner, 2007). From a family-centered approach, the successes of these accommodations are not measured solely in terms of child outcomes, but in terms of benefits to other family members, and whether the accommodations are sustainable over time (Karst & Van Hecke, 2012; Stahmer & Pellecchia, 2015). For some families, attending frequent appointments, and coordinating and helping to implement a highly time intensive early intervention program, is not sustainable for a variety of reasons. Therefore, in clinical practice, consideration of issues and concerns beyond the individual learning needs of the child with ASD is needed to support the overall health of the family system (Gallimore et al., 1999; Keen, 2007).

**Costs to Families Raising a Preschooler with an ASD**

Inadequately treated ASDs have substantial costs, both to the quality of life of the person with an ASD and their family, and in terms of the global economic burden (see Dillenburger et al., 2014; for a review). Costs to families raising a child with an ASD come from two main sources; loss of income and treatment-related expenses (Dillenburger et al., 2014). Mothers, in particular, experience changes in their workforce participation and earning potential due to the demands of caregiving (Baker & Drapela, 2010; Cidav, Marcus, & Mandell, 2012; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). A large-scale study conducted in the United States found that mothers of children with ASDs (n=261) were less likely to participate in the work force, worked fewer hours per week, and earned less money than mothers of children with no
known health limitations \((n=64,349; \text{Cidav et al.}, 2012)\). This was despite mothers of children with ASDs being older and more highly educated.

Recent research conducted in Western Australia identified that the median cost of raising a child (aged < 18 years) with an ASD incurred by families was $34,900 annually. Of this figure, 89% was associated with loss of income, 8% for treatment costs, and 3% were costs associated with travelling to and from appointments (Horlin et al., 2014). Annual costs were higher depending on the number of symptoms experienced by the individual with an ASD, increasing by $1,400 per symptom, illustrating the importance of managing and treating these difficulties (Horlin et al., 2014). Horlin and colleagues (2014) suspected that the participants were not necessarily able to afford their desired level of intervention for their child with ASD. Their findings might have underestimated the expense of providing comprehensive, multi-disciplinary care to a child with an ASD.

The annual cost of ASDs to the Australian economy has been conservatively estimated as being in the range of 8.1 to 11.2 billion dollars (Synergies Economic Consulting, 2011). Much of the estimated lifetime cost for individuals with ASD are incurred during adulthood when, depending on level of functioning, care facilities may be needed, or the individual may be unemployed or under-employed (Baldwin, Costley, & Warren, 2014; Dillenburger et al., 2014; Gray et al., 2014). Although expensive, early intervention can help people with ASDs develop a greater degree of independence and self-sufficiency, reducing later costs in their education, work, and living (Peters-Scheffer et al., 2012).

Studies of the economic impact of ASDs at both the national and family level indicate that intervention for children is of critical importance, yet receiving the recommended standard of intervention is financially inaccessible for many families. Further complexity is added when parental family income is reduced, or when families live in rural or regional areas with fewer services, which increases the time and travel costs of intervention. Such barriers could be addressed by working with parents to develop interventions that fit within their family life, so that children are still provided with daily opportunities to develop their skills (Meadan, Ostrosky, Zaghlawan, & Yu, 2009; Moes & Frea, 2002). As it stands, the difficulty accessing support to improve children’s educational and developmental outcomes has been receiving international attention as a human rights issue (Dillenburger et al., 2014).
The Helping Children with Autism (HCWA) Package

The United Nations (UN) expressed concern over the difficulties individuals with ASD have in accessing health, education, and intervention services worldwide (2013). Additionally, the World Health Organisation (WHO) acknowledged the burden placed on families of individuals with ASD in their 2013 meeting report, stating:

Worldwide, people with ASDs and other developmental disorders represent a vulnerable group. They are often subject to stigma, discrimination and human rights violations, including unjust deprivation of health, education and social opportunities. Globally, access to services and support for people with developmental disorders is inadequate, and families of those affected often carry substantial emotional and economic burdens (, 2013, p. 18)

Resolutions were introduced to address the socioeconomic needs of individuals, families, and societies affected by ASDs (UN, 2013) and to advocate for coordinated management of these conditions (World Health Assembly [WHA], 2013). These resolution documents emphasised the importance of providing people with ASDs opportunities to learn the skills that they need to participate in education and the community, and the importance of assisting with the difficulties faced by families supporting someone with an ASD (UN 2013; WHA, 2013).

In Australia, the Government provides funding to families of preschoolers with ASDs through the HCWA package, largely funded by the department of Families, Housing, Community Services, and Indigenous Affairs (FaHCSIA). This $190 million Federal Government initiative was rolled out in Australia between June 2008 and June 2012 with the aim of reducing the financial burden placed on families while also improving access to services nationally (Department of Social Services, 2010). Under this scheme, when a child (younger than 6 years) receives a diagnosis of an ASD from a paediatrician, families are entitled to up to $12,000 in funding (no more than $6,000 annually). The funding helps families pay for resources (e.g., an iPad, books) and intervention services (e.g., speech pathology) through approved providers, but must be used prior to their child’s seventh birthday.

As part of the HCWA package, caregivers have access to Autism Advisors who assist them in navigating available services. Parents can also attend Early Days workshops and PlayConnect playgroups to receive information and support. The ASD
component of the Raising Children Network website was funded to provide reliable information about the condition and available treatments. The HCWA package follows an individual treatment model whereby caregivers are responsible for selecting services for their preschooler and managing the allocated funding through approved providers.

The HCWA package was evaluated in terms of its effectiveness in meeting the Australian guidelines for good practice throughout the four-year rollout period (Maloney et al., 2012; Prior & Roberts, 2006). Parents and service providers from various backgrounds were surveyed and interviewed about the program. Findings from the final evaluation indicated that the HCWA package reached the target population effectively and increased access to early intervention services, which in turn, produced positive educational and developmental gains for preschoolers with ASDs (Maloney et al., 2012). However, the program did not necessarily meet guidelines for good practice in terms of providing family-centred care and a multidisciplinary approach to treatment, with some service providers raising concerns that an individual, medical model was being favoured (Maloney et al., 2012). In addition, not all families seemed able to use the funding in a way that maximised benefits for their diagnosed child (Johnston et al., 2013).

Living in a rural, remote, or regional area was identified as a barrier to accessing FaHCSIA funded services (Maloney et al., 2012). Families from remote and regional areas were less likely to make claims for services than families living in urban areas, possibly because FaHCSIA funding does not cover costs associated with travel to and from appointments. Families from lower socioeconomic backgrounds, or from rural/remote areas were also less likely to report improvements in their child’s functioning, and may not have received sufficient intervention intensity. Maloney et al. (2012) suspected that the families and children who benefitted most from the HCWA package were those who were supplementing the intervention their child received through the package with privately funded services. Support provided by parents within the family environment might also have contributed to children’s gains. The FaHCSIA funding model might not be sufficient to support all families raising a child with an ASD, suggesting a better understanding of the strengths and needs of different families is vital.

As demonstrated by the concern of international assemblies as well as the recent evaluation of Australia’s HCWA package, processes are currently in place to identify
and reduce barriers to intervention for individuals with ASDs and their families. As alluded to in the evaluation by Maloney and colleagues (2012), there continues to be unmet needs for families, and preschoolers with ASDs might have different levels of access to services based on socio-demographic factors. Parents are in a position of selecting and coordinating treatment services, at a time when they may be under emotional stress, and when they may be unfamiliar with ASDs and the range of therapies offered to them (Johnston et al., 2013; Valentine et al., 2010). These factors may contribute to what has been identified in the literature as a gap between the evidence-base and the practice of ASD intervention (Szatmari et al., 2012).

The Gap between Evidence and Practice

A disparity exists between the recommended intervention approaches for children with ASDs, and those being accessed by families (Siller, Reyes, Hotez, Hutman, & Sigman et al., 2014; Szatmari et al., 2012). Numerous treatments for ASDs are made available, many of which have inadequate empirical support (Levy & Hyman, 2005; Schreck, 2014). Information is provided to parents online, via other parents and family members, and from practitioners, and this information is not always reliable (Mackintosh, Myers, & Goin-Kochel, 2005). Even information on the websites of national ASD associations is not always aligned with the most recent research outcomes, which can be confusing for parents (Stephenson, Carter, & Kemp, 2012). Therefore, parents may not receive adequate guidance in selecting evidenced-based programs for their children with ASDs (Mackintosh, Myers, & Goin-Kochel, 2005).

Professionals are limited in the guidance they can offer to parents as there continues to be inconsistent treatment outcomes from early intervention, where some children show substantial gains and others do not (Vivanti et al., 2014; Williams et al., 2014). When positive outcomes are not a certainty, some service providers believe that recommending very expensive interventions is unethical, given the financial impact on families (Valentine et al., 2010). This situation makes it difficult for parents to decide which intervention approach or service provider to choose after their child is diagnosed with an ASD. Many parents report a sense of confusion, or feeling overwhelmed about making treatment choices (Karst & Van Hecke, 2012; Roberts & Prior, 2006, Valentine, 2010).
A number of factors are implicated in parents’ decision-making process regarding which therapies to access for their child with an ASD (Bowker, D'Angelo, Hicks, & Wells, 2011; Carlon, Carter, & Stephenson, 2014; Goin-Kochel, Myers, & Mackintosh, 2007; Matson & Williams, 2015). In many cases, the child’s needs are given the highest consideration when making treatment decisions (Carlon et al., 2014). Parents must also take into consideration the fit between the therapy, their parenting approach, and family life (Goin-Kochel et al., 2007). Parents who are feeling desperate to help their child, while simultaneously trying to manage the emergence of challenging behaviours and symptoms, may be eager to try a variety of interventions (Matson & Williams, 2015; Schreck, 2014) despite recommendations suggesting families should try implementing one intervention at a time (Prior & Roberts, 2012). In some cases, multiple approaches are needed to target the array of difficulties faced by any one child with an ASD (Matson & Williams, 2015).

On average, parents report implementing between four and seven different therapies concurrently with their child with an ASD, and they are likely to have tried and discontinued others (Goin-Kochel et al., 2007; Green, 2007). An Australian study indicated that parents living in metropolitan Sydney (N=84) were using an average of 2.6 educational or therapy interventions, and 1.6 complementary or alternative treatments with their preschooler with ASD (Carter et al., 2011). The services used most commonly were speech therapy (62%), attending preschool (55%), generic early intervention programs (34%), childcare (33%) occupational therapy (33%), multi-vitamins (32%), and elimination diets (29%). Only 12% of the families accessed ABA therapy, whereas a majority used generic programs not specially tailored to children with ASDs. The authors suggested the costs and time demands of ABA therapy might have been barriers to accessing this intervention (Carter et al., 2011).

In her qualitative study, Valentine (2010) interviewed parents and service providers in Australia about the choices that parents are faced with regarding treatments for their child with an ASD. Valentine proposed that choice is currently imposed on parents, who are required to make decisions about their child’s treatment, whether or not they feel capable of doing so. Through the qualitative analysis, two different experiences of choice in ASD intervention were identified, “choice as obligation”, and “choosing to engage” (Valentine, 2010, p. 953-954). For some parents, making decisions about their child’s treatment was distressing, and the number of different
options available was overwhelming. However, other parents became actively engaged as therapists and advocates for their children. These parents became research literate, undertook training, and developed expertise in treatment approaches. Although these actively engaged parents felt that taking these steps was driven out of necessity, they responded in an empowered manner, rather than being overwhelmed and immobilised.

The difficulties translating evidence-based practices into the homes of young children with ASDs has potentially negative consequences in terms of wasted time, resources, and a delay in finding an appropriate intervention for a particular child (Kornack et al., 2014; Matson & Williams, 2015; Szatmari et al., 2012). Although researchers have begun to investigate parents’ treatment choices and factors influencing this choice, less is known about the other ways the family system accommodates raising a child with an ASD and the support parents provide on a day-to-day basis in the family home. Working closely with families to tailor interventions that would fit cohesively within the family ecology could help to make targeted and sustainable treatment plans (Moes & Frea, 2002). The next section provides an overview of the importance of the family environment, and the available information on this topic for families of children with ASDs.

**The Family Environment**

The family environment is the most significant developmental context for young children (Bonfenbrenner, 1986). A child’s family environment incorporates relationships within the family system, parenting practices, qualities and characteristics of family members, and the provision of a home learning environment. A cohesive family environment is characterised by high levels of warm parenting, low levels of hostile parenting, supportive family relationships, and regularly engaging children in shared activities (Mullan & Higgins, 2014). When the family system is operating well, there are benefits for the wellbeing of family members, and for some specific child outcomes such as social and behavioural functioning (Mullan & Higgins, 2014). Supporting the family environment has been identified as an important public health initiative due to the positive associations between this environment and children’s social and emotional wellbeing (Mullan & Higgins, 2014; Renzaho et al., 2013).

Findings from a large, nationally representative Australian study indicated that growing up in a cohesive family environment was conducive to positive behavioural
outcomes for children (Mullan & Higgins, 2014). In contrast, growing up in a disengaged family, characterised by high levels of hostile parenting, low parental warmth, low levels of shared activities, and conflict in the parents’ couple relationship, was a risk factor for behaviour problems (Mullan & Higgins, 2014). Improvements in these elements of the family environment lead to improvements in children’s social and emotional behaviours over time. Likewise, when family cohesion decreased over time, it was to the child’s detriment (Mullan & Higgins, 2014). Although families of children with ASDs were not excluded from this sample, it is unclear as to whether the findings also reflect their experiences.

The family environments of children diagnosed with ASDs have received limited attention in research (Benson, 2015). Totsika et al. (2014) argued that the importance of the family environment is intensified for children with developmental disorders, due to their long-term dependence on caregivers, and their parents’ important role in intervention. Furthermore, the nature of their disorder may mean that the facets of the family environment needed to best support them differ to those needed by TD children (Totsika et al., 2014). For example, for children with ASDs, parents might be focussed on improving the behaviours, communication, play, and social skills that come more naturally to TD children (Benson et al., 2008; Kuhn & Carter, 2006).

Midouhas, Yogaratnam, Flouri, and Charman (2013) investigated the family environment biannually with a large, United Kingdom population-based sample of children, from ages 3 to 7 years old (the Millennium Cohort Study). In this study, the sample was biased to over-represent families facing socio-economic disadvantage. Findings indicated that families raising a child with an ASD ($n=209$) reported lower parental warmth, more household chaos, and more socio-economic disadvantage than parents in the community ($n=13,737$); however, there was no difference in parental involvement. This differs from previous research where involvement has been highlighted as an area of difficulty when there is a child with an ASD (Osborne & Reed, 2010). Both socioeconomic disadvantage, and chaotic household environments were associated with more difficult child behaviour. Maternal warmth emerged as an important parenting practice for children with ASDs. More warmth was associated with reduced future behaviour problems in the child with ASD. Furthermore, warmth mediated the effects of socio-economic disadvantage on the child’s behaviour problems, suggesting parental warmth could be an important target for intervention, to help
overcome family difficulties that are often outside of parents’ control. Midouhas et al.’s longitudinal findings indicated that warmth had a stronger positive impact on children when they were in the preschool years, but became less important thereafter. The results of this study highlight the importance of considering parenting practices during the preschool years.

Having a child with an ASD affects family dynamics in other ways. It has been well established that raising a child with an ASD is a risk factor for parent stress (see Hayes & Watson, 2013). In addition to personal distress and the demands of raising a child with an ASD, parents may have less time and energy available to be involved in home learning activities, and the child may be difficult to engage in shared activities (Johnson & Hastings, 2002). For example, when caregivers are preoccupied with managing behaviour problems, or are highly distressed, they may have less capacity for providing support in the home (Benson et al., 2008; Kuhn & Carter, 2006). These differences in childrens’ needs and parents’ roles are likely to be reflected in the type and intensity of support parents’ provide for their child in the family environment.

The Home Learning Environment

The home learning environment relates specifically to the facilitation of educational and developmentally oriented activities within the home and requires active involvement from parents (Benson, 2015). Home learning activities enhance development of specific skills for children, and may build their interest in learning (Melhuish et al., 2008). In the broader early childhood literature, provision of a home learning environment is associated with a number of benefits for TD children.

Longitudinal research suggests a child’s early learning experience can influence their future educational and developmental outcomes. One study mapped home learning experiences and child developmental outcomes from birth to 13 years (Bradley et al., 2001). Results indicated that for families from a variety of socio-economic and ethnic backgrounds, opportunities for learning in the home were associated with children’s future social, language, and motor development. The effects of the environment were stronger for younger children (Bradley et al., 2001). Other studies have indicated a link between the home learning environment and academic skills, and achievement in the early years of school (Froyden, Skibbe, Bowles, Blow, & Gerde, 2013; Haak, Downer, & Reeve, 2012; Melhuish et al., 2008; Rodriguez & Tamis-
LeMonda, 2011; Son & Morrison, 2010). For example, controlling for other aspects of the parent-child relationship, the home learning environment when a child is aged 3 years is predictive of their academic skills the following year (Leerkes et al., 2011).

Studies of the family environment when there is a child with an ASD tend to explore parents’ implementation of early intervention programs within the family home (e.g., Hastings & Johnson, 2001; Strauss et al., 2013). A meta-analysis of 21 studies indicated that children made greater gains in their adaptive functioning when EIBIs included a parent-training component. Parent training involved having parents use specific teaching strategies at home (Strauss et al., 2013). Programs that were directed by intervention staff, but involved parents seemed more effective than programs that were fully parent-mediated (Strauss et al., 2013).

Being involved in the provision of EIBIs generally has positive effects on parents, helping to alleviate their distress and boost their self-efficacy (Johnson & Hastings, 2002; Strauss et al., 2012). However, in some cases, parents implementing EIBIs show higher levels of stress than parents accessing an eclectic approach in the community, where they are not as directly involved in the therapeutic component (Strauss et al., 2012). The demands on parents in the EIBI may have been too high, as the EIBI was the more time-intensive approach. Another study found that when children received home-based ABA therapy, time intensity was associated with lower levels of parental depression. However, being more highly involved in the implementation of the program was associated with higher levels of personal strain for mothers (Schwichtenberg & Poehlmann, 2007).

Implementing interventions seems to become stressful when the parent feels that he/she lacks the time and energy required (Johnson & Hastings, 2002). Home-based programs can be intrusive on family life, with some parents reporting disruptions to their privacy and routines when therapists are regularly working with their child in their home (Grindle, Kovshoff, Hastings, & Remington, 2009; Johnson & Hastings, 2002). When the intervention procedures do not fit well within daily family routines, the implementation may also become more stressful, and less efficacious for the child (Moes & Frea, 2002). Reduced parental wellbeing can also mean these interventions become less effective (Osborne et al., 2008a).

Findings regarding the experiences of parents involved in the provision of home-based interventions provide some insights into the home learning environment in
this group. However, the results of intervention studies do not necessarily apply to family life more generally, as most families are not implementing structured behavioural interventions, and are more likely to have an eclectic combination of therapies in place for their child (Benson, 2015; Carter et al., 2011). Therefore, clinicians need to be aware of the family environment in naturalistic, rather than clinical, settings (Bernheimer & Weisner, 2007). Outside of the context of early intervention literature, only a small number of studies have been conducted to investigate the home learning environment in this group and the home learning environment has been conceptualised differently across these studies (Benson, 2015; Benson et al., 2008; Kuhn & Carter, 2006; Maljaars, Boonen, Lambrechts, Van Leeuwen, & Noens, 2014).

The provision of a home learning environment for children with ASDs seems to be influenced by both child factors and family resources. Severity of child behaviour problems, for example, is associated with a reduced capacity for parents to provide a home learning environment (Benson et al., 2008). When behaviour problems are severe, some parents feel that their energy is directed toward managing these difficulties and keeping the child safe, leaving them little opportunity to engage in learning activities (Benson et al., 2008). Additionally, when children have language impairments, it can also be more difficult for parents to engage in them in educational activities (Benson et al., 2008). Characteristics of the child with ASD, including their language proficiency and behaviour problems, accounted for 18.7% of the variance in home learning involvement in the study by Benson and colleagues (2008). The impact of these child qualities on maternal educational involvement may also have been related to the parents’ wellbeing. Parents who interpret behaviour problems as being highly distressing may be more likely to become overwhelmed, which was not directly explored in this study. Facilitation of educational activities in the home was also more achievable for parents when they felt well supported by teachers or other professionals involved with their child, and when the mothers (N=110) were more highly educated with higher family income (Benson et al., 2008).

The qualitative component of the study by Benson and colleagues (2008) provided some insight into the ways parents built learning activities in to their home life. Parents tended to embed learning activities within daily routines, such as mealtimes, rather than having additional pre-planned activities or structured tasks.
Daily routines were used as opportunities for children to practice communication, self-care, and social skills. These learning activities were sometimes so well integrated into family life that parents took them for granted, viewing it as “just the way things are” (Benson et al., 2008, p. 61). These findings suggest more sustainable interventions may be planned when clinicians have a good understanding of the accommodations families make and their daily routines (Benson et al., 2008).

Providing educational opportunities at home is likely to change in intensity over time, and may also exert an influence on other components of the family environment. A longitudinal study by Benson (2015) indicated that educational involvement tended to decrease over time. Participants in this study included 113 mothers who completed assessments in the years 2006, 2008, and 2010. Over this time, their children’s ages ranged between 7 and 14 years. The findings indicated that the level of involvement was not associated with parental or family distress; rather involvement had the potential to increase parents’ sense of efficacy and family cohesion. Higher levels of educational involvement seemed particularly useful to increase the self-efficacy of parents in managing severe behaviour problems. It is of note that involvement did not have a positive influence on the family system when the mother felt that stressors associated with ASD spilled over into other areas of family life.

The concept of maternal agency is also related to the home learning environment of children with ASDs. Maternal agency reflects mothers’ beliefs and attitudes about the extent to which they actively support their child’s development, and reduce behaviour problems (Kuhn & Carter, 2006). Higher levels of maternal agency were found to be more common in mothers with lower levels of guilt, and higher levels of self-efficacy, that is, a sense of competence in their role as a mother. Of their sample of 170 mothers, 80% reported feeling guilty that they were not doing enough to support their child with an ASD. These guilty feelings were associated with a lower sense of agency, whereas a better understanding and knowledge base of ASDs was associated with higher agency.

Findings thus far suggest that children’s behaviour problems can exert an influence on the family environment, whereby managing behaviour problems may preoccupy or overwhelm parents making it more difficult for them to provide a home learning environment. The family environments of children with ASDs involve complexities that are less relevant to families of TD children. Parents are likely to be
adjusting to having a child diagnosed with an ASD, and the child’s care requires them to take on multiple roles. There may be a risk of increasing parental guilt if interventions do not take into consideration the availability of the parent and the resources they have available to work with their child (Harris, 1984).

Although not having been addressed in research, home learning activities have a potentially positive impact on the development of children with ASDs. Parents of children with ASDs tend to report adapting the environment to suit the needs of their child to a greater extent than parents of TD children (Maljaars et al., 2014). An accurate description of this environment would provide an important foundation for home-based intervention development. Harris (1984) suggested that behavioural interventions could be improved upon by considering how they could be delivered in a family therapy context. Yet it seems that interventions for young children with ASD continue to overlook family context and that there continues to be barriers to delivery of early intervention in a natural environment (Schertz, Baker, Hurwitz & Benner, 2010). In clinical practice, more sensitivity to the emotional experiences of parents and families whose child is newly diagnosed with an ASD is also needed. It may be counter-productive to place additional demands and expectations on parents and families who are known to be under high levels of stress, particularly because the majority of these parents feel guilty for not doing enough for their child with ASD (Kuhn & Carter, 2006).

**Summary**

The current state of intervention services does not adequately meet the needs of all preschoolers with ASDs (Maloney et al., 2012). As a result, many parents take on responsibility for their child’s intervention and education (Valentine 2010; Valentine et al., 2010). Part of this responsibility involves navigating services, with some assistance from allocated funding. Another part involves taking an active role in developing expertise on ASDs, and adopting multiple roles to support the child, while simultaneously adjusting to raising a child with this condition. Further research is needed to understand how the pragmatics of raising a child with an ASD are integrated alongside the emotional experiences of parents and families adjusting to having a child diagnosed with a lifelong condition, and managing their child’s difficult symptoms and behaviours.
Parents of children with ASDs are likely to have developed informal methods of managing their child’s ASD and promoting skill development; for example, by working persistently to engage their children in everyday activities, providing appropriate play materials, and encouraging social interaction and participation (Benson et al., 2008). Given that the parent-child dyad and family microsystem provides the primary developmental context for young children, parents are in an ideal situation to take advantage of teachable moments in their every day life (Meadan et al., 2009). This provides an opportunity for parents to informally implement interventions for their child more regularly.

Behavioural interventions often require parents to interact with their children in systematic ways, which they may be unfamiliar with (Moore & Symons, 2009). Parents receiving home-based intervention for their child may endure significant disruption to their privacy and routines by having therapists regularly working with their child in their home (Grindle et al., 2009; Hastings & Johnson, 2001). Drawing on parents existing knowledge and skill base, may increase the sustainability of interventions. As stated by Meadan and colleagues:

Researchers are encouraged to take advantage of many parents’ interest in and motivation to work with their children to support learning and development. As experts on their children, parents can assist professionals in designing high-quality, individually appropriate interventions with the potential to make the interventions more efficient and effective (2009, p.103).
Chapter 5. Theoretical Basis for the Current Research

The literature review has drawn attention to some of the challenges faced by children with ASD, their parents and families. Of particular interest have been the reciprocal processes that occur within families, at the level of the child, parent, and family system. Aspects of the home environment have also been described as important resources for early learning.

The literature in this field is currently limited by inconsistent and infrequent reference to a theoretical framework (Cridland et al., 2013) and inconsistent conceptualisation and measurement of parent and family wellbeing (Tint & Weiss, 2015). This limits the extent to which findings can be integrated across studies (Cridland et al., 2013; Tint & Weiss, 2015). Incorporating a theoretical model can highlight patterns across studies and assist in generalising and communicating findings. Furthermore, theory may help to explain how and why raising a child with an ASD is associated with parent and family distress (Hayes & Watson, 2013). As such, the current research program is guided by developmental science, defined as:

**Developmental Science** is the systematic scientific study of the conditions and processes producing **continuity and change over time** in the biopsychological characteristics of human beings—be it over the life course, across successive generations, retrospectively through historical time, or prospectively in terms of implications for the course of human development in the future (Bronfenbrenner & Evans, 2000, p. 117).

Tint and Weiss (2015) argue that a single theoretical orientation is unlikely to capture the complexities of family research in this field. Based on a review of the literature, they concluded that socio-ecological and family systems models would be beneficial in research on ASD and the family, as these capture influences on the family system at various levels, along with the dynamics between family members. Such approaches also recognise that difficulties experienced within families of children with ASDs are often relational (Tint & Weiss, 2015). Therefore, within the current program of research, bioecological and transactional models of child development provided a framework for investigating the family environment. From these theoretical orientations, the child is viewed as an active agent bringing personal qualities and
characteristics to their developmental setting (Bronfenbrenner & Morris, 2006; Sameroff, 2009). These approaches also highlight the importance of contextual factors and interpersonal processes in human development. To explore these models in their entirety, a longitudinal approach is necessary, so that the interconnectedness of child, parent, and family factors can be explored. This was beyond the scope of the current, cross-sectional program of research. Therefore, bioecological (Bronfenbrenner, 1986) and transactional (Sameroff, 2009) theories provided a framework from which to conceptualise the impact individual family members have on the family system. Existing literature regarding the impact of children with ASDs on their families and the way family processes might affect children with ASDs, can be interpreted and integrated from a bioecological and transactional theoretical orientation.

The aim of this chapter is to provide an overview of bioecological and transactional models of child development. The application of these theoretical models to research in ASDs will then be explained. This will lead in to the purpose statement and design of the current program of research, followed by the research aims and hypotheses.

**Bioecological and Transactional Models**

Bronfenbrenner developed the ecological model of human development in the 1970s. He proposed that human development occurs within various interdependent environmental systems, each having differing levels of impact on the person (Bronfenbrenner, 1979). For example, an individual influences, and is shaped by, factors within his/her microsystem (e.g., home and family environment), mesosystem (e.g., school, peer group), exosystem (e.g., parent’s workplace), and macrosystem (e.g., community and culture; Bronfenbrenner, 1979). The microsystem provides the most immediate developmental context for preschoolers, and parents are typically the primary source of interaction, and as such, the microsystem is the focus of the current research program (Bronfenbrenner, 1986).

Over his lifetime, Bronfenbrenner continued to revise concepts within ecological theory, so that later versions of the model shifted focus (Bronfenbrenner, 2005; Rosa & Tudge, 2013). The theory was renamed *bioecological* to stress that individual qualities also contribute to development (Bronfenbrenner & Evans, 2000; Rosa & Tudge, 2013). Proximal processes became central to the theory in later revisions. Proximal processes
are the reciprocal interactions between an individual and other people, objects and symbols in their environment, and are considered to be the “engines of development” (Bronfenbrenner & Evans, 2000, p. 118). Proximal processes can encourage competence or dysfunction, if they occur on a regular basis over time. For example, a proximal process of playing with a child regularly is likely to lead to competence whereas living in a chaotic environment may impede development (Bronfenbrenner, 2005; Ferguson, Cassells, MacAllister, & Evans, 2013).

Bioecological theory and Sameroff’s transactional model show many parallels. Both approaches state that the child and his/her environment reciprocally influence one another over time (Bronfenbrenner & Morris, 2006; Sameroff, 1975, 2009; Sameroff & Chandler, 1975). These models also give emphasis to the idea that personal qualities and behaviours of the child impact on the environment, and thus children actively participate in their own development (Gershoff, Aber, & Clements, 2009; Sameroff & Fiese, 2000). During infancy, when a child is most dependent on others for caregiving, the influence of the environment is at its peak and then gradually decreases across the lifespan (Sameroff & Fiese, 2000). These theoretical approaches also acknowledge that the psychological development of parents, and their behaviour, is influenced by qualities of their child (Bronfenbrenner, 2005). This is particularly relevant to ASD research, where qualities of the child provide unique joys and challenges to parents (Myers et al., 2009).

The transactional model offers a broad perspective on intervention, suggesting that changes in one aspect of a child’s environment might then have flow-on effects for their growth and the functioning of other family members. Sameroff (2009) suggested that the scope of interventions could be minimised, and less costly, if a thorough understanding of the strengths and weaknesses of a system are taken in to consideration. Based on the needs of the family, intervention can be aimed at either remediation (changing the behaviour of the child); redefinition (altering parental interpretations); or re-education (targeting parent-child interactions; Sameroff & Fiese, 2000). A majority of ASD intervention approaches focus on remediation, whereby advancing a child’s skills might help them to be better able to operate within their environment. However, depending on the child’s focus of attention, motivation, cognitive capacity, and other abilities, children with ASDs may not necessarily be able to fully experience what is available to them in their environment (Sameroff & Fiese, 2000).
Despite its prominence in human development literature, very few studies have drawn upon bioecological or transactional theories in ASD research. Some researchers have investigated the influence of family dynamics on children and vice versa (e.g., Kelly et al., 2008). A number of studies have investigated unidirectional or reciprocal aspects of the parent-child relationship in ASD, occasionally placing the study within a transactional framework (e.g., Totsika et al., 2014). Further exploration of the family environment is warranted, because this microsystem provides the primary developmental context for preschoolers. Furthermore, the preschool years are currently viewed as the most important time for ASD intervention. Interventions are also increasingly being brought in to the family home. Investigating the ecological setting in which children on the spectrum do most of their learning is therefore of clinical and theoretical relevance.

Developmental Theory and ASDs

The transactions between children with developmental disabilities and family processes have been outlined in a model proposed by Hastings (2002) and this is presented in Figure 1. This model specifically focuses on the relationship between child behaviour problems and parenting stress, and proposes that each factor maintains and exacerbates the others over time. In particular, child behaviour influences parents’ stress levels, which in turn affects parenting behaviour. This can then serve to maintain and escalate the child’s behaviour problems (Hastings 2002). Other factors were also acknowledged as warranting attention within this system, including parents’ beliefs, coping, and resilience (Hastings 2002).

![Figure 1. Hastings’ transactional model of the relationship between child behaviour problems, parenting stress and parent behaviour (adapted from Hastings, 2002, p. 151).](image-url)
Hastings’ model helps draw together important associations between children’s behaviour problems and their parents’ mental health, and assists in conceptualising proximal processes within the family environment. As described in Chapter 3, other aspects of the microsystem are affected by having a preschooler with an ASD, ranging from practical to emotional demands (Karst & Van Hecke, 2012). Modern families also live within an era that encourages intensive intervention for preschoolers on the spectrum, yet it is unclear what this means for family life. Consequently, there is a need to develop interventions that can be implemented with the child in the family environment, without overextending parents (Anan, Warner, McGillivary, Chong, & Hines, 2008; Dillenburger et al., 2004; Solomon, Necheles, Ferch, & Bruckman; 2007). This shift in the provision of intervention means that understanding and supporting the family environment is of increasing importance in families of children with ASDs. Further insights into the family and home environment provided for preschoolers with ASD, and the impact on parents, is likely to inform family friendly intervention, and give professionals a better understanding of factors in the ecology of these preschoolers and their parents.

**Purpose Statement and Study Design**

The purpose of the current study was to understand and describe the family environment as perceived by parents of preschoolers with an ASD diagnosis. The family environment referred to contextual factors that were hypothesised to be important for a child’s development based on transactional (Sameroff, 2009) and bioecological (Bronfenbrenner, 1986) theories. Family environment factors explored in the present study included the extent to which educational and developmentally oriented activities were facilitated within the home, the wellbeing of parents, their parenting practices, and family functioning. The family environment provides the primary developmental context for preschoolers and is often used as a setting for intervention, meaning exploration of this microsystem is of clinical importance. Gaining a comprehensive understanding of these factors is needed to inform interventions and develop programs to build upon and accommodate the strengths and needs of families of children with ASDs, as well as to increase insight amongst professionals working in the area.
The study was conducted using a mixed-methods design, beginning with statistical analysis of questionnaire data from parents, followed by qualitative analysis of interview responses provided by parents during home visits. A mixed-methods approach was selected to provide an understanding of trends and relationships between child, parent, and family factors, complemented by rich and detailed descriptions reflecting the experiences of parents and families in their own words. The questionnaire included measures of child behaviour problems and family environment variables (parental wellbeing, parenting practices, and family functioning). Questionnaires were selected on the basis of their psychometric properties, suitability for the sample, and administration time. Semi-structured interviews were then used in the qualitative stage to gain insight into the shared and unique experiences of each family, which would not be gleaned from questionnaire responses.

In both stages of this research, the sample was restricted to parents of preschoolers with ASDs, due to the unique experiences associated with this life stage. This was not an intervention study, and although understanding the way in which the intervention was situated within the family context was of interest, the “success” or improvements seen in the preschooler were not a research focus. Given the research was directed toward describing and exploring the family environment when there was a preschooler with an ASD specifically, no control or comparison groups were included in the study.

**Research Aims**

The aims of the study were to:

1. Explore parents’ perceptions of the impact raising a preschooler with an ASD has on the family environment; including (a) parental wellbeing, (b) family functioning, and (c) parenting practices.
2. Understand the ways in which parents adapt their approach to parenting and family life to accommodate their child’s needs.
3. Explore the ways parents support their children’s learning and development.

**Study 1: An investigation of the pathways between child behaviour problems, parental wellbeing, family functioning, and parenting practices.** This stage of the study involved using questionnaire data to describe the functioning of the
parents and families relative to normative data. Parents of children with ASDs were compared to available normative data on measures of stress, depression, fatigue, family functioning, and parenting warmth. Whereas previous research has shown that behaviour problems in children with an ASD can impact on parental wellbeing, less is known about the implications for the broader family system. Additionally, when parental wellbeing and family functioning difficulties are present, it might impact on parenting practices. The aim of this study was to investigate the association between child behaviour problems and family functioning, and the role of parental wellbeing in mediating this relationship. Relationships between parental wellbeing, family functioning, and parenting practices were also investigated. Two hypotheses were formulated regarding these relationships.

**Hypothesis 1.** It was hypothesised that child behaviour problems would be associated with less effective family functioning, and that this relationship would be mediated by parental wellbeing (as indicated by levels of stress, depression, and fatigue). This hypothesis was tested using path analysis with child behaviour problems as the independent variable, family functioning as the dependent variable, and parent stress, depression, and fatigue as mediators.

**Hypothesis 2.** If parental wellbeing is associated with family functioning as proposed in Hypothesis 1, there might in turn, be associations with lower levels of parenting warmth, hostility, and involvement. Based on prior literature and the outcomes of Hypothesis 1, it was proposed that depressive symptoms would be associated with parenting practices, and that this would be mediated by family functioning. This hypothesis was tested using path analysis.

**Study 2: A qualitative exploration of the family environment for preschoolers with ASDs.** Both questionnaire data, along with the outcomes of semi-structured interviews were used to describe the family environment when there is a preschooler with an ASD. The questionnaire data was used to describe the participants’ perceptions of their wellbeing, family functioning, and parenting practices. This assisted in better describing the qualities and characteristics of families participating in this stage of the study. The interview data extended this, by using the parents’ voices to
add rich detail about their views on the impact raising a preschooler with an ASD had on their family. Parents also described their parenting approach, and their provision of a home learning environment to support a preschooler with an ASD. No hypotheses were formulated, however, the following research questions were addressed in line with the overall aims of this program of research.

**Research Question 1.** What is the perceived impact of raising a preschooler with an ASD on parental wellbeing and family functioning?

**Research Question 2.** How do parents adapt their parenting approach to meet the needs of a preschooler with an ASD?

**Research Question 3.** How do parents of preschoolers with an ASD integrate early learning and therapeutic activities into the home environment?

It is well established that raising a child with an ASD is associated with increased risk for poor parental wellbeing, and that children’s behaviour problems are a consistent predictor of such difficulties (Jones et al., 2013; McStay et al., 2013; McStay, Trembath, & Dissanayake, 2015). Much less is known about whether poor parental wellbeing has consequences for parenting practices and the family environment. When parents experience wellbeing difficulties, they might have less capacity to contribute to healthy family functioning. Poor parental wellbeing and family difficulties might make it difficult for parents to enjoy time with their children by engaging in shared activities, or displaying warm, affectionate behaviours (Edwards & Maguire, 2011; Lovejoy et al., 2000; Turney, 2011).

As described in Chapter 3, several studies have been conducted to investigate the impact of children’s behaviour problems on either parental wellbeing or family functioning. However, further work is needed to integrate these areas so as to better understand these processes within the family system. Furthermore, very few researchers have investigated parenting practices (e.g., warmth, hostility, involvement) in families where there is a child with an ASD. Therefore, little is known about the conditions under which parents can implement positive parenting practices, and whether this is facilitated by a well-functioning family system. Findings from families of TD children indicate parental wellbeing difficulties are a risk factor for suboptimal parenting practices, including lower warmth, higher levels of hostility, and lower levels of engagement with the child in shared activities (Lovejoy et al., 2000; Edwards & Maguire, 2011; Turney 2011). Establishing whether this is also the case when parenting a child with an ASD has important clinical implications, particularly when this cohort of parents have previously been identified as being at risk of experiencing poor wellbeing (Eisenhower et al., 2005; Estes et al., 2009; Hayes & Watson, 2013).

The present study was conducted to advance knowledge of parenting and family processes when raising a preschooler with an ASD. The first aim of the study was to assess the extent to which families of children with ASDs experience wellbeing, family functioning, and parenting difficulties. This was investigated by comparing the participant data to available norms from community samples of parents of children.
without ASDs. The second aim of the study was to investigate the relationship between child behaviour problems and family functioning, and examine mediation pathways via parental wellbeing. Fatigue was included as an indicator of parental wellbeing in line with recent research showing its relevance to this population (e.g., Giallo, Wood, et al., 2013; Seymour et al., 2013). It was hypothesised that children’s behaviour problems would be associated with poor parental wellbeing (as defined by symptoms of stress, depression, and fatigue) and these wellbeing variables, in turn would be associated with less effective family functioning (Hypothesis 1). This component of Study 1 formed the basis of a paper by Jellett, Wood, Giallo, and Seymour (2015). Finally, to extend findings based on parenting a TD child, a second model was proposed. It was hypothesised that parents’ depressive symptoms would be associated with levels of parental warmth, hostility, and involvement, and that this relationship would be mediated by family functioning (Hypothesis 2).

Method

Participants

Participants were 97 parents of children (aged 16-71 months) diagnosed with an ASD. Sample demographic characteristics are displayed in Table 2.
Table 2

Demographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parents (N=97)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (M, SD)</td>
<td>36.08 (5.51)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>88 (90.7%)</td>
</tr>
<tr>
<td>Male</td>
<td>9 (9.3%)</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>76 (78.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>21 (21.6%)</td>
</tr>
<tr>
<td>Language spoken</td>
<td></td>
</tr>
<tr>
<td>English only</td>
<td>96 (99%)</td>
</tr>
<tr>
<td>Bilingual</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Aboriginal or Torres-Strait Islander</td>
<td>2 (2.1%)</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>18 (18.6%)</td>
</tr>
<tr>
<td>Part-time or casual</td>
<td>37 (38.1%)</td>
</tr>
<tr>
<td>Not in paid employment</td>
<td>42 (43.3%)</td>
</tr>
<tr>
<td>Highest level of education completed</td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>8 (8.2%)</td>
</tr>
<tr>
<td>Completed high school</td>
<td>13 (13.4%)</td>
</tr>
<tr>
<td>TAFE, trade certificate or diploma</td>
<td>22 (22.7%)</td>
</tr>
<tr>
<td>Tertiary (degree or postgraduate)</td>
<td>54 (55.7%)</td>
</tr>
<tr>
<td>Family type</td>
<td></td>
</tr>
<tr>
<td>Couple</td>
<td>87 (89.7)</td>
</tr>
<tr>
<td>Single-parent family</td>
<td>10 (10.3)</td>
</tr>
<tr>
<td>State of residence</td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>46 (47.4%)</td>
</tr>
<tr>
<td>New South Wales</td>
<td>22 (22.7%)</td>
</tr>
<tr>
<td>Queensland</td>
<td>18 (18.6%)</td>
</tr>
<tr>
<td>Western Australia</td>
<td>5 (5.1%)</td>
</tr>
<tr>
<td>South Australia</td>
<td>3 (3.1%)</td>
</tr>
<tr>
<td>Tasmania</td>
<td>3 (3.1%)</td>
</tr>
<tr>
<td>SEIFA Decile Score</td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>18 (18.5%)</td>
</tr>
<tr>
<td>4-6</td>
<td>22 (22.7%)</td>
</tr>
<tr>
<td>7-8</td>
<td>29 (29.9%)</td>
</tr>
<tr>
<td>9-10</td>
<td>28 (28.9%)</td>
</tr>
<tr>
<td>Number of children in the family (M, SD)</td>
<td>2.25 (1.02)</td>
</tr>
<tr>
<td>Number of children with an ASD</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>80 (82.5%)</td>
</tr>
<tr>
<td>Two</td>
<td>15 (15.5%)</td>
</tr>
<tr>
<td>Three or more</td>
<td>2 (2.1%)</td>
</tr>
</tbody>
</table>

Note. M = Mean. SD = Standard Deviation. TAFE = Technical and Further Education. SEIFA = Socio-Economic Index for Areas - disadvantage score (ABS, 2011).
As shown in Table 2, the majority of parents were female, tertiary educated, Australian born, partnered, and had one child diagnosed with an ASD in their family. Close to half of the participants lived in Victoria. Participants provided their postcode, which was used to assign a Socio-Economic Index for Areas (SEIFA) disadvantage score, which is based on information from the 2011 Australian census (ABS, 2011). A number of factors contribute to SEIFA disadvantage scores, including the percentage of families in the neighbourhood reporting low income, low skill employment, low home rental costs, and overcrowding in the home (ABS, 2011). This score does not take into account individual family circumstances, but is based on the overall composition of each neighbourhood. The SEIFA index has a Mean of 1000 ($SD = 100$) with higher scores representing lower levels of social disadvantage. The mean SEIFA score for the current sample ($M = 1014.76$, $SD = 59.63$) was in the seventh decile suggesting that, on average, the families lived in neighbourhoods with relatively low levels of social disadvantage. Information that parents provided about their preschooler with an ASD is presented in Table 3.
Table 3 shows that the majority of focus children were boys and had been diagnosed with Autism (DSM-IV-TR Autistic Disorder; APA, 2000). In most cases, the participants indicated a paediatrician had made their child’s diagnosis. On average, the diagnosis had been made 14 months previously.

**Measures**

The measures were included in a self-report questionnaire that was available in paper format or online via Opinio web-based software. The questionnaire began with demographic questions; followed by measures of problematic child behaviours, parent mental health, parenting practices, and family functioning. A copy of these measures is provided in Appendix A. The diagnosis of an ASD was based on parent-report rather
than administration of a standardised assessment tool. This was in line with evidence showing that parent reports of an ASD diagnosis are valid (Daniels et al., 2012).

**Demographic and family background questionnaire.** Participants provided information about their age, gender, relationship status, family composition, country of birth, language spoken at home, educational attainment, employment status, and postcode. Information about the child with an ASD including their age, gender, diagnosis, age at diagnosis, and the types/hours of intervention in a typical week was also collected.

**Family Assessment Device, General Functioning Scale (FAD-GF; Epstein, Baldwin, & Bishop, 1983).** The FAD-GF assesses family functioning across the domains of communication, problem solving, role clarity, behaviour control, affective responsiveness, and affective involvement (Epstein et al., 1983). Participants rated how well the 12 items (e.g., “Planning family activites is difficult because we misunderstand each other”) described their family using a four-point scale ranging from 1 = *strongly agree* to 4 = *strongly disagree*. After reverse scoring six items, scores were averaged with higher scores representing less optimal functioning. The authors reported a high internal consistency for the FAD-GF (Cronbach’s $\alpha = .92$; Epstein et al., 1983). Cronbach’s $\alpha$ for the present sample was .91.

The FAD has been shown to give a good indication of family functioning across both community and clinical samples (see Staccini, Tomba, Grandi, & Keitner, 2014, for a review). The authors reported that scores of 2.20 or above are indicative of dissatisfaction with family functioning (Miller, Epstein, Bishop, & Keitner, 1985). Mansfield, Keitner, and Dealy (2014) recently administered the FAD to a community sample of 151 families as well as a sample of families seeking family therapy ($n=46$) with the intention of determining whether the original norms and cut-off scores were accurate for modern families. The authors concluded that the FAD effectively discriminated between healthy and distressed families, and that the original norms and cut-off scores continue to be relevant as the study findings substantiated the original normative data (Mansfield et al., 2014).

With only one informant, the FAD reflects that person’s satisfaction with family functioning, which may be different to other individuals within the same family. By
administering the FAD-GF to multiple informants from the same family \((N=11,023\) families; 26,614 individuals) it was found that approximately 46% of the variance in family functioning was common to family members whereas 54% was unique to the individual completing the measure (Georgiades et al., 2008). This indicates scores are best interpreted as the informant’s perception of family functioning.

**Developmental Behaviour Checklist – Short Form (DBC-P24; Taffe et al., 2007).** The DBC is a 96-item questionnaire completed by parents to give an indication of their child’s emotional and behavioural problems (Einfeld & Tonge, 2002). The DBC generates five subscale scores as well as a Total Behaviour Problem Score, which is useful in clinical settings (Taffe et al., 2007). The short form of the DBC (DBC-P24; Taffe et al., 2007) was used for this study because it provides a brief assessment that accurately reflects the Total Behaviour Problem Score, and has been evaluated as an appropriate tool to estimate problem behaviours in a research setting (Taffe et al., 2007). Participants rated the DBC-P24 items (e.g., “Becomes overexcited”) on a 3-point scale where 0 = *not true as far as you know* and 2 = *very true or often true*. Scores were averaged, with mean scores above 0.48 being indicative of clinically significant difficulties.

The DBC was normed using a sample of 539 individuals from geographically defined local government areas of New South Wales and Victoria, representative of the Australian population (Einfeld & Tonge, 1996). The norm group included individuals with intellectual disability aged between 4 and 18 years (Einfeld & Tonge, 1996). For these individuals, the Total Behaviour Problem Score had a mean of .450 and a standard deviation of .253. The DBC-P24 items were extrapolated from this data, and the mean of the 24 items closely matched the original measure \((M=.451; SD=.272\); Taffe et al., 2007).

The DBC (Einfeld & Tonge, 2002) is one of the few measures specifically designed to assess behaviour problems in children with developmental disabilities, and has sound psychometric properties and Australian norms. Although the DBC was designed for use by parents of children (aged 4 to 18 years) with an intellectual or developmental disability, a number of studies have used this instrument to measure behaviour problems in preschoolers with ASDs, and reported that the scale was reliable
Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995). The depression and stress subscales (7-items each) from the DASS-21 (Lovibond & Lovibond, 1995) were used as indicators of parental wellbeing in the current study. The DASS-21 is a commonly used measure of negative emotional states that was developed and normed in Australia. The DASS-21 is intended to screen individuals in the population making it appropriate for use in non-clinical samples. Subscales from the full version of the DASS include 14 items each, however, the short form is more efficient in research settings, particularly due to the smaller number of items and improved factor structure (Antony, Bieling, Cox, Enns, & Swinton, 1998).

The stress subscale assesses non-specific arousal including agitation, irritability, impatience, nervousness, and difficulty relaxing (e.g., “I found it hard to wind down”). The depression subscale assesses dysphoria, hopelessness, anhedonia, and self-contempt (e.g., “I couldn’t seem to experience any positive feeling at all”). Items are rated on a 4-point scale ranging from 0 = did not apply to me at all to 3 = applied to me very much, or most of the time in relation to the last week. Scores are summed and multiplied by two, with higher scores reflecting greater distress. By multiplying subscale scores by two, DASS-21 scores can be compared to normative data available for the original 42-item version. Score ranges for the depression subscale are described as normal (0-9), mild (10-13), moderate (14-20), severe (21-27), or extremely severe (≥28). Score ranges for the stress subscales are also classified as normal (0-14), mild (15-18), moderate (19-25), severe (26-33) or extremely severe (≥34). Cronbach’s α for the present sample were .88 and .83 for the depression and stress subscales respectively.

Adapted Fatigue Assessment Scale (a-FAS; Giallo, Wade, & Keinhaus, 2014; Michielsen, De Vries, & Van Heck, 2003). The FAS consists of 10 statements that measure chronic fatigue (Michielsen et al., 2003). When this measure was administered to a large community sample of Australian parents with preschool aged children, there was limited variability in the parents’ responses and significant skewness for a number of items (e.g., “I don’t do much during the day”; Giallo et al., 2014, p. 128). Giallo et al. (2014) developed the a-FAS based on the outcome of a confirmatory
factor analysis. The five items (e.g., “I get tired very quickly”) were proposed to accurately reflect the experience of fatigue among parents of young children, and so these were used in the current study. Discriminant validity between the a-FAS and the depression subscale of the DASS-21 (Lovibond & Lovibond, 1995) has been established (Giallo et al., 2014). The a-FAS items are rated on a 5-point scale based on how the participant usually feels, where 1 = never and 5 = always. One item is reverse scored, and scores are summed with higher scores reflecting higher levels of fatigue. Cronbach’s α for the current study was .86.

**Parenting Practices Scales (Sanson et al., 2002).** Items from Growing Up in Australia - the Longitudinal Study of Australian Children (LSAC; Sanson et al. 2002) were used to assess parents’ levels of warmth, hostility, and involvement. The warmth subscale includes six items to assess the frequency of affectionate behaviours over the last six months (e.g., “Thinking about the last six months, how often did you hug or hold your child for no particular reason?”). The hostility subscale includes four items that assess anger or frustration toward the child over the last four weeks (e.g., “Over the past four weeks, how often have you raised your voice or shouted at this child?”). Items for both subscales were rated on a five-point scale where 1 = never and 5 = always/almost always. The involvement subscale asks parents how many days in the past week they had involved their children in games and activities (e.g., “played with toys/games indoors [e.g., board/card games]”). Items were rated as 0 = none, 1 = one or two days, 2 = three to five days, or 3 = six or seven days. Mean scores were computed, with higher scores reflecting higher levels of warmth, hostility, or involvement. Cronbach’s α for the warmth, hostility, and involvement scales were .83, .86, and .63 respectively.

These parenting practice measures were administered as part of the LSAC to gain an understanding of the typical pattern of parenting behaviours within Australian families (Lucas et al., 2010). Normative data for the warmth measure was based on a sample of Australian parents (n = 3800 mothers; n = 2766 fathers) of children aged between 4 and 5 years, comprising the “B-cohort, wave 3” of the LSAC (Lucas et al., 2010). This group were chosen as a basis for comparison as the children’s ages most closely matched the ages of the preschoolers with ASDs in the current sample. Parents in the B-cohort rated their hostility on a 10-point scale rather than the 5-point scale used
in the current study, and descriptive statistics for the involvement scale have not been published within the LSAC. As such, normative data for these measures were unavailable.

**Procedure**

The study was approved by Swinburne University of Technology’s Human Research Ethics Committee, Melbourne Australia (see Appendix B). Data for this stage of the study were collected collaboratively with an Honours who was conducting a separate research project. ASD related support groups and services across Australia were contacted to assist in advertising the study. Approximately 40 groups assisted by emailing their group members, including an advertisement in their newsletter or website, or by displaying a flyer (see Appendix C) in their waiting-room. It was not possible to determine how many parents were informed about the study meaning that response rates could not be determined.

The first page of the questionnaire included a plain language statement (see Appendix D) providing information about the study, and explaining that participation was voluntary and responses were confidential. Participants then provided demographic information followed by the questionnaire scales. Additional measures were included as part of a separate project. Most parents completed the questionnaire online, but 10 were mailed a paper copy. Completing the questionnaire implied consent. Parents with more than one child with an ASD in the target age group (n = 10) were asked to select one child as their *focus child*. At the end of the questionnaire, parents in Victoria were given the option of leaving their name, phone number, and email address to be contacted for the second phase of this research project. Participants were redirected to a separate online page so that their contact details were not matched to their questionnaire responses, preserving the anonymity of the data.

**Results**

**Overview of Data Analysis Procedure**

Online questionnaire responses were transferred into the Statistical Package for the Social Sciences, version 22 (SPSS-22; IBM Corp, 2013) and paper questionnaire
responses were entered manually and checked for accuracy. Descriptive statistics were generated by calculating means, standard deviations, and ranges to get a sense of child, parent, and family characteristics. As part of this descriptive investigation, participant data were compared to population norms where these were available. Data screening and assumptions testing were conducted prior to comparing the data to norms and testing the hypothesised models.

Path analysis using Mplus version 7.11 (Muthén & Muthén, 1998-2013) was conducted to test the hypothesised mediation models. In the first model, it was hypothesised that parental wellbeing would mediate the relationship between child behaviour problems and family functioning (see Figure 2). In the second model, it was hypothesised that family functioning would mediate the relationship between parental depressive symptoms and parenting practices (see Figure 3). Mediation models help to explain sequential processes amongst associated variables (MacKinnon, 2011; MacKinnon & Pirlott, 2015). Within this regression-based approach the complex relationships between a set of independent, intermediate, and dependent variables are estimated simultaneously. All regression coefficients are calculated based on the relationships specified in the model, making this approach more refined than standard regression (MacKinnon & Pirlott, 2015). Model fit statistics are generated along with estimates of the direct and indirect paths. Model fit was assessed using the chi-square test, and other practical fit indices including the Tucker–Lewis Index (TLI), Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and the Standardised Root Mean Square Residual (SRMR). Indices for the TLI and CFI should exceed .90 for an acceptable fit, and values close to or below .05 for the RMSEA and the SRMR were considered acceptable (Hu & Bentler, 1999).

Preliminary Data Analysis

First, the data file was screened for missing data and out of range values. In total, 108 individuals attempted the survey; three participants were excluded as they reported that their child was older than 6 years and was attending school. A further eight participants were excluded due to having more than 20% missing data. In these cases, the participant had discontinued the questionnaire after completing only some measures. The excluded cases did not significantly differ from the final sample (N=97) in age, gender, family size, single/couple family composition, focus child age, focus
child diagnosis, focus child age at diagnosis, hours spent at work in a typical week, language spoken at home, education attainment, or employment status ($p > .05$). Therefore, excluding these cases was unlikely to introduce systematic bias. For the remaining 97 participants, data screening showed that missing data were less than 5% and were missing at random (Little MCAR test, $p > .05$). The expectation-maximisation algorithm in SPSS-22 (IBM Corp, 2013) was used to impute missing values.

More mothers ($n = 88$) than fathers ($n = 9$) participated in this study. This is a common difficulty in parenting research, which can result in the experiences of fathers being under-represented or overlooked (Cassano, Adrian, Veits, & Zeman, 2006; Phares, Lopez, Fields, Kamboukos, & Duhig, 2005; Seymour, Dunning, Cooklin, & Giallo, 2014). Data from mothers and fathers were compared on each of the key variables. Fathers were found to report significantly less child behaviour problems ($F(1, 95) = 4.86, p < .05, \eta^2 = .05$), significantly lower levels of fatigue ($F(1, 95) = 13.71, p < .001; \eta^2 = .13$), and parenting warmth ($F(1, 95) = 11.24, p < .01, \eta^2 = .11$) than mothers. The effect sizes associated with these differences were small, and so it was decided to include fathers in the final analysis. This was deemed favourable to excluding fathers’ experiences entirely. Furthermore, it has been suggested that despite differences in the magnitude of difficulty reported by mothers and fathers, similar overall patterns predict parental wellbeing across both genders (Jones et al., 2013).

The data were screened for univariate outliers by inspecting box plots and standardised scores. One case showed higher levels of hostility than the majority and one scored highly on the measure of behaviour problems. Neither of these scores was considered extreme based on their standardised score ($z < 3.29$; Tabachnick & Fidell, 2013) and so were not altered or deleted. Mahalanobis distance statistics indicated that there were no significant multivariate outliers. Skewness and kurtosis statistics, and graphical plots were used to assess normality (see Table 4). No significant kurtosis was identified. Skewness statistics indicated that the family functioning and depression measures were positively skewed suggesting a propensity for low scores in this sample. By contrast, parental warmth was negatively skewed indicating a tendency towards high scores. These violations in the normality assumption were addressed by using Robust Maximum Likelihood (MLR) and Maximum Likelihood Mean adjusted (MLM) as the estimation methods.
Confounding variables can compromise the validity of any model. Prior to conducting the analysis, correlations between demographic variables and the variables of interest were conducted. Where demographic variables correlated with the scale measures, they were included as covariates.

Describing the Sample Relative to Published Norms

Descriptive statistics were generated for each of the questionnaire measures, and these are displayed in Table 4, along with available population norms. Where possible, normative data were reported separately for men and women. For the DBC-P24 (Taffe et al., 2007) and FAD-GF (Epstein et al., 2013) population norms were not published separately for men and women so are listed for the total normative sample.
Table 4

*Population Norms, Means, Standard Deviations, and Ranges for Questionnaire Measures*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Population Norms (Women)</th>
<th>Population Norms (Men)</th>
<th>Mothers (n = 88)</th>
<th>Fathers (n = 9)</th>
<th>Total Sample (N = 97)</th>
<th>Range</th>
<th>Skewness&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Kurtosis&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DBC-P24&lt;sup&gt;c&lt;/sup&gt;</td>
<td>.45 (.27)</td>
<td>-</td>
<td>.88 (.32)</td>
<td>.64 (.44)</td>
<td>.86 (.31)</td>
<td>.17 – 1.71</td>
<td>.08</td>
<td>-.34</td>
</tr>
<tr>
<td>FAD-GF&lt;sup&gt;c&lt;/sup&gt;</td>
<td>1.84 (.43)</td>
<td>-</td>
<td>2.13 (.63)</td>
<td>2.21 (.64)</td>
<td>2.11 (.59)</td>
<td>1 – 3.75</td>
<td>.54</td>
<td>.31</td>
</tr>
<tr>
<td>a-FAS</td>
<td>14.20 (4.00)</td>
<td>12.30 (3.9)</td>
<td>17.09 (4.30)</td>
<td>11.67 (2.65)</td>
<td>16.60 (4.46)</td>
<td>7 – 25</td>
<td>-.09</td>
<td>-.78</td>
</tr>
<tr>
<td>Stress Scale</td>
<td>10.29 (8.16)</td>
<td>9.93 (7.66)</td>
<td>20.19 (8.45)</td>
<td>15.33 (5.00)</td>
<td>19.75 (8.32)</td>
<td>2 – 38</td>
<td>.04</td>
<td>-.29</td>
</tr>
<tr>
<td>Depression Scale</td>
<td>6.14 (6.92)</td>
<td>6.55 (7.01)</td>
<td>11.97 (8.96)</td>
<td>9.33 (4.80)</td>
<td>11.75 (8.68)</td>
<td>0 – 38</td>
<td>.88</td>
<td>.36</td>
</tr>
<tr>
<td>Warmth&lt;sup&gt;d&lt;/sup&gt;</td>
<td>4.51 (.01)</td>
<td>4.23 (.01)</td>
<td>4.42 (.06)</td>
<td>3.76 (.21)</td>
<td>4.36 (.59)</td>
<td>2.50 – 5</td>
<td>-.82</td>
<td>.01</td>
</tr>
<tr>
<td>Involvement</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.80 – 4</td>
<td>-.06</td>
<td>-.35</td>
</tr>
<tr>
<td>Hostility</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2.92 (.77)</td>
<td>1 – 4.75</td>
<td>-.16</td>
</tr>
</tbody>
</table>

*Note. M = Mean. SD = Standard Deviation. DBC-P24 = Developmental Behaviour Checklist – Parent Short Form; a-FAS = Adapted Fatigue Assessment Scale; FAD-GF = Family Assessment Device-General Functioning Scale.

<sup>a</sup>Standard error skewness = .25. <sup>b</sup>Standard error kurtosis = .49. <sup>c</sup>Population norms included combined data from men and women. <sup>d</sup>Standard error rather than standard deviation is reported for the warmth scale.
As shown in Table 4, mean scores for the DBC-P24 (Taffe et al., 2007) were above the clinical cut-off of 0.48 indicating participants, on average, reported that their preschooler showed clinically significant emotional and behaviour problems. The majority of participants rated their child’s behaviour above the clinical cut-off for this measure ($n=81; 83.5\%$). Parents in the current sample reported more severe child behaviour problems (Taffe et al., 2007) than parents ($N=539$) in the normative sample ($t(634) = 13.448, p < .001$) which included parents of older children with intellectual disabilities. Cohen’s (1992) $d$ indicated a large difference between these groups ($d=1.46$).

Of the 97 parents, 36% rated their family functioning above the cut-off indicative of family difficulties. Mothers’ mean scores fell just below the clinical cutoff, indicating family functioning within the healthy range. Although, compared to adults in the FAD normative sample ($N=627$), mothers in the current study reported significantly higher levels of family difficulties ($t(713) = 5.549, p < .001$, $d=.632$). Fathers’ mean scores were slightly above the clinical cut-off suggesting on average, they reported ineffective family functioning. Fathers reported significantly higher FAD-GF scores than available norms ($t(634)-2.544, p<.05, d=.730$).

Levels of depressive symptoms for the parents were classified as normal ($n=44, 45.4\%$); mild ($n=13, 13.4\%$); moderate ($n=25, 25.8\%$); severe ($n=9, 9.3\%$); or extremely severe ($n=6, 6.2\%$). Mothers’ mean scores for the DASS-21 depression scale (Lovibond & Lovibond, 1995) were in the mild range, and fathers’ mean scores were on the border of the normal/mild range. The parents rated their stress as normal ($n=29, 29.9\%$); mild ($n=17, 17.5\%$); moderate ($n=26, 26.8\%$); severe ($n=19, 19.6\%$); or extremely severe ($n=6, 6.2\%$). Mothers’ mean stress scores were on the border of the mild/moderate range, whereas fathers’ mean stress scores were in the mild range.

The participants’ DASS-21 (Lovibond & Lovibond, 1995) depression and stress scores were compared to Australian normative data from 1870 women and 1044 men. The mothers’ were found to report significantly higher scores than women in the community sample for symptoms of both depression ($t(1956) = 7.610, p<.001, d =0.83$), and stress ($t(1956) = 11.205, p<.001, d =1.21$). Fathers in the present study reported significantly higher levels of stress than men in the Australian community, with the Cohen’s $d$ value indicating a large difference between the two group means ($t(1051) =$
The difference in depression scores was not significant for fathers ($t(1051)=1.05, p = .296$).

The participants’ levels of fatigue were compared to a large community sample ($N=1276$; 1122 mothers, 154 fathers) of Australian parents with children less than 6 years of age (Cooklin et al., 2011). The mothers in the present study reported significantly higher levels of fatigue than mothers in the community sample, and the effect size was large ($t(1208) = 6.490, p < .001, d=0.72$). No significant difference was apparent for fathers’ fatigue ($t(161) = .48, p = .634$).

Parenting warmth was compared to normative data from an Australian sample of parents of children who were aged between 4 and 5 years ($n = 3800$ mothers; $n = 2766$ fathers; Lucas et al., 2010). There were no significant differences in parental warmth for mothers ($t(3886) = 1.357, p = .175$). However, fathers in the current sample reported significantly lower levels of warmth than the normative data, and the effect size was large ($t(2773) = 2.679, p < .05, d = 0.89$).

**Testing the Hypothesised Models**

Prior to testing the hypothesised models, pearson correlations were calculated. These correlations explored the associations between the study variables, and selected demographic variables. These correlations are presented in Table 5.
Table 5

**Correlations between the Study Variables and Covariates**

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
<th>9.</th>
<th>10.</th>
<th>11.</th>
<th>12.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parent Age</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Educationa</td>
<td>.13</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Employmentb</td>
<td>.12</td>
<td>.05</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. SEIFA</td>
<td>.06</td>
<td>.17</td>
<td>.26*</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sibling has an ASDc</td>
<td>.26*</td>
<td>-.05</td>
<td>.01</td>
<td>-.04</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Family functioning</td>
<td>.10</td>
<td>.02</td>
<td>-.02</td>
<td>-.13</td>
<td>.25*</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Child behaviour problems</td>
<td>-.20</td>
<td>-.10</td>
<td>-.21*</td>
<td>-.17</td>
<td>.13</td>
<td>.22*</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Stress</td>
<td>-.11</td>
<td>-.04</td>
<td>-.13</td>
<td>-.01</td>
<td>.21*</td>
<td>.22*</td>
<td>.36**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Depression</td>
<td>-.15</td>
<td>-.08</td>
<td>-.15</td>
<td>-.07</td>
<td>.14</td>
<td>.43**</td>
<td>.26**</td>
<td>.65**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Fatigue</td>
<td>-.29**</td>
<td>.09</td>
<td>-.21*</td>
<td>-.02</td>
<td>.05</td>
<td>.15</td>
<td>.36**</td>
<td>.54**</td>
<td>.44**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Warmth</td>
<td>.08</td>
<td>-.04</td>
<td>-.19</td>
<td>-.14</td>
<td>-.18</td>
<td>-.28**</td>
<td>.01</td>
<td>-.08</td>
<td>-.29**</td>
<td>.04</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>12. Hostility</td>
<td>-.19</td>
<td>-.05</td>
<td>-.04</td>
<td>.04</td>
<td>.09</td>
<td>.09</td>
<td>.19</td>
<td>.24*</td>
<td>.27**</td>
<td>.22*</td>
<td>-.19</td>
<td>-</td>
</tr>
<tr>
<td>13. Involvement</td>
<td>-.01</td>
<td>.33**</td>
<td>-.15</td>
<td>.07</td>
<td>.08</td>
<td>-.19</td>
<td>.03</td>
<td>.02</td>
<td>-.06</td>
<td>.09</td>
<td>.23*</td>
<td>.05</td>
</tr>
</tbody>
</table>

**Note:** N = 97

SEIFA = Socio-Economic Index for Areas – Disadvantage Score. ASD = Autism Spectrum Disorder

*a* = Did not complete high school; 2 = Completed high school. *b* = Not in paid employment; 2 = Employed part-time or full-time. *c* = No siblings have an ASD. 2 = One or more siblings have an ASD

* *p <.05; **p <.01; ***p <.001
As shown in Table 5, there were moderate positive correlations between children’s behaviour problems and parental stress, depression, fatigue, and family functioning. Moderate, positive correlations between the stress, depression, and fatigue scores suggested these were separate but related constructs. Higher levels of depression were associated with more family difficulties, lower parental warmth, and higher parental hostility. Higher levels of parental stress were weakly associated with family difficulties and parental hostility, and higher fatigue ratings were associated with more hostile parenting. Family difficulties were negatively correlated with warm parenting. Having more than one child with an ASD was associated with parental stress and family difficulties. Higher educational obtainment amongst parents was associated with higher levels of involvement. Participation in the workforce was associated with lower child behaviour problems and parental fatigue.

Model 1. It was hypothesised that child behaviour problems would indirectly influence family functioning via parent mental health (as indicated by levels of stress, depression, and fatigue). The number of parameters to be estimated was 17 including correlations of the residual variances between depressive, stress, and fatigue symptoms to account for the interrelationships between the parent mental health variables. The sample size was adequate for Model 1, adhering to the recommended ratio of five participants to every free parameter to be estimated (Tanaka, 1987). The MLR estimation method was used to account for non-normal multivariate data. The hypothesised model was an excellent fit to the data, $\chi^2 (1, N=97) = 12.9, p = .381$; RMSEA (90%CI) = .00 (.00 - .26), CFI=1.00, TLI=1.02. The model accounted for 20% of the variance in family functioning, 14% of the variance in stress, 7% of the variance in depressive symptoms, and 14% of the variance in fatigue. The standardised parameter estimates for the model are shown in Figure 2.
As can be seen in Figure 2, higher levels of problematic child behaviours were associated with greater depressive, stress, and fatigue symptoms in parents, and these direct paths were significant. Only depressive symptoms were, in turn, associated with more problematic family functioning. The total indirect effect of difficult child behaviour on family functioning approached significance (\(t = 1.78, p = .074\)). The indirect pathway from child behaviour problems to family functioning via parent depressive symptoms (\(p = .02\)) was significant providing some evidence for mediation. The indirect pathways via parent stress (\(-.03, p = .594\)) and parental fatigue (\(-.002, p = .952\)) were not significant.

**Model 2.** Model 1 highlighted the potential for parental depression to impact on the family environment through its effects on family functioning. In Model 2, it was hypothesised that parental depressive symptoms would indirectly be associated with the parenting practices of warmth, hostility, and involvement, via family functioning. Child behaviour problems and parents’ education were included as covariates due to their associations with the measured variables of interest. Child behaviour problems were correlated with depression in the model, and parents’ education was correlated with both depression and involvement. The hypothesised model was an acceptable fit to the data based on the chi square, CFI and RMSEA indices (\(\chi^2(11, N=97) = 16.05, p = .139; CFI = .913; \text{RMSEA (90\%CI)} = .07 (.00 - .14)\)). However, according to the TLI and SRMR, the model was a poor fit to the data (TLI = .841, SRMR = .06). The standardised parameter estimates for the model are shown in Figure 3.
For model 2, the ratio of cases to parameters \((N=24)\) was below the recommended minimum of 1:5, which reduces the statistical power. This affects the precision of the parameter estimates, as well as the ability to generalise the findings (Tanaka, 1987). The estimation method used was maximum likelihood with standard errors and a mean-adjusted chi-square test (MLM), which accounts for non-normal multivariate data and also helps manage difficulties with model under-identification.

*Figure 3. Model for the indirect effect of parental depressive symptoms on warmth, hostility, and involvement, with family functioning as a mediator.*

As shown in Figure 3, parents’ depressive symptoms were associated with family functioning. Family functioning was also directly associated with parental warmth and involvement, but not hostility. The model explained 18.8% of the variance in family functioning, 7.7% of the variance in parental warmth, 15.7% of the variance in involvement, and 8% of the variance in hostility. The indirect pathway from parental depressive symptoms to involvement via family functioning was significant providing some evidence for mediation \((-0.08, p = 0.029)\). Although family functioning was a direct predictor of parenting warmth, it did not mediate the relationship between depressive symptoms and warmth as the indirect pathway was non-significant \((-0.12, p = 0.081)\). The indirect pathways predicting parenting hostility via family functioning was also non-significant \((0.04, p = 0.479)\).
Model 3. The results from Model 2 indicated that the association between depressive symptoms and family functioning had flow-on effects, in terms of a reduction in parental involvement. Given the importance of parental depressive symptoms, which have implications for the family, the direct effects of this variable on parenting warmth and hostility were modelled as an extension of Model 2. Covariates were added whereby parental education was modelled to correlate with depression and involvement, and behaviour problems were correlated with depression. Although no mediated effects of depression on warmth or hostility were identified with Model 2, depressive symptoms cannot be ruled out as an important predictor of these parenting practices, and has been shown to be associated with suboptimal parenting in prior research (e.g., Lovejoy et al., 2000). Model 3 was found to be an excellent fit to the data $\chi^2(9, N=97) = 6.39, p = .700$; RMSEA (90%CI) = .00 (.00 - .09), CFI=1.00, TLI=1.10, SRMR=.04. Standardised parameter estimates are shown in Figure 4.

![Figure 4](image)

Figure 4. Model for the direct effect of parent depressive symptoms on warmth and hostility, and the indirect effect of parental depressive symptoms on involvement, with family functioning as a mediator.

As shown in Figure 4, when controlling for behaviour problems and parental education, parents’ depressive symptoms predicted family difficulties, lower levels of parental warmth, and higher levels of hostility. Parents’ depressive symptoms indirectly predicted involvement via family functioning and this path was significant.
Model 3 explained 18.8% of the variance in family functioning, 11.7% of the variance in warmth, 15.8% of the variance in involvement and 7% of the variance in hostility.

**Comparison between Models 2 and 3.** A scaled-difference chi-square test (Satorra & Bentler, 1999) indicated that Model 3 was a significantly better fit to the data than Model 2 ($\Delta \chi^2(2) = 8.63, p = .013$).

**Summary of the Findings**

An overview of the main findings from Study 1 is presented in this section. A comprehensive discussion of the findings in the context of prior research is presented in the final chapter of this thesis (see Chapter 8), along with the limitations and implications of the study.

To explore the impact of raising a preschooler with an ASD on parental wellbeing, parenting warmth, and family functioning, data from the current study were compared to norms. This analysis indicated that the participants reported significantly higher levels of stress, depression, fatigue, and family difficulties compared to normative data from community samples. Mothers in the current sample reported similar levels of warmth to Australian mothers of preschoolers. Although fathers made up a small proportion of the current sample, this group reported lower levels of parenting warmth than is typically reported by Australian dads (Lucas et al., 2010). Parents of children with an ASD in the current study reported significantly higher levels of problematic behaviour when compared to parents of older children with an intellectual disability in the DBC normative sample (Einfield & Tonge, 1996).

It was hypothesised that children’s behaviour problems would be associated with increased parental mental health difficulties (as defined by symptoms of stress, depression, and fatigue), and these in turn would be associated with less effective family functioning. This hypothesis was partially supported. While behaviour problems were associated with increased stress, fatigue, and depressive symptoms in parents, parental stress and fatigue were not associated with family functioning after
accounting for behaviour problems. The relationship between behaviour problems and family functioning was only mediated by parental depressive symptoms. This finding suggests that when children’s behaviour problems predict depressive symptoms in parents, depressive symptoms then have a negative relationship with family functioning.

Parents’ depressive symptoms were found to be associated with suboptimal parenting practices. Controlling for the impact of behaviour problems, higher levels of depressive symptoms were directly associated with higher levels of hostility, and lower levels of parenting warmth. Parents’ depressive symptoms levels were related to family difficulties, which in turn, were associated with less involvement in daily activities with the child with an ASD. These significant findings further characterise some of the problematic transactions that occur in the family environment when parents are affected by depressive symptoms. The implications of these finding will be discussed in Chapter 8.
Chapter 7. Study 2: A Qualitative Exploration of the Family Environments for Preschoolers with ASDs

The overall aim of this second study was to develop a detailed understanding of the family environment for preschoolers with ASDs. This included examining the ways in which early home learning activities and interactions were situated within family life. The Australian guidelines for good practice (Prior & Roberts, 2006; Prior et al., 2011) recommend that intervention decisions and procedures be made taking the family system into consideration. However, this does not clearly translate to clinical practice, which is often child-focussed. For most early intervention programs, therapy involves techniques aimed to modify behaviours and advance children’s educational and developmental skills, usually requiring input from parents (Matson & Williams, 2015; Schertz et al., 2010). These intervention strategies do not necessarily adapt to the needs of parents and families, or address the wellbeing of family members. Clinicians can sometimes lack an understanding of the everyday experiences of parents and families raising preschoolers diagnosed with an ASD. As such, clinicians are not always cognisant of the strengths and limitations of the parents who are often asked to take an active role in selecting and implementing interventions, and to incorporate intervention into their daily life (Valentine, 2010). The more specific aims of this study were outlined in Chapter 5 and are restated below:

1. To explore parents’ perceptions of the impact raising a preschooler with an ASD has on their family.
2. To understand the ways in which parents adapt their approach to parenting and family life to accommodate for the child’s needs.
3. To explore the ways in which parents support their children’s learning and development.

Given the results from Study 1 showing that parental wellbeing is linked with children’s behaviour problems, parenting practices, and family functioning, it was important to gain an understanding of these characteristics amongst the Study 2 participants. Of interest were the parents’ stress, depression, fatigue, warmth, and perceptions of family functioning relative to other parents or adults in the general population. Characteristics of the preschoolers with ASDs such as the severity of
behaviour problems, level of adaptive functioning, and early developmental skills, were also of interest. As such, a mixed-methods framework was used to position the interview data amongst a demographic analysis of child, parent, and family functioning.

**Study Design**

A convergent mixed-methods design was used in this study, whereby both quantitative and qualitative data were collected concurrently (Creswell, 2013; Creswell, Klassen, Plano-Clark, & Smith, 2011). The qualitative data were given priority, and the quantitative data took a secondary role, to assist in describing the sample in detail. This methodology allowed for a comprehensive understanding of the family environment and associated variables in this group, and enabled commonalities and individual differences between parents’ experiences to be explored. Integrating these two data types based on the triangulated approach gave context to the qualitative data, and enabled comparisons to be made across data types (Creswell et al., 2011).

Rather than purely adhering to a single methodology, a pragmatic approach was adopted. The research methods were selected to generate knowledge of the topic while taking into consideration the issues surrounding the research question and population of interest (Angen, 2000; Whittemore, Chase, & Mandle, 2001). Conducting research within a real-world context, such as the family home, is likely to result in outcomes that have practical value to inform clinical work (Angen, 2000). Similarly to clinical practice, engaging with participants to generate data through discussions and observations involves human interaction, diversity, and interpretations, which adds to the authenticity and applicability of the findings (Angen, 2000).

**Personal Statement**

Being a family member of someone with an ASD is a uniquely challenging and enriching experience. Across many professional and personal encounters with parents of children on the Autism Spectrum, there is an undercurrent to the conversation – you cannot fully appreciate what this is like unless you have lived it. My personal experiences having “lived it” as a relative of someone with autism inspired my research interest in this area.

I have developed a particular curiosity about parents of very young children with ASDs. These parents face a steep learning curve, and yet often show remarkable
dedication to their child’s growth. I have witnessed this in my family, and in families I have worked with as an integration aide, volunteer, and on my clinical placements. Over the course of this research project, the research participants have broadened my perspectives on this topic and reaffirmed by belief that parents are often the strongest source of support for their children.

Being close to this research topic influences the extent to which I was able to engage in bracketing, that is, putting aside preconceptions at the outset of the study, and separating my views from the participants’ perspectives across the course of data collection and integration (Gearing, 2004). Some preconceptions that may have permeated my analysis and interpretation of the qualitative data are my personal orientation toward advocacy for parents of children with ASDs, and perhaps in some ways, over-identifying with the families’ experiences. Furthermore, my personal beliefs about ASDs err toward these conditions being an expression of neurodiversity, a difference to be celebrated, and not a defect to be fixed.

To assist in addressing these potential biases, the supervisory team, as well as peer consultation, were used throughout the data collection and analysis. Being a sibling rather than a parent of someone with an ASD and noticing the stark differences between raising a child with an ASD in the 2010s rather than 1990s also enabled me to remain curious and open to new insights on the area of investigation. Throughout the project, I viewed my prior experiences as advantageous, and felt this enabled me to engage with participants with authenticity and understanding.

Overall this research project has strongly influenced the way in which I have approached my clinical training towards becoming a psychologist, and the way I will approach my work with people with ASDs and their families in the future. Undertaking this project has taught me to always acknowledge and respect the expertise of parents. I also intend to be cautious of placing demands on parents, and making sure their views, wellbeing, and capacity to work with the child are carefully considered as part of their child’s intervention. I will be open-minded and eager to learn from parents approaching clinical work as a partnership. In summary, the experiences and values described in this section have informed my personal perspective on the family environment when raising a child with an ASD. These experiences will inevitably have shaped and informed the manner in which I engaged in the collection and analysis of the interview data.
Method

Participants

Twenty-one families participated in the present study. All of the mothers completed the questionnaires, and 10 of the fathers also agreed to complete these measures, meaning responses were available from 31 parents. When both the mother and father were home during the visit (n = 5), parents were asked to decide who would be the main interviewee. In these cases, the family chose the mother, although statements volunteered by the fathers were also transcribed and included in the analysis with their permission. In two of the families the fathers became actively engaged in the interviews, and shared many of their experiences and insights. Demographic characteristics of the participants are shown in Table 6.

Table 6

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers (n=21)</th>
<th>Fathers (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (M, SD)</td>
<td>36.9 (5.2)</td>
<td>39.2 (6.8)</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Part-time</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Casual</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Not in paid employment</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Highest level of education completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>TAFE, Trade Certificate, or Diploma</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Completed High School</td>
<td>3</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. M = Mean, SD = Standard Deviation. TAFE = Technical and Further Education

As displayed in Table 6, the mean age for mothers was 37 years, and for fathers, 39 years. The majority of participants held a university qualification. Although a number of parents were born overseas, only one family reported speaking a language other than English in the family home. None of the participants identified as being of
Aboriginal or Torres Strait Islander background. Across the 21 families, it was most common for the father to be working full-time while the mother was not in paid employment \((n = 13\) families). For five families, the father worked full-time while the mother worked part-time. It was less common for both parents to work full-time \((n = 1)\), for the mother to work part-time while the father was not in paid employment \((n = 1)\), or for neither parent to be in the workforce \((n = 1)\). Further information about the family composition in this sample is shown in Table 7.

Table 7

*Demographic Characteristics of the Families \((N=21)\)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of children in the family</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>6</td>
</tr>
<tr>
<td>Two</td>
<td>11</td>
</tr>
<tr>
<td>Three</td>
<td>2</td>
</tr>
<tr>
<td>Four or more</td>
<td>2</td>
</tr>
<tr>
<td>Number of children with an ASD</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>20</td>
</tr>
<tr>
<td>Two</td>
<td>1</td>
</tr>
<tr>
<td>SEIFA Decile Score</td>
<td></td>
</tr>
<tr>
<td>3 – 4</td>
<td>4</td>
</tr>
<tr>
<td>5 – 6</td>
<td>3</td>
</tr>
<tr>
<td>7 – 8</td>
<td>8</td>
</tr>
<tr>
<td>9 – 10</td>
<td>6</td>
</tr>
</tbody>
</table>

*Note. SEIFA = Socio-Economic Index for Areas - disadvantage score (ABS, 2011)*

Of the 21 families, all were two parent households, and in most cases the focus child’s parents were married \((n = 20)\). As shown in Table 7, the SEIFA index scores suggested that the majority of families lived in neighbourhoods with relatively low levels of socio-economic disadvantage. As noted in Study 1 (p. 73) the SEIFA score reflects levels of disadvantage based on geographical regions and does not necessarily reflect the resources available to a particular family (ABS, 2011).

To be included in the study, the parents needed to have a child with an ASD who had not yet begun school. For 15 of the 21 families, the focus child was the first-born child. One family reported they had another child who had been diagnosed with
an ASD, although some parents \((n=3)\) expressed concerns that a younger sibling may be showing early signs of an ASD during the home visits. The focus children for the current study were aged between 2 years 9 months, and 6 years. Information about the focus children is shown in Table 8.

Table 8

Demographic Characteristics of the Focus Children \((N=21)\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in months; (M, SD))</td>
<td>52 (11)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>20</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Autism (Low Functioning)</td>
<td>1 (4.8%)</td>
</tr>
<tr>
<td>Autism (High Functioning)</td>
<td>6 (28.6%)</td>
</tr>
<tr>
<td>Asperger’s Disorder</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Pervasive Developmental Disorder – NOS</td>
<td>2 (9.5%)</td>
</tr>
<tr>
<td>Other (e.g., ASD - Level of functioning unknown)</td>
<td>8 (38.1%)</td>
</tr>
<tr>
<td>Age of diagnosis (in months; (M, SD))</td>
<td>39 (11)</td>
</tr>
<tr>
<td>Time since diagnosis (in months; (M, SD))</td>
<td>13 (11)</td>
</tr>
<tr>
<td>Professional who made the diagnosis</td>
<td></td>
</tr>
<tr>
<td>Paediatrician</td>
<td>9</td>
</tr>
<tr>
<td>Psychologist</td>
<td>3</td>
</tr>
<tr>
<td>Multi-disciplinary team(^a)</td>
<td>9</td>
</tr>
<tr>
<td>Hours per week at childcare, kinder, or preschool ((M, SD))</td>
<td>13.7 (11.0)</td>
</tr>
</tbody>
</table>

Note. \(M =\) Mean. \(SD =\) Standard Deviation. ASD = Autism Spectrum Disorder.
NOS = Not Otherwise Specified
\(^a\)A combination of two or more professionals (e.g., psychologist and paediatrician)

As shown in Table 8, the mean age of the focus children was 4 years and 4 months old. On average, the children had received an ASD diagnosis 13 months prior to participating in the study. Only one of the children was a girl, which may be related to the difficulty diagnosing girls with ASDs, and that the average age of diagnosis for girls is often later than for boys (Giarelli et al., 2010). Although the data collection for the current study was conducted prior to the release of DSM-5 (APA, 2013), a number of clinicians had used ASD as a diagnostic label, but had not indicated the child’s level of functioning.
The children were participating in a range of interventions, including occupational therapy \((n=16)\), ABA \((n=4)\), unspecified early intervention programs \((n=5)\), social skills groups \((n=3)\), psychological therapy \((n=3)\), or dietary restrictions \((n=4)\). All of the children had received speech therapy at some point, and for most \((n=17)\), this was ongoing at the time of the visit. Other interventions being implemented included combinations of parent-instructed language programs, gymnastics, fish oil supplements, massage, DIR-Floortime, RDI, or music therapy. All of the parents reported they were accessing FaHCSIA funding for their child through the HCWA package.

**Questionnaire Measures**

The participants completed the demographic and family background questionnaire as described in Study 1. Participants then completed the same quantitative measures of child, parent, and family functioning as described in Study 1, and summarised briefly below (see Appendix A for copies of these measures). Additional measures were administered to provide a more thorough assessment of the family environment, and these are also described below. A copy of these additional measures is in Appendix E.

**Measures of parent functioning.** Participants completed the depression and stress subscales from the DASS-21 (Lovibond & Lovibond, 1995) as well as the a-FAS (Giallo et al., 2014; Michielsen et al., 2003). These self-report questionnaire measures were used in Study 1 and are described on pages 77-78. Cronbach’s Alphas for these scales in the current sample were .86, .86, and .90 respectively. Parents also completed the LSAC warmth, hostility, and involvement subscales (see page 78; Sanson et al., 2002) to provide indications of their usual parenting practices, along with additional measures included as part of a separate study. Cronbach’s Alphas for these scales were .75 for warmth, .75 for involvement, and .84 for hostility in the current sample.

**Measures of child functioning.** Participants completed the DBC-P24 (Taffe et al., 2007) as described on page 76. This measure showed good internal consistency in the current sample (Cronbach’s \(\alpha=.83\)). Parents also completed the Vineland Adaptive Behaviour Scales, Version-II, Parent/Caregiver Rating Form (Vineland-II; Sparrow,
Cicchetti, & Balla, 2005) and the child was administered the Psycho-educational Profile, Third Edition (PEP-3; Schopler, Lansing, Reichler, & Marcus, 2005) during the home visit.

*Vineland Adaptive Behaviour Scales, Version-II, Parent/Caregiver Rating Form (Sparrow et al., 2005).* The mothers in this study completed the Vineland-II to measure their child’s adaptive functioning. The mothers were asked to rate items based on how often their child carried out the behaviour independently, on a three point scale where 0 = *never*; 1 = *sometimes or partially*; and 2 = *usually*. The behaviours listed in each subdomain become increasingly complex, and go beyond the skills expected of a preschooler, so parents were able to discontinue completing items according to the ceiling rules.

The Vineland –II is used to generate subdomain scores, domain scores, and a total adaptive behaviour composite. To score each subdomain, a basal (four consecutive scores of *usually*) and ceiling (four consecutive scores of *never*) are established, and the items falling between the basal and ceiling are summed. Raw scores are compared to age-based norms and converted to standard scores (*M*=100, *SD*=15) and percentile ranks. The subdomain scores are clustered to give an indication of the child’s Communication (99 items), Daily Living Skills (109 items), Socialisation (99 items), and Motor Skills (76 items). Vineland-II scores fall in to one of five categories: low (<2<sup>nd</sup> percentile); moderately low (3<sup>rd</sup> to 17<sup>th</sup> percentiles); adequate (18<sup>th</sup> to 83<sup>rd</sup> percentile); moderately high (84<sup>th</sup> to 97<sup>th</sup> percentile); and high (>98<sup>th</sup> percentile).

The Vineland-II normative sample comprised 1395 children in the birth to 5-year age group. These children were representative of the United States population based on gender, ethnicity, geographic region, and socio-economic status. The data were collected between 2003 and 2004, and in approximately 85% of cases, the mother was the primary informant rather than the father or another caregiver. Children with disabilities were not excluded from the standardisation sample.

The Vineland-II is commonly used in clinical and research settings. Reliability has previously been analysed for narrowly defined age-ranges, meaning a number of estimates were available for children aged between 2 and 7 years, which was relevant to the current sample. The split-half reliability for the Communication, Daily Living Skills and Socialisation domains have been reported at .90 or higher for children aged...
between 2 and 7 years. The Motor Skills domain split-half reliability is ranked at .83 or higher for this age range (Sparrow et al., 2005).

**Psycho-educational Profile, Third Edition (PEP-3; Schopler et al., 2005):** The PEP-3 is a play-based assessment used to gauge the developmental abilities of children with ASDs aged between 2 and 7 years. The PEP-3 can be administered to children who are non-verbal. The flexible administration procedure is pragmatic when working with preschoolers with ASDs. Item administration typically takes between 45 and 90 minutes. Materials such as puzzles, play-dough, picture books, noisemakers, and puppets are used to assess the child’s abilities in six key areas as described below.

- The Cognitive Verbal/Preverbal subscale (34 items) assesses problem solving, verbal naming, sequencing, and visual-motor integration. The Expressive Language (25 items) and Receptive Language (19 items) subscales measure the child’s use and understanding of speech and gesture. The Fine Motor subscale (20 items) tests the child’s coordination, with example activities including blowing bubbles, picking up small objects, stringing beads, and colouring. Gross Motor (15 items) focuses on the movement of different body parts by asking the child to demonstrate skills such as throwing and catching a ball, walking upstairs using alternating feet, and swinging beads on a string. Visual Motor Imitation (10 items) explored the child’s ability to imitate different movements and to imitate the use of objects.

PEP-3 items are rated as 2 = *passing* (the task was completed successfully without demonstration); 1 = *emerging* (the child understood some of the task but was not able to complete it without repeated demonstrations); or 0 = *failing* (the child did not attempt the task, or was unable to do any part of the task; Schopler et al., 2005). Raw scores are converted to percentile ranks based on the results of an age-matched normative group. The norm group relevant to the current study included 283 children aged between 2 and 7 years, who lived across 21 states of America. These children were diagnosed with an ASD, and the majority (80%) were boys. Schopler et al. (2005) reported strong internal consistency for the PEP-3 subscales with Cronbach’s Alphas ranging from .78 to .97. PEP-3 scores can be described as adequate (>89th percentile); mild (75th to 89th percentile); moderate (25th to 75th percentile) or severe (<25th percentile) based on the child’s developmental level (Schopler et al., 2005).
The PEP-3 (Schopler et al., 2005) has been used in a number of studies (e.g., Chen et al., 2011; Fu et al., 2010; Fulton & D'Entremont, 2013) and is a complementary measure to the Vineland-II (Fulton & D'Entremont, 2013). A study by Villa and colleagues (2010) using the PEP – Revised (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) and Vineland-II (Sparrow et al., 2005) found that although these measures correlated significantly when looking at group scores, a high degree of intra-individual variability was apparent. The authors suggested using both the PEP and Vineland-II would provide a more thorough assessment of child functioning that takes into account both parent and clinician ratings (Villa et al., 2010).

**Measures of family functioning.** Family functioning was measured using both quantitative and qualitative methods. Participants completed the Family Assessment Device (FAD; Epstein et al., 1983) and participated in a semi-structured interview.

*Family Assessment Device (FAD; Epstein et al., 1983).* The FAD-GF scale was used in Study 1 and is described on page 75. Participants in Study 2 completed the FAD in its entirety (60-items) so that the seven subscale scores could be calculated. Participants rated each item on a 4-point scale (1 = strongly agree; 4 = strongly disagree). After reverse scoring 35 items, scores were averaged resulting in subscale scores with a theoretical range of 1 to 4, with higher scores indicating less optimal functioning.

The Communication subscale (9 items) reflects the extent to which family members exchange information directly, including information about how they are feeling. The Problem Solving subscale (6 items) gives insight in to how the family solves problems, and makes and acts on decisions. The Roles subscale (11 items) assesses whether family members have clear duties and responsibilities, and whether individuals carry out family tasks as expected. The Affective Responsiveness subscale (6 items) assesses the way family members express and respond to emotional information, such as showing tenderness and affection to one another. Affective Involvement (7 items) is about whether family members value and invest in one another’s interests, and also contains items relating to family members being overly involved or enmeshed. The Behaviour Control subscale (9 items) is about whether the family have clear expectations and rules in the household, rather than an “anything
goes” attitude (Epstein et al., 1983, p. 174). The FAD-GF scale (12 items) correlates highly with all other subscales and is intended as an overall estimate of family functioning (Miller et al., 2000).

The FAD was normed by using a non-clinical sample of 627 American families, and this data included responses from men (43% of sample), women (45% of sample), and children (12% of sample; Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). The authors provided cut-off values for each subscale demarcating healthy/unhealthy family functioning (Miller, et al., 1985). The original cut-off values were recently re-evaluated, confirming their accuracy in distinguishing families seeking therapy from families in a community sample (Mansfield et al., 2014). The subscales have also been reported to have good internal consistency, with Cronbach’s Alphas ranging from .72 to .92 (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). The FAD subscale cutoff scores as reported by the authors, and Cronbach’s Alphas for each subscale in the current study, were as follows: Communication (2.2, α = .76); Problem Solving (2.2, α = .82); Roles (2.3, α = .47); Affective Responsiveness (2.2, α = .82); Affective Involvement (2.1, α = .84); Behaviour Control (1.9, α = .67); and General Functioning scale (2.0, α = .89).

Qualitative Interview Measures

**Semi-structured interview.** A semi-structured interview was administered in two parts. These included the Home Observation for the Measurement of the Environment (HOME) Inventory (Caldwell & Bradley, 2003) as well as four broader questions designed for the purpose of this study:

1. Are there some ways you feel your family environment is different to other families because of having a child with ASD?
2. Are there things you do with your child that you think would be classified as treatment or intervention?
3. What resources do you access to learn about parenting your child?
4. Can you tell me about some aspects of your parenting and family life that may have been altered to accommodate for your child’s needs?

These questions were developed through collaboration with the research supervisors. The questions were piloted on families of TD children, along with the entire study
procedure. The questions were not piloted on a family raising a preschooler with an ASD, as when these parents volunteered to be involved in the study, they were included as participants. The piloting process enabled the wording of the questions to be refined to ensure the questions were easy to understand, and generated information relevant to the study aims.

**HOME Inventory (Caldwell & Bradley, 2003).** The HOME Inventory is an interview protocol designed to establish insight into a child’s daily life and the quality of stimulation provided in their home environment (Caldwell & Bradley, 2003). This inventory generates detailed information about daily routines, provision of learning opportunities in the home, teaching methods, and behaviour management strategies. The HOME Inventory was designed by Caldwell in 1968 and is one of the most commonly used measures of the home environment (Totsika & Sylva, 2004). This tool has been described as a more adequate and valid measure of a child’s home environment than measures of socio-economic status or parental education levels (Bradley, 1993). The HOME inventory is administered in conversational style. The script that was used to guide the interviews and score the items is shown in Appendix F.

The Disability Adapted Early Childhood version of the HOME Inventory was used in the current study. This version was designed for use with families of children (aged 3-6 years) with a developmental disability. Modifications include the addition of items relating to the family’s engagement with intervention services, as well as questions about the parents’ efforts to help the child with communication, self-care, and social skills (Caldwell & Bradley, 2003). The availability of more specialised toys in the home is also included in the Disability Adapted HOME Inventory. This measure was normed using a small sample (N=67) of children with developmental delays (Caldwell & Bradley, 2003).

Throughout the HOME Inventory administration, 64 items are given binary ratings (plus or minus). Items are scored based on interview responses, observations, and in some cases, by either interview or observation. Items marked with a plus are summed which produces a total score, and subscale scores for learning materials (13 items), language stimulation (9 items), physical environment (7 items), responsivity (8 items), academic stimulation (6 items), modelling (7 items), variety (10 items), and acceptance (4 items). Cronbach’s alpha for the total scale score was good in the current
sample ($\alpha = .79$). However, in the current study, the subscales showed poor internal consistency with five subscales (learning materials, responsiveness, modelling, variety, acceptance) rating below .40. Three subscales showed moderate reliability (language stimulation, $\alpha = .47$; physical environment, $\alpha = .58$; academic stimulation, $\alpha = .58$). Average inter-rater agreement between the researcher and research assistant was greater than 90% for each home visit. Where items were rated differently, consensus was reached through discussions after the home visit, and where required, reviewing the audio recording for clarification and confirmation of the scoring. In the current study, parents’ responses to the HOME Inventory (Bradley & Caldwell, 2003) were transcribed and used as part of the qualitative investigation of the home learning environment.

**Procedure**

Prior to the commencement of data collection, this study was approved by Swinburne University of Technology’s Human Research Ethics Committee, Melbourne Australia (see Appendix G). Participant recruitment involved contacting any parents who had expressed interest in participating in this phase of the study through the Study 1 online questionnaire. This procedure recruited just one family, and so parent support groups, as well as ASD specific organisations and services in Victoria, Australia were contacted to help advertise the study. Some groups assisted in advertising the study by emailing group members, or including an advertisement in their newsletter or waiting room (see Appendix H for a copy of this advertisement). Interested parents were invited to contact the researcher via email or phone. These parents were sent a plain language statement (Appendix I) and consent form (Appendix J) to assist them in deciding whether or not to participate in the study. Email and phone correspondence were used to arrange the home visits and these were conducted between July 2011 and October 2013 at a time convenient to the participant. During home visits, children’s diagnostic assessment reports were viewed to support the child’s diagnosis of an ASD.

Prior to conducting the home visits, the researcher received training in administering the PEP-3 (Schopler et al., 2005). This involved attending three training sessions with a clinician experienced in administering this assessment. This clinician observed the researcher administering the PEP-3 to a TD child, as well as the child who participated in the first home visit, to ensure that it was being administered in line with
the standardised protocol. HOME Inventory (Bradley & Caldwell, 2003) training involved reviewing a training video produced by the University of Wisconsin (2006). The video included a number of case examples, so that the researcher was able to score the measure in a way that was consistent with the training materials provided. The entire home visit procedure was piloted on a family of a TD preschooler known to the researcher to estimate the time the visits took to complete, and to identify any difficulties prior to meeting the first participant.

Home visits involved interviewing parents and observing their interactions with the focus child following the HOME Inventory (Bradley & Caldwell, 2003) protocol. Parents were also asked open-ended questions about aspects of their parenting and family environment that might be unique to families of children with ASDs. Parents also completed a self-report questionnaire and the Vineland-II (Sparrow et al., 2005), although in some cases, parents completed the questionnaires after the visit and returned them via reply-paid envelope. One participant did not return the Vineland-II questionnaire and so the responses for this measure were only available for 20 of the focus children. The focus child was administered the PEP-3 (Schopler et al., 2005) to give a clinician-rated indication of their current cognitive development and skills.

The researcher attended each home visit with a second student who was working towards an Honours degree in psychology. The role of the second student was to provide general assistance with completing the visits in a timely manner, and to independently rate the HOME Inventory items during the interview so the final results could be cross validated. The second student did not attend three of the home visits due to illness. These families were contacted prior to the visit and informed the process would take longer for this reason, and offered an alternative time, which they declined. On average, visits took 2.5 hours, and each family was provided with a summary report of their child’s PEP-3 and Vineland-II scores, which was overseen by the research supervisor who is an experienced clinical psychologist.

**Data Analysis Procedure**

**Quantitative data analysis.** The questionnaire data were used to characterise the sample by describing children, parents, and families. Means, standard deviations, and ranges for each measure were generated in SPSS-22 (IBM Corp, 2013) for mothers and fathers separately, and for the total sample. Participants’ scores were then
compared to available norms from adults and children in the general population using $t$-tests.

**Qualitative data analysis.** Interview data were analysed using an inductive approach, following recommendations from Braun and Clarke (2006) and Creswell (2013). A 7-step process was used in the analysis, as summarised in Figure 5 below.

![Figure 5. Summary of qualitative data analysis process](image-url)
As shown in Figure 5, to begin the analysis, interview data were transcribed verbatim and checked against the audio recordings; all transcripts were de-identified. The transcripts were read multiple times so that the researcher was familiar with the overall content. Important statements were highlighted within each interview and were then coded into meaning units. The codes were then grouped to form clusters (themes) judged to reflect the overall meaning participants ascribed to their experiences of parenting and family life with a preschooler with ASD (reconstructing the data). The themes were made up of subthemes, which described some of the different ideas captured by the main concept. As shown in Figure 5, the process of coding the data was cyclical meaning the themes were refined and revised during these steps, and with the assistance of a peer review process.

To improve the rigor of the qualitative data analysis process, peer review was conducted throughout the data collection and analysis phases (Creswell, 2013). Following each interview, the researcher and assistant discussed their observations and salient ideas that had emerged from the home visits. These were recorded and reflected on as additional sources of information during the analysis phase. The project supervisors assisted with forming and reviewing the data coding process. Two team members worked collaboratively with the coded data to reach consensus on the final themes. This involved reviewing the meaning codes, discussing counter-examples within these categories, and reaching agreement on the boundaries between different themes.

Consistent with the recommendation by Creswell (2013), a selection (20%) of the key statements were cross-coded by an independent researcher who was deemed suitably qualified based on her experience and knowledge about the mental health of parents who have children with disabilities (BA (Hons), PhD Candidate). This cross-validation procedure has been used in other qualitative studies investigating the experiences of parents (e.g., Grindle et al., 2009). This cross-validation process resulted in an agreement rate of 84%, suggesting that although the final themes captured the data well, there was some overlap across themes. This was followed by a discussion about whether the independent researcher could verify that the themes accurately captured the experiences shown in the data, and refinement of the final theme descriptions. Data
statements that diverged from these themes were also discussed and were interpreted as indications of the diversity within the 21 families (Creswell, 2013).

In addition to peer review, the analysis procedure was thoroughly documented. The participants and themes were described in detail for transparency, and to provide enough information for others to decide whether or not the themes faithfully represented the experiences of participants. Identification of researcher bias was another validation strategy that involved self-reflection to identify preconceived ideas the researcher may have had about the topic based on their experiences (Creswell, 2013).

Through the process of evaluating responses of multiple informants and selecting themes through qualitative analysis, the researcher inevitably plays an active role in the way in which the participants’ experience is constructed. Therefore, prior to conducting the qualitative data analysis, the researcher identified some key assumptions held about the family environment in this group, and reflected on personal experiences relating to this topic. The researcher attempted to be cognisant of the potential impact of these assumptions on the interviews and data analysis, and approached the task with the goal of being open-minded and guided by the experiences of participants.

Results

Quantitative Results

Descriptive statistics for the DBC-P24 (Taffe et al., 2007), FAD (Epstein et al., 1983), DASS-21 depression and stress scales (Lovibond & Lovibond, 1995), a-FAS (Giallo et al., 2014; Michielsen et al., 2003), and LSAC warmth, hostility and involvement scales (Sanson et al., 2002) are displayed in Table 9. Data are displayed for mothers, fathers, and the total sample.
Table 9

Means, Standard Deviations and Ranges for Questionnaire Measures

<table>
<thead>
<tr>
<th>Measures</th>
<th>Mothers (n=21)</th>
<th>Fathers (n=10)</th>
<th>Total Sample (N=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>Range</td>
<td>M(SD)</td>
</tr>
<tr>
<td>Child Behaviour Problems</td>
<td>.74 (.30)</td>
<td>.33 – 1.38</td>
<td>.72 (.30)</td>
</tr>
<tr>
<td>FAD - Communication</td>
<td>1.87 (.42)</td>
<td>1.00 – 3.00</td>
<td>2.18 (.25)</td>
</tr>
<tr>
<td>FAD - Problem Solving</td>
<td>1.77 (.51)</td>
<td>1.00 – 3.33</td>
<td>2.01 (.35)</td>
</tr>
<tr>
<td>FAD - Affective Involvement</td>
<td>1.84 (.48)</td>
<td>1.00 – 2.71</td>
<td>2.16 (.43)</td>
</tr>
<tr>
<td>FAD - Affective Responsiveness</td>
<td>1.76 (.48)</td>
<td>1.00 – 2.67</td>
<td>2.30 (.55)</td>
</tr>
<tr>
<td>FAD - Roles</td>
<td>2.20 (.27)</td>
<td>1.55 – 2.82</td>
<td>2.25 (.28)</td>
</tr>
<tr>
<td>FAD - Behaviour Control</td>
<td>1.61 (.33)</td>
<td>1.11 – 2.11</td>
<td>1.86 (.28)</td>
</tr>
<tr>
<td>FAD - General Functioning</td>
<td>1.69 (.44)</td>
<td>1.00 – 2.50</td>
<td>1.98 (.37)</td>
</tr>
<tr>
<td>Depression</td>
<td>5.00 (6.61)</td>
<td>0 – 26</td>
<td>12 (6.67)</td>
</tr>
<tr>
<td>Stress</td>
<td>14.28 (9.53)</td>
<td>2 – 36</td>
<td>7.80 (8.13)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>13.90 (4.78)</td>
<td>8 – 23</td>
<td>13.2 (3.61)</td>
</tr>
<tr>
<td>Warmth</td>
<td>4.53 (.39)</td>
<td>3.67 – 5.00</td>
<td>4.05 (.42)</td>
</tr>
<tr>
<td>Involvement</td>
<td>3.00 (.65)</td>
<td>1.40 – 3.80</td>
<td>2.36 (.56)</td>
</tr>
<tr>
<td>Hostility</td>
<td>2.58 (.62)</td>
<td>1.20 – 3.60</td>
<td>2.60 (.81)</td>
</tr>
</tbody>
</table>

Note. M = Mean. SD = Standard Deviation. FAD = Family Assessment Device
Describing the focus children relative to norms. On average, the children in the current study scored above the clinical cut-off for the DBC-P24 (0.48; Taffe et al., 2007) based on both mother and father report. Seventeen mothers and eight fathers rated their child’s behaviour problems in the clinically significant range, which equated to 18 of the focus children being rated as having clinically significant behaviour problems by at least one parent. A t-test indicated parents in the current study rated their children’s behavior problems significantly higher than children in the DBC normative sample ($t(558) = 4.809, p < .001, d=1.04$) which included older children with intellectual disabilities. The adaptive functioning and developmental skills of the focus children are summarised in Table 10 below. Percentile ranks are displayed for ease of interpretation of the children’s average functioning relative to age matched peers from a community sample (Vineland-II; Sparrow et al., 2005), and age matched peers from a clinical sample of children with ASDs (PEP-3; Schopler et al., 2005).

Table 10

<table>
<thead>
<tr>
<th>Measure</th>
<th>Percentile M (SD)</th>
<th>Percentile Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vineland-IIa</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>21.57 (21.43)</td>
<td>.10 - 66</td>
<td>Adequate</td>
</tr>
<tr>
<td>Daily Living Skills</td>
<td>27.80 (33.98)</td>
<td>1 - 96</td>
<td>Adequate</td>
</tr>
<tr>
<td>Socialisation</td>
<td>15.28 (18.36)</td>
<td>.20 - 58</td>
<td>Moderately Low</td>
</tr>
<tr>
<td>Motor Skills</td>
<td>33.10 (31.81)</td>
<td>1 - 95</td>
<td>Adequate</td>
</tr>
<tr>
<td>TABC</td>
<td>21.60 (27.49)</td>
<td>.20 - 79</td>
<td>Adequate</td>
</tr>
<tr>
<td>PEP-3b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Verbal/Preverbal</td>
<td>72.29 (24.80)</td>
<td>6 - 99</td>
<td>Moderate</td>
</tr>
<tr>
<td>Expressive Language</td>
<td>76.19 (25.43)</td>
<td>6 - 99</td>
<td>Mild</td>
</tr>
<tr>
<td>Receptive Language</td>
<td>75.86 (28.25)</td>
<td>3 - 98</td>
<td>Mild</td>
</tr>
<tr>
<td>Visual-Motor Imitation</td>
<td>77.24 (27.32)</td>
<td>3 - 99</td>
<td>Mild</td>
</tr>
<tr>
<td>Gross Motor</td>
<td>73.29 (26.80)</td>
<td>7 - 94</td>
<td>Moderate</td>
</tr>
<tr>
<td>Fine Motor</td>
<td>75.43 (24.62)</td>
<td>8 - 99</td>
<td>Mild</td>
</tr>
</tbody>
</table>

As shown in Table 10, the children in the current study showed a broad range of skills and abilities based on the Vineland-II (Sparrow et al., 2005) and PEP-3 (Schopler et al., 2005). To give a clearer indication of the spread of scores for the Vineland-II, the children’s total adaptive behavior composites were rated as adequate \((n=6)\), moderately low \((n=11)\), or low \((n=3)\). The children’s communication abilities were ranked as adequate \((n=9)\), moderately low \((n=7)\), and low \((n=4)\). Daily Living Skills were described as high \((n=4)\), adequate \((n=5)\), moderately low \((n=9)\) and low \((n=2)\). Socialisation domain scores ranged from adequate \((n=6)\), moderately low \((n=9)\), to low \((n=5)\). The children’s motor skills were moderately high \((n=2)\), adequate \((n=9)\), moderately low \((n=7)\), and low \((n=2)\).

Unlike the Vineland-II (Sparrow et al., 2005), scores on the PEP-3 (Schopler et al., 2005) are compared to other children diagnosed with an ASD who formed the normative sample. Relative to other children with ASDs the focus children had verbal skills ranging from adequate \((n=5)\), mild \((n=9)\), moderate \((n=6)\), to severe \((n=1)\). Their expressive language was adequate \((n=8)\), mild \((n=8)\), moderate \((n=3)\), or severe \((n=2)\). Their receptive language was adequate \((n=11)\), mild \((n=5)\), moderate \((n=3)\), or severe \((n=2)\). Their visual motor imitation scores were adequate \((n=8)\), mild \((n=6)\), moderate \((n=5)\), or severe \((n=2)\). Their gross motor skills were adequate \((n=10)\), mild \((n=5)\), moderate \((n=4)\), or severe \((n=2)\) and fine motor skills were adequate \((n=7)\), mild \((n=6)\), moderate \((n=6)\), or severe \((n=2)\).

**Describing parental wellbeing and parenting warmth relative to norms.**

Mothers’ and fathers’ self-reported symptoms of depression and stress were compared to normative data for women and men in the general population. The normative sample for the DASS-21 (Lovibond & Lovibond, 1995) comprised 2914 Australian adults, including 1044 men and 1870 women aged between 17 and 69 years. Participants’ fatigue scores were compared to a large community sample of Australian parents (1122 mothers, 154 fathers) with children under 6 years old (Cooklin et al., 2011). Warmth scores were compared to Australian parents (3800 mothers, 2766 fathers) of children aged 4 to 5 years. The comparisons are summarised in Table 11 for mothers and fathers.
Table 11

*Descriptive Statistics and Comparisons to Normative Data for Mothers’ and Fathers’ Wellbeing and Parenting Warmth*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Parents (N=31)</th>
<th>Normative Sample</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>Range</td>
<td>M(SD)</td>
</tr>
<tr>
<td>Mothers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>5.00 (6.61)</td>
<td>0 - 26</td>
<td>6.14 (6.92)</td>
</tr>
<tr>
<td>Stress</td>
<td>14.28 (9.93)</td>
<td>2 - 36</td>
<td>10.29 (8.16)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>13.90 (4.78)</td>
<td>8 - 23</td>
<td>14.20 (4.0)</td>
</tr>
<tr>
<td>Warmth</td>
<td>4.53 (.09)</td>
<td>3.7 - 5</td>
<td>4.51 (.01)</td>
</tr>
<tr>
<td>Fathers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>12.00 (6.67)</td>
<td>0 - 20</td>
<td>6.55(7.01)</td>
</tr>
<tr>
<td>Stress</td>
<td>7.80 (8.13)</td>
<td>2 - 28</td>
<td>9.93(7.66)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>13.20 (3.61)</td>
<td>6 - 18</td>
<td>12.30 (3.9)</td>
</tr>
<tr>
<td>Warmth</td>
<td>4.05 (.13)</td>
<td>3.3 - 4.7</td>
<td>4.23 (.01)</td>
</tr>
</tbody>
</table>

*Note.*  M = Mean.  SD = Standard Deviation.

*Number in brackets is standard error for warmth scales.

**Mothers.** The majority of mothers in the current study (n=18) reported depressive symptoms within the normal range of the DASS-21 (Lovibond & Lovibond, 1995). Levels of depressive symptoms for the remaining mothers were classified as mild (n=1), moderate (n=1), or severe (n=1). On average, the mothers in this sample reported similar levels of depression to Australian adult women. The mothers in the current study rated their stress as normal (n=13), mild (n=1), moderate (n=5), severe (n=1), or extremely severe (n=1). As shown in Table 11, an unpaired t-test comparing these mothers to women in the normative sample suggested mothers in the current study were experiencing significantly higher levels of stress. The mothers in the current study reported similar levels of fatigue, and warmth, to mothers in the community sample.

**Fathers.** Fathers in the current study reported depressive symptom scores classified as normal (n=2), mild (n=4), or moderate (n=4). As shown in Table 11, these fathers reported significantly higher levels of depressive symptoms than men in the normative sample. Fathers’ stress scores were scored as normal (n=2), mild (n=3), moderate (n=4), or severe (n=1) and were not significantly different from normative
data from Australian men. Fathers in the current study reported similar levels of fatigue, and warmth, to fathers in the community samples.

**Describing the family environment relative to norms.** Mean scores for the FAD subscales were generated for both mothers and fathers, and are displayed in Table 12. The HOME Inventory data were available for the mothers only, as during all home visits, the mother was the primary interviewee. Comparisons to published norms for these measures are also shown in Table 12.
### Table 12

**Means, Standard Deviations, Ranges and Normative Comparisons for Measures of Family Functioning and the Home Environment**

<table>
<thead>
<tr>
<th>Measures</th>
<th>Mothers ((n=21))</th>
<th>Fathers ((n=10))</th>
<th>Norm. (N=627)</th>
<th>(t)-test Mothers</th>
<th>(t)-test Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(M(SD))</td>
<td>Range</td>
<td>(M(SD))</td>
<td>Range</td>
<td>(M(SD))</td>
</tr>
<tr>
<td><strong>FAD</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>1.87 (.42)</td>
<td>1.00 – 3.00</td>
<td>2.18 (.25)</td>
<td>1.67 – 2.56</td>
<td>2.09 (.40)</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>1.77 (.51)</td>
<td>1.00 – 3.33</td>
<td>2.01 (.35)</td>
<td>1.50 – 2.67</td>
<td>1.91 (.40)</td>
</tr>
<tr>
<td>Affective Involvement</td>
<td>1.84 (.48)</td>
<td>1.00 – 2.71</td>
<td>2.16 (.43)</td>
<td>1.57 – 2.86</td>
<td>2.00 (.50)</td>
</tr>
<tr>
<td>Affective Responsiveness</td>
<td>1.76 (.48)</td>
<td>1.00 – 2.67</td>
<td>2.30 (.55)</td>
<td>1.17 – 3.17</td>
<td>2.08 (.53)</td>
</tr>
<tr>
<td>Roles</td>
<td>2.20(.27)</td>
<td>1.55 – 2.82</td>
<td>2.25 (.28)</td>
<td>1.82 – 2.55</td>
<td>2.16 (.34)</td>
</tr>
<tr>
<td>Behaviour Control</td>
<td>1.61 (.33)</td>
<td>1.11 – 2.11</td>
<td>1.86 (.28)</td>
<td>1.33 – 2.25</td>
<td>1.94 (.44)</td>
</tr>
<tr>
<td>General Functioning</td>
<td>1.69 (.44)</td>
<td>1.00 – 2.50</td>
<td>1.98 (.37)</td>
<td>1.33 – 2.58</td>
<td>1.84 (.43)</td>
</tr>
<tr>
<td><strong>HOME Inventory</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning Materials</td>
<td>10.48 (1.36)</td>
<td>7 – 12</td>
<td>-</td>
<td>-</td>
<td>6.1 (3.8)</td>
</tr>
<tr>
<td>Language Stimulation</td>
<td>8.57 (.81)</td>
<td>6 – 9</td>
<td>-</td>
<td>-</td>
<td>5.7 (2.2)</td>
</tr>
<tr>
<td>Physical Environment</td>
<td>6.90 (.44)</td>
<td>5 – 7</td>
<td>-</td>
<td>-</td>
<td>5.6 (1.9)</td>
</tr>
<tr>
<td>Responsivity</td>
<td>7.52 (.68)</td>
<td>6 – 8</td>
<td>-</td>
<td>-</td>
<td>5.1 (2.3)</td>
</tr>
<tr>
<td>Academic Stimulation</td>
<td>5.67 (.80)</td>
<td>3 – 6</td>
<td>-</td>
<td>-</td>
<td>3.0 (2.2)</td>
</tr>
<tr>
<td>Modeling</td>
<td>6.48 (.68)</td>
<td>5 – 7</td>
<td>-</td>
<td>-</td>
<td>5.6 (1.7)</td>
</tr>
<tr>
<td>Variety</td>
<td>7.81 (1.29)</td>
<td>4 – 10</td>
<td>-</td>
<td>-</td>
<td>5.7 (2.3)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>3.90 (.30)</td>
<td>3 – 4</td>
<td>-</td>
<td>-</td>
<td>3.3 (1.4)</td>
</tr>
<tr>
<td>Total Score</td>
<td>57.33 (4.42)</td>
<td>42 – 63</td>
<td>-</td>
<td>-</td>
<td>40.3 (13.3)</td>
</tr>
</tbody>
</table>

*Note:* M = Mean. SD = Standard Deviation. FAD = Family Assessment Device; HOME = Home Observation for the Measurement of the Environment. FAD Normative Sample \(N=627\); HOME Normative Sample \(N = 67\)
As shown in Table 12, mothers’ mean scores for each subscale of the FAD (Epstein et al., 1983) were in the healthy range based on the published cut-off scores. Fathers’ mean scores were in the healthy range for all subscales except for affective responsiveness and affective involvement, which were above the clinical cut-off, but not significantly different to normative data. Mothers in the current sample reported significantly lower scores (reflecting better functioning) on the communication, affective responsiveness, and behavior control subscales compared to normative data (Cohen’s $d = 0.55, 0.61,$ and $0.76$ respectively). They also scored significantly higher than normative data for the HOME Inventory (Bradley & Caldwell, 2003) total score ($d=1.44$) and all subscales aside from the acceptance subscale, which approached significance. Effect sizes for the HOME Inventory normative comparisons were very large for the language stimulation ($d=1.46$) and academic stimulation ($d=1.36$) subscales. Effect sizes were large for the learning materials ($d=1.29$), responsivity ($d=1.19$), and variety ($d=1.00$) subscales; and medium for the physical environment ($d=0.78$) and modeling ($d=0.58$) subscales.

**Qualitative Results**

Results from the thematic analysis are presented below. Participants were assigned pseudonyms to preserve their anonymity. Where a focus child’s name was part of a participant quote [Child] is presented in place of their name. Where the focus child’s father is mentioned by name it has been replaced with [Dad]. Some participant statements used in this chapter have been edited as indicated by an ellipsis […] to improve readability and conciseness. The quotations from parents were not edited for grammar to preserve their authenticity. Information about individual participants and their focus child is shown in Table 13.
Table 13

Summary of Participant Age, Focus Child Age, and Time Since Diagnosis

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Child Age</th>
<th>Time since ASD diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karla</td>
<td>28</td>
<td>4 years 4 months</td>
<td>1 year, 4 months</td>
</tr>
<tr>
<td>Ava</td>
<td>42</td>
<td>4 years, 11 months</td>
<td>1 year, 7 months</td>
</tr>
<tr>
<td>Toni</td>
<td>31</td>
<td>4 years, 9 months</td>
<td>3 years, 3 months</td>
</tr>
<tr>
<td>Grace</td>
<td>33</td>
<td>3 years, 6 months</td>
<td>4 months</td>
</tr>
<tr>
<td>Lucy</td>
<td>35</td>
<td>5 years, 6 months</td>
<td>1 year, 9 months</td>
</tr>
<tr>
<td>Linda(^a)</td>
<td>41</td>
<td>2 years, 9 months</td>
<td>1 year, 2 months</td>
</tr>
<tr>
<td>Steven(^a)</td>
<td>46</td>
<td>2 years, 9 months</td>
<td>1 year, 2 months</td>
</tr>
<tr>
<td>Michelle</td>
<td>42</td>
<td>4 years, 10 months</td>
<td>1 month</td>
</tr>
<tr>
<td>Ashlea</td>
<td>30</td>
<td>3 years, 3 months</td>
<td>1 year, 5 months</td>
</tr>
<tr>
<td>Ingrid</td>
<td>41</td>
<td>3 years, 5 months</td>
<td>3 months</td>
</tr>
<tr>
<td>Alysha(^a)</td>
<td>42</td>
<td>4 years, 11 months</td>
<td>1 year</td>
</tr>
<tr>
<td>Adam(^a)</td>
<td>34</td>
<td>4 years, 11 months</td>
<td>1 year</td>
</tr>
<tr>
<td>Emily</td>
<td>33</td>
<td>5 years, 1 month</td>
<td>2 years, 3 months</td>
</tr>
<tr>
<td>Meryl</td>
<td>45</td>
<td>6 years, 0 months</td>
<td>2 years, 7 months</td>
</tr>
<tr>
<td>Kate</td>
<td>37</td>
<td>3 years, 1 month</td>
<td>5 months</td>
</tr>
<tr>
<td>Jasmine</td>
<td>36</td>
<td>4 years, 9 months</td>
<td>4 months</td>
</tr>
<tr>
<td>Elinor</td>
<td>35</td>
<td>5 years, 9 months</td>
<td>1 year, 9 months</td>
</tr>
<tr>
<td>Cora</td>
<td>32</td>
<td>3 years, 9 months</td>
<td>4 months</td>
</tr>
<tr>
<td>Charlotte</td>
<td>44</td>
<td>5 years, 0 months</td>
<td>1 year, 9 months</td>
</tr>
<tr>
<td>Megan</td>
<td>37</td>
<td>3 years, 0 months</td>
<td>2 months</td>
</tr>
<tr>
<td>Helen</td>
<td>39</td>
<td>3 years, 6 months</td>
<td>3 months</td>
</tr>
<tr>
<td>Amy</td>
<td>43</td>
<td>5 years, 1 month</td>
<td>5 months</td>
</tr>
<tr>
<td>Jackie</td>
<td>30</td>
<td>4 years, 5 months</td>
<td>2 months</td>
</tr>
</tbody>
</table>

\(^a\)Parents are a couple

As shown in Table 13, there were two couples included in the interview data. All transcripts were drawn from to provide illustrative quotes. The HOME Inventory (and interview procedure) began with an open question asking parents to describe a typical day with their child. One parent (Toni) joked: “I don’t really have typical days
with [Child]” and Jasmine explained: “well because we do kinder, there is no real typical day I suppose”. Jackie mentioned that depending on the child’s characteristics, “you never know what kind of day you’re going to get”. The majority of parents described an extensive therapy schedule where they were travelling to appointments throughout the week, often alongside their child’s participation at kinder or child-care services.

When the children were at home, parents were often working closely with them to encourage skill attainment or development, to help their child learn and grow. Parents were implementing strategies and techniques to help their child stay calm and to manage behaviour problems and prevent meltdowns. They gave examples of reflexively responding to their child’s capability on any given day, as well as strategies they used to adapt to raising a child with an ASD. For example, Alysha explained she was using “lots of repetition, lots of speech intervention, and lots of modelling”. When working with her son, Jackie would “try and follow whatever the interest is at the time. If he wants to learn about it, we’ll learn about it” and Toni noticed she and her husband “needed to change the way that we spoke to him [...] explaining things more, giving him more of a choice with everything to make him speak”. Each morning, Ashlea would follow her son’s lead in play, explaining: “Whatever he decides to play with I’ll go and try to join in, try to get his attention, get him asking for help”.

Throughout the interviews, information was gained regarding the changes families made to accommodate the needs of a child with an ASD, and the lengths parents went to, often at personal sacrifice, to “make it [therapy] part of your everyday life” (Elinor). These experiences were reduced to four themes as shown in Table 14. This table summarises the names given to the theme, the interpretation of the meaning ascribed to the experience, and the number of key statement(s) that aligned with each theme.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowing the child (N=158)</strong></td>
<td>The parent described their child, most frequently in terms of his/her abilities, skills, and interests. Parents also gave examples of their child’s challenging behaviour and difficulties, which were sometimes related to their sensory profile.</td>
</tr>
<tr>
<td>- Abilities</td>
<td></td>
</tr>
<tr>
<td>- Behaviour problems</td>
<td></td>
</tr>
<tr>
<td><strong>Therapy in daily life (N=482)</strong></td>
<td>Parents explained how their parenting approach had changed to accommodate their child’s needs. Part of this involved becoming experts in ASD through their own learning and research. Parents described a variety of learning strategies and interventions that were used at home. This also included comments parents made about their role as a therapist, and some of the challenges they faced in this role.</td>
</tr>
<tr>
<td>- Home learning</td>
<td></td>
</tr>
<tr>
<td>- Parenting approach</td>
<td></td>
</tr>
<tr>
<td>- Self-education</td>
<td></td>
</tr>
<tr>
<td>- Challenges</td>
<td></td>
</tr>
<tr>
<td><strong>Emotional impact on parents (N=164)</strong></td>
<td>Parents described some ways in which raising a child with an ASD impacted on their wellbeing. This included factors that may have been associated with parents’ emotions and coping, forming the subthemes social support and self-care.</td>
</tr>
<tr>
<td>- Emotional Impact</td>
<td></td>
</tr>
<tr>
<td>- Social Support</td>
<td></td>
</tr>
<tr>
<td>- Self-care</td>
<td></td>
</tr>
<tr>
<td><strong>ASD as a family priority (N=139)</strong></td>
<td>This theme included statements about the impact raising a preschooler with ASD had on family life. Parents described family routines, and having a busy therapy schedule. Parents also described some of the adjustments the family had made to accommodate a child with ASD (e.g., financial, family holidays, activities, relationships).</td>
</tr>
<tr>
<td>- The therapy schedule</td>
<td></td>
</tr>
<tr>
<td>- Family activities and relationships</td>
<td></td>
</tr>
</tbody>
</table>

*Note. Numbers in brackets show the number of key statements forming each theme*
The themes shown in Table 14 reflect multiple aspects of the family experience of raising a preschooler with an ASD, from descriptions of the children, adjustments made by parents, and broader implications for parental wellbeing and family life. The four themes are described in detail with illustrative quotes below.

**Theme 1: Knowing the Child: “I know what makes him tick” (Emily).** This theme was developed from key statements where parents described characteristics of their child with an ASD. Throughout the process of asking parents about their parenting and family life, numerous descriptions and examples of the child’s qualities and abilities were offered by the parents. Despite the content of the theme initially seeming to reflect characteristics of the children, the essence of the theme is about the knowledge parents have of their child’s development and behaviour across multiple domains. This essence is captured in the words of Emily who stated:

\[\text{Whilst it is exhausting, it’s also allowed me to know him better. Like I know [Child] so well, I know what makes him tick, you know, and I don’t think that would necessarily have been the case if we, if I, didn’t spend so much time working with him.}\]

By attending appointments, working with their children, and building their knowledge base about ASDs (as described later in this chapter) parents were able to monitor and describe their child’s development using specific phrases such as “parallel play”, “bad sensory day”, or distinguishing between “tantrums” and “meltdowns”. In summary, *Knowing the Child* captured the knowledge and expertise of parents regarding their child’s qualities, abilities, and preferences. This theme included two subthemes, relating to parents’ descriptions of their child’s abilities or behaviour problems.

**Abilities.** Through working with their children, parents had a good understanding of their current skills and abilities, and Emily in particular believed she knew her child better than she would have had he been TD. Parents explained in detail the skills their children had attained, and how those skills may have developed over time. Parents often expressed pleasure or amazement at these abilities, and took the opportunity to reflect on the progress their child had made. Kate had noticed her son’s social skills had improved at playgroup, stating:
I’ve noticed lately there’s more communication happening now with the children, especially with mine, and he’s trying to communicate with the other little kids. For a long time he was just playing, and he still plays a lot of parallel play, but now they’re actually trying to engage each other.

It was clear through the interviews that the parents had been monitoring and responding to their child’s current level of progress across a range of educational and developmental domains. Some of the parents reported being surprised by very advanced abilities shown by their child, and were often bewildered about how their child had learned particular numeracy and literacy skills. Ingrid used the term “splinter skill” to describe her son’s maths abilities:

It’s one of these things he’s just been interested in, it’s just, at intervention they call it a splinter skill. That he’s just almost obsessed by them, just counting, he already recognises big numbers now, he’ll see a hundred and sixty he’ll tell you it’s a hundred and sixty, which is really advanced for a 3 year old.

Parents also praised their children’s abilities in other areas. Some of these areas included their child’s ability to get dressed, follow routines, recite times tables, speak, or read short sentences. Parents also pointed out examples of their children being gentle or thoughtful when interacting with their siblings or other children. These parents described the child’s abilities across multiple domains including their social skills and communication.

**Behaviour problems.** In addition to discussing the strengths of their son or daughter, the parents in the study made comments about behaviour problems and other difficulties they were experiencing with their child. Parents were managing behaviours such as whining or screaming, destroying books and toys, over-familiarity with strangers, hyperactivity, as well as the child showing inflexibly by needing to follow their own agenda. Some parents described extreme and violent behaviour like kicking, biting or scratching, however, across the sample such violent behaviour was uncommon.

We had to actually stop speech therapy because he was getting very frustrated in the session and just basically attacking me pulling my hair, biting, kicking,
and that’s really hard to try to contain him in that, and in the end I just thought it wasn’t worth it (Charlotte).

We’d go up to console him and he’d start biting, hitting, head butting, and he’s a really big boy out of control so we’d try and give him a cuddle and calm him down and he’s thrashing and going like that and [Dad’s] had several black eyes and I’ve had several bite marks up my arms and scratches on my face and stuff like that. It was really difficult at that time (Cora).

Charlotte’s example suggests behaviour problems were a barrier to her child’s therapy, and Cora was unable to attend appointments with her child without her partner being present to help manage behaviours. In less extreme cases, the parents explained that they had not realised their child’s behaviour was particularly difficult or unusual. This may have been due to the fact that many of the focus children in this study were first-born meaning parents did not have an older child as a basis for comparison. For one mother, it took an outside perspective for her to understand the magnitude of behaviour problems that she was dealing with:

My Mum was over one day and he was having a meltdown and he was unwell I think, and I was thinking about keeping him home from day-care the next day; and I said to Mum; “oh do you think you’d be able to look after him tomorrow?” She said; “if he’s like this, no”. She was like “I wouldn’t know what to do”. I thought, oh, OK, well they are severe then, because to me it’s just him and it’s what we’re used to (Emily).

When describing children’s behaviour problems, some parents had an explanation or interpretation of the behaviour, or could describe a strategy that helped manage or prevent the behaviour problem. For some parents, the behaviour problems seemed to have been worse at an earlier stage, and had improved over time.

Usually a tantrum is because they can’t express what they want or they can’t get what they need, so it’s, we seem to be getting a lot less of them (Kate).

If he’s upset because he’s in a place that’s just way too unfamiliar, crowded, or anything like that, I’ll just remove him from the situation (Ashlea).
Summary. Parents in the current study used terminology and described specific characteristics of their children that indicated they knew them very well. This knowledge assisted them to work collaboratively with professionals to address concerns and monitor their child’s progress. Seeing improvements in their children’s abilities was often a source of joy and confidence. Some of the parents described severe behaviour problems, but also mentioned strategies to manage the behaviour or interpretations of the behaviour in relation to their child’s ASD. In most cases the diagnosis of an ASD helped to contextualise some of the child’s difficulties, which assisted parents in adapting their parenting, as described below.

Theme 2: Therapy in Daily Life “Don’t make therapy, therapy. Make it part of your everyday life” – (Elinor). This theme was constructed from statements where parents described approaches to parenting, including their efforts toward supporting the learning and development of their preschooler. Parents described some specific strategies that they used in the home to cater to a child with an ASD, such as having to learn signs to assist a child with language delay, creating and displaying a visual schedule in the home, and trying to incorporate the child’s special interests to keep them engaged in activities. Parents often targeted their child’s communication, emotion regulation, social skills, and in some families, motor skills in home activities. In addition, parents worked with their children to improve their numeracy and literacy abilities. Theme 2 was built from subthemes about home learning, the parenting approach, self-education, and challenges for parents.

Home learning. Based on the information provided in the interviews, it was apparent that in addition to any formal intervention the children were receiving, therapy had also become a part of day-to-day life at home. When parents were asked whether they did anything that might be considered treatment or intervention with their child, many answered that everything they did at home was treatment in one way or another.

Everything. Everything we do, like literally. Every...the way we approach absolutely everything from you know, how we run our day, to how we interact,
to just getting him to stop and think before he reacts and getting him to think about how he’s feeling, getting him to think about how he’s responding to things and if there are better ways of doing things. The way we play with him, just trying to get him to extend himself and not get stuck in ruts because he does that like all kids with an ASD, yeah, pretty much everything. Everything is early intervention I reckon, yeah (Jasmine).

I suppose we put a lot of thought into what we are doing that will be fun for him and fun for us but we will pick something that’s going to be more therapeutic than just for the sake of it. So like I’ll dig out in the garden with him and think well I can give him that, and that will be good for his strength and his gross motor (Adam).

In the last few months probably once or twice I’ve done something with him just for the sake of doing it, just for fun (Adam).

A lot of the games we play I’m always finding a way to teach him things with them. Like even when we’re outside and he’s swinging and sliding, I’ll stop him swinging and he has to say something for me. Everything is like therapy for us. Every opportunity I can, that he wants to play with, I use it as therapy. So, I don’t think that there’s really anything we do that isn’t (Ashlea).

In addition to these broad statements, parents provided specific examples of activities or strategies they used to help their child learn, and these were varied. Some strategies were based on a particular therapeutic approach, and others took advantage of opportunities for incidental learning. The activities parents used in the home targeted educational skills, such as introducing numeracy and literacy, working toward improving their child’s language abilities, social skills, or emotion regulation.

We just try to expose him to as much language as we can every day, you know, tell him what we’re doing, and tell him what things are [...] keep exposing him to it (Karla).

Always trying to generalise and reinforce. So I think constantly trying to create ways of generalising skills or try to constantly involve him, keep his
attention, and constantly trying to get interactions going [...] with children particularly (Meryl).

We’ve been teaching him, you know, things to say when you see someone you
know, like hello, how are you, good thanks, all that sort of thing; and saying
sorry if you do something wrong or something to hurt someone. Yeah, and
just, and I’ve been trying to teach him about playing with other kids too, and
recognising when kids don’t want to play with him in particular because
that’s been happening a little bit, it’s a bit upsetting (Michelle).

Parents also used specific materials and resources in the home such as visual
schedules, sensory toys, and games aimed to encourage taking turns.

The things that we have are very specific [...] it’s not just that you have toys
because your child likes them, it’s because they are part of his therapy
(Charlotte).

I’ve got cards up in a lot of places showing him symbols of what to do. I have
to keep the doors constantly locked, because he wanders off, we’ve had to
spend money on putting a fence up because he runs away to the park across
the road (Ashlea).

In addition to describing specific strategies used with their child, parents reflected on
the way ‘therapist’ had become part of their parental role.

I see myself more as a therapist than a parent in a way, like I’m still a parent,
but every single thing that we do I try to, it’s got to be fun, but it’s also got a,
it’s not just, we can do so much more. And so whenever I see the therapist I
just say look I want you to tell me what to do (Grace).

And then learning to deal with it in your everyday life, so learning to use those
therapies as second nature and to juggle that with the rest of the family
(Charlotte).

Although parents were using multiple strategies to help their preschoolers learn, some
felt a little uncertain about what they “should” be doing, or wondered if there was more
they could be doing to help their child. A great deal of information is available about
the importance of early intervention, and some parents were cognizant of doing as much as they could while their child was at this important stage for development.

*I worry sometimes that I don’t read enough [about ASD]. There’s some mums I know that have jumped in with their entire beings into the Autism research and stuff like that, and I’m very choosy about what I select and also I really didn’t start reading until about a year and a half ago mainly because it was too confronting and I was having enough trouble dealing with my own acceptance let alone reading about it otherwise. And now, once you skip, get over that hurdle, and there’s still days when you don’t accept it and it’s hard to accept but mainly once you’ve hit that acceptance point then you can jump in and do the research and learn stuff (Elinor).

If there was more that I could be doing I wish I knew what it would be […] So you just feel like, I have the guilt that there’d be so much out there that I haven’t been able to tap into that could change his life, because I believe we’ve got until seven, and once we’re at seven he […] won’t be as malleable I don’t think (Amy).

The big problem that we have is that we’re not teachers, and we’re not educated in all the early interventions stuff, so all we can do is what we think, and what, say the OT and speech therapist have mentioned to us. And it’s also hard when you’re a parent […] because um, that’s where you can get disheartened when you’re doing something with her when there’s no response. So you go, well she’s not responding so what’s the point […] it’s hard because you want to help her develop but if you don’t have, you don’t know enough how to do it, and also when I go back to work then you have less time as well (Linda).

The experiences of these parents provided further insight into their motivation to support their child’s learning and development, as well as some of the concerns and uncertainty they had about their capability to carry out these tasks. When home learning strategies were not working well, as Linda explained, it was much harder to manage as a parent, as compared to a professional. The personal investment in the outcomes for the child is much stronger than for a professional.
Furthermore, parents might be more likely to second-guess their approach and skills when their children’s progress does not match their expectations, whereas professionals might be aware of this heterogeneity, and the potential for therapy to progress slowly. As indicated by Elinor, in some cases, parents needed to reach a point of acceptance of having a child with an ASD before they had the capacity to become actively involved in learning and therapy for their child. Charlotte and Helen described going through a similar process:

[Child’s] diagnosis was March but for a while, sort of, it took us to absorb the shock [...] and then we just started to learn what we can do for him in terms of activities (Helen).

When you get the diagnosis you’re kind of I think probably grieving, and then you’ve got to go through the process of learning about, the learning is phenomenal [...] and then getting connected with the right, and that’s been a bit of a hit and miss process as well, because not every experience has been a good experience. So finding the right professionals that you feel happy and comfortable with, that’s a process (Charlotte).

**Parenting approach.** In addition to providing specific activities to assist their child’s development and education, parents also described how they adapted their parenting to meet the specific needs of a preschooler with an ASD. Some of the strategies parents used included preparing their child for change, altering their use of language, staying calm, and responding to meltdowns.

We just talk about whatever we’re going to do today and make sure he’s really aware of everything like if we are going to a playgroup we’ll talk about that for a few hours just to throw it in there here and there so he knows exactly what to expect (Grace).

We became a lot calmer in our approach, well tried to, once we knew that there was actually, it was not just behaviour, and not our parenting (Cora).

I suppose I’m even more conscious of using my GPS voice because I know as soon as any emotion enters into my voice he just latches on to that and can’t
hear past that. I am more conscious of him being a visual thinker and visual learner I am more conscious of his auditory processing delays (Jasmine).

I do think we’re different because we have to look at things a bit differently and we have to understand what, how [Child] might perceive situations, so we do a lot of preparation with him (Lucy).

The parents in this study discussed their efforts to change their own methods and strategies to better meet the needs of a child with an ASD. As indicated by Jasmine and Cora, staying calm was one way for them to be more effective when communicating with their children. Cora also alluded to the way the diagnosis of an ASD helped her to stay calm, and accept that her parenting was not necessarily the reason for the difficulties they were having managing their child. A number of parents also discussed the importance of giving their child preparation for specific events or routines, and of structuring his/her day to make it more predictable. Understanding the diagnosis of ASD also helped some parents adapt their approach to managing their child’s behaviour problems.

*If he’s having a four-year-old tantrum, then it’s dealt with as a four-year-old tantrum otherwise if it’s an autistic meltdown then we deal with it very differently (Jasmine).*

*When you’re learning about what works for [Child] it was a bit of a hit and miss process as well, so having some big disasters out in public and then you know, and being really frustrated with that, and then going, OK, well we can’t actually do it that way we have to find a new way to do that. (Charlotte)*

*I try and make it intermittent I’ll go you were really lovely to your sisters today therefore let’s all go out for ice cream, that sort of thing and I try and make it as much a reward that occurs for good behaviour that wasn’t elicited only because of the reward, yeah I just try and reward it without it being sort of dangling the carrot, you know what I mean. Because yeah otherwise he expects that next time, he’ll go well I’m not doing that unless I get and that’s not going to work around here (Jackie)*
As described by Charlotte, the parents in this study trialed different approaches and strategies to help parent their preschooler with an ASD. Across the participants, various parenting approaches and adaptations were described, and some parents mentioned that they needed to be flexible because strategies might work differently from one day to the next. Finally, when it came to parenting his son with ASD, Adam noted:

*We’ve just put to the backburner stuff that’s not really important, like tidiness and all that sort of stuff doesn’t matter. It’s just, focus your energy on what’s important (father).*

**Self-education.** The parents in this study explained their process of self-directed learning about ASD. Parents read material to help them to understand the condition, used the Internet to research specific topics or issues they were facing, and often read online forums as a source of information and support from other parents. Learning about ASDs often took the place of reading for leisure.

*We’ve got an Autism handbook we’ve got another book, we probably, everything we read is Autism related, apart from the paper (Steven).*

Parents described some of the ways navigating the available information could be a challenge, identifying the heterogeneity inherent in the condition, the importance of being selective about what to read, and a sense sometimes of “information overload.”

*I think that’s one of the most difficult bits is managing the dynamics of the research for this because no situation’s the same (Elinor).*

*Information overload, that’s the thing. You sort of get to skim stuff and not absorb it all properly; I mean I’m constantly on the internet looking for things (Linda).*

The parents in the study read about a range of topics, and the information seemed to assist them in understanding and parenting their child.

*Last year I was reading a lot of the research; what is ASD, how to teach a child with ASD, sensory issues, learning all that stuff. Now being in the*
second year I’m more in to the stories of other families, and seeing what experiences they’ve gone through. ‘Cause now I pretty much know what Autism, what it is, whereas I didn’t at the start (Ashlea).

As was explained by Ashlea, some parents did not have a good understanding of ASDs at the time of their child’s diagnosis. Much of their learning about this condition was self-initiated, by accessing books, websites, and talking to therapy providers. Therefore in the time immediately after a child’s diagnosis of an ASD it can be difficult for parents to decide on a course of treatment, and to understand how to best support their child.

**Challenges for parents.** Many parents described the challenges that they faced when working with their children. These were often about the difficulty engaging the child based on his/her interest levels. Parents often found that they needed to work on their child’s terms, or follow his/her level of interest and found it very difficult to engage the child in activities. Some parents also found it difficult to generalise their child’s skills. For example, their child might have been able to complete a task with the mother but not with another adult.

*I try to actually do it when he’s interested, or like when he shows interest that’s the best, the best time when he learn, that’s what I’ve been taught anyway, with the workshops and everything. And that’s actually the hard part as well because not all the time that he’s interested. So if he’s not interested then even if I try it like, “oh come on [Child], have a look” and then he just totally ignores (Megan).*

*Because it’s such a step-by-step process that it’s difficult for other people to understand, so that’s why I’m able to get more I guess out of him at home whereas my husband finds it really difficult that he can’t get those same responses (Meryl).*

**Summary.** Participants in the current study provided examples of both broad parenting approaches and specific activities that they worked on with their children at home. The participants were motivated to develop knowledge in the
area of ASD, and as stated by Charlotte, after the diagnosis, “the learning is phenomenal”. Parents applied their knowledge by implementing strategies to support their child’s learning and development in the home, and a number of examples of these approaches were provided during the interviews. The majority of parents, arguably, took on tasks that crossed the boundary between parent and therapist, and in some cases, parents felt these two roles were almost indistinguishable. Parents also offered some insight into the challenges associated with providing intensive support to their children in the home.

**Theme 3: Emotional Impact on Parents:** “We get so caught up in what’s happening with him that we forget to actually take proper time for ourselves” (*Alysha*). This theme included parents’ expressions of the impact raising a preschooler with ASD had on them personally, because as stated by Ava, “unless you have a child with autism it’s very difficult to know what it’s like”. Sub-themes included the emotional impact on parents, their social support, and self-care, which related to the way parents managed raising a preschooler with an ASD.

**Emotional Impact.** When describing the emotional impact of raising a preschooler with an ASD, a number of participants expressed their worries about their child’s future.

*I think all parents do worry about their kid’s future but in his case there’s a bit more uncertainty than you have for the other kids [...] How independent is he going to be when he grows up? (Ava).*

Some parents discussed their changed plans, such as being unable to return to work, and comments about the demands of meeting the child’s care needs were made by many mothers. For example, Cora and Adam described feeling exhausted, and Linda experienced a sense of hopelessness.

*Fatigue, exhaustion, I guess, because our day doesn’t stop, it’s a 24/7 thing, we don’t have somebody to just come and take the kids for a while, or give us a break, I’ve either got him [child’s father] to give me a break, or I take the kids to give him a break [...] one of us is always tired (Cora).*
It’s mainly just the evening where you just think, oh God, I’m stuffed, but you
don’t really think about what you might be able to do about it and how it’s
impacting on everything else, work, you know, friends, other family members
like his sister (Adam).

I get quite anxious about when I go back to full-time work, because you can’t,
you still have to live your life, you still have to work, you still have to do
things when you get home from work, and what I find difficult with it is with a
neurotypically developing child, they just pick these things up [...] they pick it
up naturally of their own accord, whereas with the kids with autism they’re
not doing that. So I do for me feel a sense of hopelessness a lot of the time
(Linda).

At times it was a bit frustrating and all a bit too much (Ingrid).

Having a child with an ASD also required parents to adjust their expectations
about their child and their parenting experience. Michelle referred to Emily Perl
Kingsley’s (1987) poem, “Welcome to Holland” when describing the adjustment
that happens when your child does not conform to your imagined future of
parenthood:

Our expectations are different I think. I think that’s probably what I’m trying
to say. I don’t expect of him what I originally would have expected of a child,
I think. It’s like that um, you’re going to Holland instead of Italy you know,
you can’t, you’re getting this different child, you’re not getting the child you
dreamed of, you’re getting this different child but you still have the child that
you really love and you dreamed of its just that they’re a little bit different
(laughs).

As indicated by the illustrative quotes, parents made a number of sacrifices so they
could raise their child with an ASD. The high care demands were experienced as
exhausting, and as described by Linda, there was difficulty managing caring for a
child with an ASD alongside other responsibilities.
**Social Support.** One of the subthemes included examples of social support, with a number of parents reaching out to others who were raising a child with an ASD, either online or in their social network. For example, Adam stated:

> I’ve got a couple of people at work who have children with ASD so they’re another, just to bounce things off [...] that’s mainly more debriefing type of stuff rather than practical help, it’s more just yeah, having a whinge and they’re just the “yeah I know what it’s like” kind of people.

Some of the therapists, teachers, and aides working with the children were another source of support with Lucy describing one agency as being “like my second family in a way, they’re fantastic”. There were also a number of counter-examples of social support included in this theme, where parents felt misunderstood or isolated from other parents.

> I’ve got some close friends that have got a neurotypical child. They know that [Child] has ASD and they’re quite understanding [...] but I feel in some ways, no matter how much, [...] sometimes when I talk about these things I feel isolated not because they make me isolated but I feel I’m in a different position with them, because no matter what, they have a neurotypical children, have different needs from [Child] (Megan).

> It’s like you’re in a bubble almost, I mean you’re connected to the outside world to a certain extent, I mean obviously we’re connected to the outside world and other people and things, but [...] we have to put up with particular behaviours, we have to deal with his fussiness, things that other people just don’t even think about we have to deal with all the time (Michelle).

**Self-care.** This sub-theme included statements about the ways parents managed their stress. Seven of the mothers, and one father, described the evening as the best or only time of day where they could take some time for themselves, when possible.

> Hopefully having a cup of tea at nine o’clock on the couch watching TV, that’s kind of the ideal day, but that might not happen (Charlotte).
Although in some cases this time was used to read or wind down, other times, there was some indication that the evenings were spent recovering from busy days, or learning about ASDs.

*I play guitar and instruments and stuff when they’re in bed I’ll go off and do that for a little while, for calming and stuff* (Adam).

*My down time consists of something mindless like Facebook or something mind numbing, and some reading, just something to totally disengage, that’s my wind down for the day* (Jackie).

*I do a lot of reading at night time. A lot of the information that I’ve read about autism has all been in the evening, I used to read you know, my own things at night time, to enjoy. I just haven’t really had time for that any more. It seems that all I do is just read information about them and try and organise things for the next day and, so like before, you know, I was reading ‘The Slap’ and I was reading novels and I just don’t have time for that anymore which is really sad* (Kate).

**Summary.** This theme captured parts of the interviews where parents expressed their emotions about raising a child with an ASD. Some experiences were common to multiple participants, such as changing career plans, or describing a sense of uncertainty about their child’s future or quality of life. Some more unique or specific examples were provided across the interviews where parents described appreciation, annoyance, fear, exhaustion, frustration, overprotectiveness, hopelessness, a sense of being disheartened, or that things were “all a bit much” (Ingrid). Parents provided examples (and counter examples) of social support, and some mentioned the strategies that they used to wind down, usually in the evenings. Some of these activities, like using the internet, did not necessarily seem to be relaxing, but rather helped parents to be distracted and “totally disengage” (Jackie).

**Theme 4: ASD as a family priority:** “It’s a very regimented lifestyle at the moment” (Ava). The parents in the current study reflected on the ways in which raising a preschooer with an ASD affected their family life, and these experiences were broadly categorised into subthemes relating to the therapy schedule, or family activities
and relationships. The central idea of this theme was that raising a preschooler with an ASD lead to changes across multiple domains of family life. The majority of parents reflected that they had to follow a strict schedule, partly to accommodate the need for this by their child with an ASD and partly to fit in an extensive therapy program. For example, Amy stated, “he is scheduled within an inch of his life, which I thought he would never be”. Parents also described limitations to their ability to participate in social or family activities. Many families stated that they did not go on holidays, and one mother explained that she and her husband had trouble going out or even having guests at their house, stating: “it’s like we’ve stopped living, for him” (Ashlea). The quotes from Elinor and Toni provide some indication of the commitments of the families:

*Tuesday mornings I leave open just for a bit of free play, because they’ve got to be kids really. They’ve got to be kids. Everything else is so structured and rushed because we’ve got to get to day-care and kinder and all that sort of stuff (Elinor).*

*I think a lot of people have a routine now for their kids, the ones that I know, yeah; but we’re probably a little bit more strict in terms of time (Toni).*

**The therapy schedule.** Across the 21 interviews, it became apparent that the therapy schedule was one factor that pervasively affected family life. This included attending therapies and appointments external to the family, as well as changes made to accommodate therapy at home. Although parents found this beneficial, they also expressed concerns about the impact on their child with ASD and other family members, as stated by Michelle:

*The impact of all going to all the therapies, yeah, that’s probably one thing I think that’s quite universal amongst parents, because other parents that I know have said the same thing. That having such a huge, a massive schedule, of going to speech therapy, OT, social skills, you know, and update assessments and things like that [...] because we are just continually doing stuff like that. I just find that the impact on the family is quite big because it impacts on his sister.*
Some parents discussed a difficulty balancing the child’s therapy with their need for time together as a family. Jasmine described this as a “catch-22” and Ava explained that family life was “regimented”:

*We just don’t have the same amount of downtime. Or the same opportunity for downtime I suppose. A lot of people have the opportunity but don’t take it. But, you know we have, I feel like we don’t have any choice other than to be doing early intervention and all that sort of thing […] And I think that [downtime] is really important. I actually think it’s more important for autistic kids than neurotypical kids and autistic kids actually get less opportunity because they get dragged to all these early intervention things and it’s really frustrating because that’s what he really really really needs. But at the same time I’ve seen such improvements with social skills and those sorts of things that I can’t not do it. Catch-22 really (Jasmine).*

*It’s a very regimented lifestyle at the moment […] because of early intervention and all of this we’re doing so the number of hours that we can spend together as a family is, it’s not much, and especially yeah, wouldn’t have spent too many hours together doing things that we do because he’s got therapy on weekends (Ava).*

Although the therapy schedule was challenging to maintain, as alluded to by Jasmine and Amy, the parents feel that this level of scheduling was necessary to meet the needs of their preschooler with an ASD:

*It’s hard see when I look at the speech therapy and all that that we do I don’t think of that as an extracurricular activity I think that as kind of like breathing living eating in that it has to be done and I can’t teach it (Amy).*

The participants in the current study highlighted the difficulty managing their children’s therapy scheduling. Parents were responsible for managing their children’s attendance at kindergartens, early learning centres, alongside numerous therapy appointments. Some parents expressed concern about the impact of this lifestyle on siblings, who often went along to appointments with their parent and sibling with an ASD.
**Family activities and relationships.** Meeting the needs of a child with an ASD was accompanied by changes in the family’s finances and work arrangements in many cases. The financial impact of ASD on the family was considerable in a number of cases, with one family making the decision to sell their house to fund a parent staying home and being trained in ABA therapy.

>[Dad] has quit his job to be at home with [child] and do therapy full time (Karla).

*We’ve had to reshuffle our financial investments [...] so we can, I guess, afford to do what we would not have ordinarily done* (Grace).

*I would probably be looking at work now if it weren’t for [child]’s condition most definitely because its all these things of um, oh, with the music you know, we’re trying to find things to stimulate her, to engage her* (Linda).

*I was hoping to you know go back to work this year, and that’s not going to happen, so um, you know. I basically become care-taker* (Kate).

In addition to the impact of routines and schedule on family life, there were also indications that the opportunities for socialising and participating in family activities were reduced when there was a child with an ASD.

*The lack of opportunities socialising and making family friendships, new family friendships is really limiting. And we don’t have the opportunities to be invited to people’s places, birthday parties, which other typical kids would be at this age* (Meryl).

Managing characteristics of the child with an ASD was a contributing factor for their reduced social participation.

*One doesn’t do as many things, seeing other families, or going out for dinner, or something that is more easy for other people; because you have to deal with behaviours* (Ingrid).

*We don’t really have a social life anymore. We’re always home. We used to go out to dinner at least once a week, now its once a month. And we have to*
go early be prepared, you know, things like that. We can’t have a lot of friends coming over at the one time because he [Child] doesn’t like having a lot of people in the house at the one time, that he doesn’t like um, we’ve pretty much changed everything. It’s like we’ve stopped living, for him. And then when he’s older we can go back and (laughs) do what we need to do again. You know, I’ve had to stop work, I can’t go to work anymore. Been going to a lot of, my free time gets spent a lot on seminars and conferences you know, we’re doing things like going to charity functions that we’ve never even considered going like the Walking for Autism, the big walk in the city, we went and did that [...] It’s a completely different, It’s a complete lifestyle overhaul you could say. It’s completely different. Can’t leave him with parents or with anyone and have a date night out or anything because he doesn’t stay with anyone (Ashlea).

As noted by Ashlea, raising a child with an ASD not only limited socialising with other families, but also meant she and her partner were restricted in being able to spend time together as a couple. Their priorities had changed so that supporting their child was prioritised over other pleasant activities. This might then impact family relationships, and some other families also mentioned the way raising a child with an ASD had impacted on their family interactions.

I think too just the way that we interact [...] we don’t really talk to each other, there’s not much conversation going on, and I think that’s probably a bit of an ASD thing, or is it because we’re so exhausted and tired? [...] it would be nice to sit and have a conversation sometimes (Michelle).

By now she would be talking and interacting a lot more than what she does, and he [brother] enjoys the fact that she’s just watching him and actually [...] engaging with him (Steven).

I suppose because of all the early intervention stuff we do and all the many many hours that we’re not at home, I just feel really guilty because I just feel like I don’t get enough time just to spend interacting with him and also her [sister] in the way that I used to (Jasmine).
It [antidepressant medication] makes him [husband] snappy, and then I get snappy at him because he’s snappy, and then he’s snappy at me and then I’m snappy and tired, and it’s all round (Cora).

The examples provided by these parents suggested they had noticed the way raising a child with an ASD influenced on other relationships within the family. In some cases, this stressor seemed to affect the couple relationship, with two of the parents suggesting being tired or exhausted was related to reduced interaction or feeling irritable. Parents also discussed difficulty distributing their time across the child with an ASD and other family members, including their partner, or the focus child’s siblings.

Summary. All families in the current study were implementing some form of intervention with their children. The parents felt this impacted on their life in terms of the time commitments, travelling to and from appointments, and the difficulty this created in terms of spending time together as a family. The therapy schedule also contributed to changes in work arrangements for a number of parents in this study. The nature of ASDs also impacted on the family in terms of upholding routines and missing out on opportunities to socialise with other families. Some parents described differences in their family relationships and interactions that were associated with raising a child with an ASD.

Summary of the Findings

Both quantitative and qualitative data were used to characterise the group of 21 families who participated in Study 2, and to explore their experiences of raising a preschooler with an ASD. A summary of the results of Study 2 is presented below. These findings will be discussed and linked to prior research in the following chapter (see Chapter 8).

The quantitative data indicated that the participants in this study were functioning similarly to parents in the population on measures of family functioning, and parental wellbeing; the exception being increased stress in mothers, and increased
depressive symptoms in fathers. This differs from the larger group parents who participated in Study 1, where mothers reported higher depressive symptoms, fatigue, and family difficulties as compared to normative data. Additionally, this differs to findings from prior research indicating risk of increased mental health and family difficulties amongst parents of children with ASDs (see Tint & Weiss, 2015, for a review). Parents in the current study reported they were managing well in terms of their wellbeing and family functioning, despite evidence that their children engaged in challenging behaviours, and had difficulties in their adaptive functioning and developmental skills.

The thematic analysis resulted in four themes that described the adjustments parents made to their approach to parenting, as well as the impact raising a preschooler with an ASD had on the themselves and their family life. The themes are summarised and linked to the research aims (RA) in parentheses. Parents in the study described their children in a way that indicated strong knowledge of their child’s individual abilities, challenges, and preferences (RA2 and RA3). In addition to their expertise regarding their child, parents dedicated time for self-initiated learning about ASDs, and worked with their children in ways that they hoped would promote skill attainment (RA3). By providing an enriched home learning environment, parents were able to implement activities to create opportunities for therapy in the home (RA3). Although the parents in the current study were rated as well functioning based on questionnaire measures, they raised a number of concerns about the impact raising a child with ASD had on their wellbeing, as well as the family system (RA1). The contribution of these themes to the literature, and the clinical implications of Study 2 are discussed in Chapter 8.
Chapter 8. General Discussion

Overview and Summary of the Findings

This research was conducted in two stages to provide an in-depth exploration of the family environment when raising a preschooler with an ASD. The over-arching aims of this study were threefold. Firstly, this research was undertaken to explore parents’ perceptions of the impact raising a preschooler with an ASD had on their family, parenting, and wellbeing. The second aim of the study was to investigate the ways in which parents adapted their approach to parenting, and made accommodations to family life, to meet the needs of a preschooler with an ASD. Thirdly, the ways in which parents supported their preschooler with an ASD through the provision of a home learning environment were explored.

In Study 1, the aims of this research were addressed using a cross-sectional design. The participants’ questionnaire responses were compared to normative data to examine the extent to which they experienced difficulties with problematic child behaviours, wellbeing, and family functioning. It was hypothesised that children’s behaviour problems would be associated with parental wellbeing difficulties (as indicated by their stress, depression, and fatigue) and wellbeing would, in turn, be associated with poorer family functioning. This hypothesis was partially supported, as depression, but not stress or fatigue, mediated the relationship between behaviour problems and family functioning. The impact of parental depressive symptoms on family functioning and parenting practices was then explored. Path analysis revealed depressive symptoms were directly associated with reduced parental warmth and increased hostility. Depressive symptoms were indirectly related to parental involvement. Depressive symptoms were associated with poor family functioning, which was, in turn, associated with less involvement in home and play activities.

In Study 2, quantitative and qualitative methods were used to characterise a separate group of 21 families, and describe their experiences of raising a child with an ASD. The questionnaire measures indicated these families were, on average, functioning similarly to families in the community, exceptions being the higher levels of maternal stress and paternal depression in the current sample. The qualitative analysis resulted in four themes. The parents showed extensive knowledge of their children’s qualities, abilities, and challenges (Theme 1: Knowing the Child). The
parents explained that the way they provided intervention to their child was an integral part of their home activities (Theme 2: Therapy in Daily Life). They were emotionally affected by raising a child with an ASD (Theme 3: Emotional Impact on Parents). Raising a preschooler with an ASD also had an impact on daily family routines and family relationships (Theme 4: ASD as a Family Priority). A summary of the key findings from the two studies is presented in Table 15.
Table 15

**Summary of Research Findings from Studies 1 and 2**

<table>
<thead>
<tr>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study 1</strong> (N=97)</td>
</tr>
<tr>
<td>1. Parents of preschoolers with ASDs reported significantly higher levels of child behaviour problems, stress, and family difficulties than available norms. Mothers reported elevated depression and fatigue relative to norms, and fathers reported lower warmth.</td>
</tr>
<tr>
<td>2. The relationship between children’s behaviour problems and family functioning was mediated by parents’ depressive symptoms, but not their symptoms of stress or fatigue.</td>
</tr>
<tr>
<td>3. When depressive symptoms lead to family difficulties, there were consequences in terms of reduced parental involvement.</td>
</tr>
<tr>
<td>4. Parents’ depressive symptoms predicted lower parenting warmth and higher hostility.</td>
</tr>
<tr>
<td><strong>Study 2</strong> (N=31)</td>
</tr>
<tr>
<td>1. Mothers in this sample (n=21) reported similar levels of depression and fatigue to women in Australian community samples. On average, these mothers reported scores in the healthy range for family functioning, and scored highly on the HOME Inventory. Their stress was significantly higher than women in the community.</td>
</tr>
<tr>
<td>2. Fathers (n=10) reported similar levels of stress, fatigue, and family functioning to fathers in the community. Their levels of depression were elevated relative to norms from Australian men.</td>
</tr>
<tr>
<td>3. The majority of focus children were rated as having clinically significant behaviour problems by at least one parent (n=18). Their total adaptive skills ranged from very low to adequate, and their abilities ranged from severe to adequate across cognitive, language, imitation, and motor skills domains.</td>
</tr>
<tr>
<td>4. Qualitative analysis resulted in four themes:</td>
</tr>
<tr>
<td>- Knowing the child</td>
</tr>
<tr>
<td>- Therapy in daily life</td>
</tr>
<tr>
<td>- Emotional impact on parents</td>
</tr>
<tr>
<td>- ASD as a family priority</td>
</tr>
</tbody>
</table>
As shown in Table 15, there was some convergence across the findings from the two studies. Study 1 emphasised the interrelatedness of child, parent, and family difficulties when there was a preschooler with an ASD. The findings from Study 2 were complementary in that this separate sample of participants described ways in which raising a preschooler with an ASD had affected their wellbeing and family life. For example, parents explained that the intense focus on the needs of the preschooler meant that they had less time and energy to direct toward other aspects of living, including their participation in work and social activities, self-care, and family relationships. Furthermore, parent reports of clinically significant behaviour problems, and high levels of maternal stress were consistent across both studies.

Areas of divergence were also apparent across the two studies. The participants in Study 2 were characterised differently to those in Study 1 based on their questionnaire responses. The heightened depression, fatigue, and family difficulties reported by participants in Study 1 were not reported by the smaller sample of parents involved in Study 2; the exception being elevated depressive symptoms reported by fathers. In fact, the Study 2 mothers reported effective family functioning across all domains, particularly in the areas of affective responsiveness, communication, and behaviour control. This finding suggested the personal accounts of the participants in Study 2 might not necessarily have reflected the typical experiences of parents adjusting to raising a preschooler with an ASD, as reported in the literature (e.g., Hayes & Watson, 2013; Myers et al., 2009). This is most likely due to the study methodology, including a self-selected sample of parents willing to participate in home visits, as will be discussed later in this chapter.

Nevertheless, the qualitative focus of Study 2 generated new information about parenting and the provision of a home learning environment for preschoolers with ASDs. These detailed insights about the activities parents embedded within home life, and the parents’ commitment to providing their preschooler with intensive support, would not have been gleaned from a questionnaire study alone. It was evident that this group of parents took an active role in supporting their child on a daily basis. They created highly specialised home learning environments for their children and attempted to incorporate therapeutic goals into most activities. This was facilitated by their knowledge and understanding of ASDs. Providing and maintaining this degree of support, which involved dedication and a substantial time input from parents might
have been feasible due to the positive wellbeing and family functioning reported by the participants. When families are functioning well, individual family members feel supported, including parents (Renzaho et al., 2013; Zubrick et al., 2000). By learning and implementing strategies to help manage their children’s behavioural problems and emotional regulation, and by teaching their children new skills, parents might have felt more confident in their capacity to manage raising a child with an ASD. This interpretation is supported by prior research showing that mothers who took a proactive approach to managing their children’s difficulties felt confident in their parenting efficacy (Kuhn & Carter, 2006).

Using a mixed-methods design across the two studies was advantageous in that the larger, quantitative sample enabled testing of relationships amongst child, parent, and family variables. The qualitative stage facilitated a more fine-grained understanding of the developmental context provided to children with ASDs within the family environment. The results from this program of research have been briefly summarised in Chapters 6 and 7. Within this final discussion chapter, the findings from the two studies are integrated. The broader interpretation and implications of the results are discussed in light of the methodological strengths and limitations.

**Impact of Raising a Child with an ASD on Family Functioning, Parental Wellbeing, and Parenting Practices**

**Study 1.** The current findings add to, and extend, the literature addressing the impact of raising a preschooler with an ASD on parents and families. Incorporating measures of parental wellbeing, parenting practices, and family functioning enabled relationships within the family system to be explored. Overall, the literature in this area is somewhat disjointed by a lack of a coherent theory that would help to integrate the findings across studies into a more unified model (Tint & Weiss, 2015). Furthermore, relationships between child and parent variables are often analysed without broader consideration of the family microsystem (Hayes & Watson, 2013). To address this concern, the current study was conceptualised drawing on transactional (Sameroff, 1975) and bioecological (Bronfenbrenner, 1986) theories. Although the transactional model makes reference to longitudinal relationships between children and their environments over time, this framework was used to portray the interconnectedness of children and their families (Sameroff, 2009). Therefore only part of the model could be
tested in the current study, rather than fully examining the cyclical nature of child and family transactions in this population.

Prior studies have often relied on parenting stress as an outcome variable when exploring the impact of ASDs on the family system (Hayes & Watson, 2013; Tint & Weiss, 2015). Although the experience of stress is clearly important to consider in parents raising a child with an ASD (Hastings, 2002; Hayes & Watson, 2013), difficulties in wellbeing are complex and multifaceted. Focusing on stress to the exclusion of other parent and family outcomes overlooks more diverse aspects of family life affected by raising a child with an ASD. Incorporating measures of family functioning, fatigue, and depressive symptoms alongside parental stress was advantageous in the current study. This is because these measures provided a comprehensive description of the participants’ wellbeing and enabled the interrelatedness of stress, depression, fatigue, and family functioning to be unpacked. This is of clinical relevance when researchers have identified a need to better understand and support children with ASDs and their parents in the context of the family system (e.g., Karst & Van Hecke, 2012).

The vast majority of parents in the current study reported that their preschooler with an ASD showed clinically significant behaviour problems, which was in line with prior research (e.g., Eisenhower et al., 2005; Estes et al., 2009; Gadow et al., 2004; Herring et al., 2006). The Study 1 mothers reported wellbeing difficulties across multiple domains. They experienced stress, depression, fatigue, and family difficulties to a greater extent than women without children with ASDs from the normative samples. This finding is consistent with previous research accentuating parent and family difficulties amongst this population (e.g., Gau et al., 2012; Giallo, Wood, et al., 2013; Higgins et al., 2005; Pisula, 2007; Sivberg, 2002). The replication of this finding indicates that wellbeing and family difficulties continue to be of concern for mothers of children with ASDs despite advancements in social policy, and an emphasis on incorporating the needs of families as a principle of good practice (e.g., Karst & Van Hecke, 2012; Phelps et al., 2009; Prior & Roberts, 2006; Stahmer & Pellecchia, 2015).

Similarly to mothers, fathers reported elevated stress and family difficulties, yet their depression and fatigue were indistinguishable from men without children with ASDs. This is consistent with previous findings (Hastings et al., 2005) where
depressive symptoms were found to affect mothers of children with ASDs more than fathers, and stress affected mothers and fathers similarly (Davis & Carter, 2008). The sample of only nine fathers in the current study does not give an indication of whether these trends are representative of fathers of children with ASDs more generally. Speculatively, the different experiences of mothers and fathers might be related to gender roles within the family. Mothers predominantly take the role of primary caregiver for children with ASDs (Baker & Drapela, 2010), which could contribute to maternal fatigue and depressive symptoms (Benderix et al., 2006; Vickers et al., 2004). Some fathers of TD infants report that going to work offers them some respite from caregiving (Giallo, Rose, et al., 2013), which might also be applicable to fathers of children with ASDs. Further research might elucidate whether experiences of stress and family dysfunction occur more generally amongst fathers of children with ASDs. These fathers might have unique perspectives and support needs (Giallo et al., 2015) that are currently underrepresented in the literature.

There are no known studies where parenting warmth has been compared between parents of preschoolers with ASDs and community samples. Mothers in Study 1 reported expressing affection and feeling close to their child to a similar extent to other Australian mothers of preschoolers. However, the fathers were lower in warmth than the community sample of Australian fathers (Lucas et al., 2010). The high level of warmth reported by the mothers in the current study suggests they make efforts to direct warm, affectionate parenting practices toward their preschoolers with ASDs. Differences between mothers and fathers might be related to the possibility that fathers of children with ASDs show characteristics of the broader autism phenotype. However, this was not assessed in the current study, and the very small sample of fathers precludes strong conclusions about their parenting warmth. Fathers might have had difficulty accepting the diagnosis of an ASD in their son or daughter. Alternatively, they might have taken on a practical, rather than emotional role within the family.

A novel finding from Study 1 was that despite being related constructs, symptoms of stress, depression, and fatigue had different relationships with family functioning. Although behaviour problems were associated with all three indicators of parental wellbeing, only depressive symptoms were then associated with perceptions of
family functioning. Relationships between behaviour problems in children with ASDs and difficulties in both family functioning (Herring et al., 2006; Khanna et al., 2011; McConkey et al., 2008; Paynter, et al., 2013; Sikora et al., 2013) and parental wellbeing (e.g., Estes et al. 2009; Hastings et al. 2005; Jones et al. 2013; Lecavalier et al. 2006; Seymour et al., 2013) are consistent with prior research. The current findings further extend the research by drawing attention to the experience of depressive symptoms amongst parents of preschoolers with ASDs, and demonstrating one pathway by which behaviour problems are associated with family difficulties.

Depression, stress, and fatigue are qualitatively different experiences (Giallo et al., 2011; Lovibond & Lovibond, 1995). It has been shown that although fatigue can be a symptom of depression, these are distinct constructs (Giallo et al., 2011). Parents might find that symptoms of stress and fatigue do not necessarily interfere with their day-to-day functioning including upholding their important role within the family system. For example, findings from a recent study indicated that it was rare for mothers to agree with the statements “I don’t do much during the day” or “I feel no desire to do anything,” despite experiencing fatigue (Giallo et al., 2014, p. 128).

Parents who feel overwhelmed and despondent in response to parenting a child with an ASD might have more difficulty adapting to this condition and establishing sustainable family routines, as compared to parents with positive health and wellbeing. Unlike stress and fatigue, depressive symptoms are associated with a sense of hopelessness and disempowerment, and can contribute to being immobilised (Lovibond & Lovibond, 1995). The implications of depressive symptoms for the family system are concerning because for a subset of mothers, depressive symptoms can remain elevated for years after their child is diagnosed with an ASD (Carter et al., 2009). Other areas of life affected by depressive symptoms warrant further investigation. This is particularly needed when parental depressive symptoms could undermine the capacity of parents to provide structure and routine in family life, support early learning, and participate actively in early intervention programs. If parents do not have the capacity to support their children with ASDs, there are missed opportunities for that child to learn new skills, and behavioural problems may escalate (Hastings, 2002).

People manage stressors such as the challenges associated with raising a child with an ASD in various ways (Pottie & Ingram, 2002). Some parents manage their stress by problem solving, seeking support, or reframing their experiences (Pottie &
Ingram, 2002). Others withdraw or try to escape their difficulties, which is a risk factor for low mood (Pottie & Ingram, 2002). Therefore, depressive symptoms might also be an indication of difficulty coping (Pottie & Ingram, 2002) or long-term fatigue (Giallo et al., 2011).

Consistent with research in families of TD children, depressive symptoms predicted suboptimal parenting practices, as indicated by reduced warmth and increased hostility (e.g., Edwards & Maguire, 2011; Lovejoy et al., 2000). Additionally, depressive symptoms indirectly predicted levels of parental involvement, which was mediated by family functioning. Depressive symptoms might reflect experiences of unresolved grief and loss associated with having a child with an ASD (Lutz et al., 2012; Wachtel & Carter, 2008). Parents having difficulty coming to terms with the complex emotions evoked by having a child diagnosed with an ASD, sometimes have difficulty engaging with their children in play, either through educational and language input, or through shared enjoyment (Wachtel & Carter, 2008). Experiencing depressive symptoms could also make it difficult to respond patiently to challenging behaviours (Lovejoy et al., 2000; Osborne & Reed, 2010) and could undermine parents’ confidence in their abilities to parent a child with an ASD effectively (Kuhn & Carter, 2006).

Extending knowledge of the basic relationships between behaviour problems and parent wellbeing difficulties, a child-driven model of intra-familial processes was tested in the present study. However, in some studies, behaviour problems are viewed as an outcome of poor parental wellbeing or family difficulties, rather than a stressor (Kelly et al., 2008; Osborne et al., 2008b; Zaidman-Zait et al., 2014). In line with a transactional model, it is acknowledged that bidirectional effects among these child, parent, and family factors are likely (Hastings, 2002; Sameroff, 2009). Initial evidence from longitudinal studies suggests that increased parenting stress impacts on future child behaviour problems, in a mutually escalating cycle of transactions (Baker et al., 2003; Osborne & Reed, 2009). However, children with ASDs show clinically significant behaviour problems form very early in development (Fodstad et al., 2012) and these affect a majority of individuals with ASDs (Brereton et al., 2006). Furthermore, evidence indicates these problematic behaviours might be entwined as a component of the disorder itself (Brereton et al., 2006; Georgiades et al., 2011). These factors suggest that behaviour problems are a pervasive issue for the majority of families raising a child with an ASD. In the current study, a child-driven model was
supported, suggesting these problems explain some of the variance in parental and family distress. This distress then becomes a risk factor for reduced warmth and more hostility, explaining how these transactions might be maintained over time. Considering the reciprocal influences of child, parent, and family factors longitudinally is an important direction for future research.

**Study 2.** The participants in Study 2 were drawn from a separate, self-selected sample of parents to those in Study 1. Only one participant was involved in both phases of this research. When exploring the impact of raising a preschooler with an ASD on this group of families, the self-report questionnaire data indicated that they were functioning differently to those in Study 1, and to prior research samples (e.g., Carter et al., 2009; Giallo, Wood, et al., 2013; Xu et al., 2014). Although the majority of participants in Study 2 rated their child as showing clinically significant behaviour problems, the parents reported functioning well in terms of their wellbeing and family functioning. Exceptions included the elevated stress reported by the mothers, and elevated depression of the fathers, as compared to normative data. Based on these findings, it can be speculated that albeit small, this sample of parents were experiencing raising a preschooler with an ASD quite differently to the way this group of parents are currently represented in the literature. The findings from this group of 21 families may therefore not accurately reflect the experiences from the majority of parents raising preschoolers diagnosed with an ASD. The findings do offer new perspectives and insights from highly resilient families.

The resilience shown in the participants in Study 2 is unlikely to be due to the characteristics of the preschoolers with ASDs. Like children in other research studies, the preschoolers with ASDs showed clinically significant behaviour problems. Some of the children also had very low adaptive and developmental skills, indicating that the parents faced many demands as caregivers. The self-report questionnaire indicated the mothers perceived their families as functioning better than is typically seen in community samples in the areas of communication, affective responsiveness, and behaviour control. Perhaps amongst this group of participants, having optimal functioning in these areas helped them adapt to raising a preschooler with an ASD. Within these families, having clear and consistent expectations around behaviours, communicating openly and directly about emotions, and responding warmly might have
been protective factors. The capacity of these parents to view their experiences in a positive light, by describing their children’s strengths and abilities alongside their challenges, might also have contributed to their resilience (Bayat, 2007; Pottie & Ingram, 2008).

Although the self-report measures indicated relatively positive wellbeing and family functioning among the Study 2 participants, raising a preschooler with an ASD affected them immensely. The thematic analysis resulted in two themes that described the impact raising a preschooler with an ASD had on the parents emotionally, and in terms of their family life. The nature of ASDs meant parents felt concerned about their child’s future. Their worry might have been related to the heterogeneity across the autism spectrum, the lifelong nature of the condition, as well as the largely unpredictable treatment response. At this point in time, the developmental trajectory of a child with an ASD is largely unknown, and so parents cannot predict the level of support that their children will require across the lifespan (Vivanti et al., 2014). This makes it difficult for parents and families to plan for their family’s future, and for them to form expectations about their own and their child’s future quality of life.

The mothers in the current study expressed concerns about balancing living their own lives with meeting their child’s high care demands. This is consistent with findings from other samples of parents (e.g., DeGrace, 2004; Hoogsteen & Woodgate, 2013). For Linda, caring for her child restricted her capacity to participate in the workforce, complete her studies, and contributed to a sense of “hopelessness”, which is a symptom of depression. This brings in to question current child-focussed models of care. Although children with ASDs are benefitted by time-intensive interventions, it is important that this is balanced with the needs of other family members. Perhaps parents could be relieved of some of the pressure and demands associated with their child’s care by the implementation of practical, family-focussed, support.

Although a relatively new research area was addressed in the current study, the findings reflected the phenomenon of “centering autism within the family” (Hoogsteen & Woodgate, 2013, p. 136). This refers to a sense that family life is focussed on the needs of the child with ASD, shown by parents anticipating and problem solving to meet their child’s needs and always considering ASD when making personal and family decisions (Hoogsteen & Woodgate, 2013). This is consistent with other qualitative studies that have identified ASD becoming a focal point for families (e.g., DeGrace,
2004; Meirsschaut et al., 2010). Findings from the current study support and expand on this concept, and give a clear picture of how “centering autism within the family” looks in the preschool period. Parents described maintaining a busy and regimented schedule, taking an active role in learning about ASDs, and becoming an integral part of their child’s therapy team. One parent (Karla) gave an extreme example of the way caring for a child with an ASD had become a priority in their family. They had given up their home so they could afford for a parent to become their child’s full-time therapist. For the participants in the current study, the daily routines and therapy schedule seemed to be a key factor around which family life was centred. Attending appointments on a regular basis with professionals from multiple disciplines (e.g., speech therapist, psychologist) put pressure on families, an experience Michelle described as “universal” amongst families of children with ASDs. During this life-stage, it seems that maintaining a high level of intervention added strain to the family system. However, when therapy is “like breathing, living, eating” (Amy) then families need more support to maintain these schedules, or the approach to therapy needs to be better integrated into family routines.

For the parents in Study 2, the therapy schedule limited the time they had available for “downtime” (Jasmine) where they could enjoy spending time together as a family. Having less time available to enjoy as a family has been reported by other parents of children with ASDs (Hutton & Caron, 2005; Myers et al., 2009). This may contribute to feelings of social isolation, and reduced wellbeing for parents. The siblings are also affected by this schedule, and may spend their time attending appointments with their sibling with ASD. It is plausible that missing out on opportunities to be in the moment with children, to be spontaneous, and unstructured in the parenting role could make the task of parenting less rewarding. Children with ASDs require structure and routine to a greater extent than TD children, and parents are constantly working to anticipate and prevent difficult experiences for that child, which might contribute to their stress. Furthermore, it is possible that for a child with an ASD, constantly being interacted with in a way that is goal directed could potentially be exhausting or communicate the message that the child needs to be “fixed”.

Although not a focus of the interviews, statements emerged about the ways in which parents engaged in self-care activities, and received social support, that might have helped them to manage raising a child with an ASD. Some parents in the current
study engaged in exercise, which has been identified as a factor to help combat fatigue and low mood in prior research (Giallo, Wood, et al., 2013). Where possible, others spent time trying to relax in the evenings. Some parents noted that they were intensely focussed on their child’s needs, which meant self-care was overlooked. Their resilience under these circumstances is therefore noteworthy. Further research into factors that contribute to parent and family resilience is needed. Perhaps the parents engaged in other adaptive coping strategies, interpreted their situation positively, or were well supported in their family relationships, meaning they were able to sustain their intense focus on supporting their child with an ASD.

**Adapting Parenting and the Home Learning Environment for Preschoolers with ASDs**

Very few studies have been conducted to investigate the family and home learning environments of preschoolers with ASDs despite the potential benefits of family input for children during this developmental stage. The experiences of the 21 families who participated in Study 2 contribute new information to this emerging area of inquiry; particularly the notion that many of these parents tried to incorporate learning and therapy in to all home activities with their child. The HOME Inventory (Bradley & Caldwell, 2003) was used to facilitate detailed conversations with parents about the ways in which they established a home learning environment for their children, including descriptions of the materials they used, their communication with intervention providers, and their methods of teaching new skills. No known studies have used the HOME Inventory (Bradley & Caldwell, 2003) as a measurement tool specifically in families where there is a child with an ASD, a procedure that had both strengths and weaknesses in the current study.

The findings from Study 2 indicated that parenting a child with an ASD was a very considered process. By engaging in self-education about ASDs, parents understood their children’s strengths and challenges, and worked towards adjusting their approach (e.g., staying calm, preparing child for change, interpreting and responding to behaviour problems) to suit their child. The parents’ knowledge and self-directed learning about ASDs might have assisted them in this process. Understanding characteristics of individuals with ASDs, such as their preference for routine, is likely to have helped inform the participants’ approach to parenting. Furthermore, understanding
ASDs is likely to mean that parents interpret behaviour problems or skill deficits as a component of this disorder rather than being intrinsic to the child, or within the child’s or parent’s control (Lancaster et al., 2014).

The parents designed home learning environments that incorporated therapeutic strategies. This was evident in their choice of toys and learning materials available in the home (e.g., special books, visual schedules) and the teaching methods incorporated into daily life. For example, one parent (Jasmine) was using a 10-point scale concept to help her child learn to recognise different degrees of their emotions. She then taught the child emotional regulation strategies such as breathing and meditation with the aim of helping him independently cope with intense emotional experiences. These parents adapted their home environment to suit the needs of a preschooler with an ASD and also altered the ways in which they interacted with their children, to the extent that some felt “more like a therapist than a parent” (Grace). Although supportive for the child with ASD, the changing nature of the parent-child relationship might be difficult for parents to uphold. Sometimes parents feel solely responsible for their child’s outcomes, and put pressure on themselves to make sacrifices and help their children achieve goals (Karp & Kuo, 2015). Therefore external support, either formal or informal, for parents needs to be considered as they undertake an intensive role in their child’s therapy.

A striking finding from Study 2 was that a number of parents perceived everything they did with their child to be a form of treatment or intervention. Play activities had a purpose, as did interactions and daily routines. For some parents, involving their child in an activity without an educational or developmental goal was rare. Findings from prior studies have indicated that parents take on multiple roles to support their children, put their own needs aside, and try to balance raising a child with an ASD with their other family commitments (Benson et al., 2008; Hoogsteen & Woodgate, 2013; Lutz et al., 2012; Myers et al., 2009; Safe et al., 2012). In these qualitative studies, parents explained that they took on the role of therapist when working with their child and dedicated many hours each day to helping their children manage having an ASD (Hoogsteen & Woodgate, 2013). In some cases, the intensive parent input was associated with feelings of fatigue and burnout (e.g., Hoogsteen & Woodgate, 2013; Myers et al., 2009). In the current study, a more balanced view was obtained, where parents described their burden of care, as well as the rewarding outcomes they gained through working closely with their children. It is possible that the
strategies and approaches used by the parents in the current sample could be exemplars for other parents (e.g., parents of newly diagnosed children, parents of children who do not yet know about ASDs, parents facing difficult circumstances).

Gallimore et al. (1999) suggested that focusing too heavily on family distress could undermine the competence of parents and families raising a child with a disability. These families are capable of establishing and sustaining effective daily routines, which was evident across most Study 2 participants. Having the knowledge and capacity to incorporate intervention strategies naturalistically within family life might have been protective of parental wellbeing and family functioning in this group. Parents might need support after their child’s diagnosis, and before they are expected to make treatment decisions and implement changes in the home (Wachtel & Carter, 2008). Three participants in Study 2 explained that they needed to process the diagnosis before they were able to launch into the learning and therapeutic support for their child. It is plausible that it would be more difficult for parents to facilitate a home learning environment without first having accepted their child’s diagnosis. However, this speculation requires further research attention. The retrospective insights from these three parents are of clinical significance.

Valentine (2010) developed a framework suggesting that parents tend to approach early intervention for their child with an ASD in one of two ways. Whereas some parents meet this situation with ambivalence and become overwhelmed, others become actively engaged in the process (Valentine, 2010). In the context of Valentine’s study, being actively engaged was about the role of parents as consumers of interventions. This concept also seems to apply to the facilitation of a home learning environment. The parents in the current study were, for the most part, reflective of Valentine’s description of “actively engaged” parents in that they dedicated time to self-directed learning about ASDs, invested in resources for their child, had a good knowledge and understanding of ASDs, and applied this in their daily lives.

Valentine (2010) identified another pattern of responding to a child’s diagnosis of an ASD, “choice as obligation”. These parents were described as being overwhelmed by making treatment choices, disempowered, and passive after receiving a diagnosis of an ASD for their child. This phenomenon was not clearly represented in the current findings, which is most likely due to the resilience shown by the participants. However, some parents (e.g., Ingrid, Linda, Cora, Charlotte) reflected on
times in the past where they became overwhelmed or found it “all a bit much” (Ingrid), particularly immediately after the diagnosis. Linda also raised her concern that when her child did not respond to her efforts she became “disheartened”, which might make it difficult to continue directing effort toward engaging a child with such a lack of response. It might have taken some time and adjustment before participants in Study 2 became actively engaged in learning about ASDs. Furthermore, even actively engaged parents are likely to require support and encouragement as they take on responsibility for implementing early intervention. Given that parents responded at a single time-point, it is unclear whether they were able to provide their child with educational support at previous time points, and whether this support would be ongoing. Parents’ approach and attitude to treatment might change over the course of their child’s development. Learning more about these patterns longitudinally would provide the information needed to determine the capacity of parents to remain actively engaged over time, and the best way for allied health professionals to facilitate this.

Theoretical Implications of the Current Findings

A critique of prior research investigating families of children with ASDs has been that it is largely atheoretical (Cridland et al., 2013; Tint & Weiss, 2015). The findings of the current study highlight the importance of conceptualising a child with an ASD in the context of their family system. Bioecological (Bronfenbrenner, 1986) and transactional (Hastings 2002; Sameroff, 1975, 2009) theories provided a useful framework to conceptualise the impact of child and parent factors on the family system. To explore these theoretical approaches to their full extent, longitudinal and bidirectional effects would need to be investigated, which was beyond the scope of this project. Nevertheless, both bioecological and transactional approaches give context to the dynamic processes that occur between individuals, and across ecological levels (e.g., individual functioning, family functioning) within families. These theories highlight the importance of the preschool years as a developmental stage. During these years, interactions between children and their family environments are most influential on development (Bronfenbrenner, 1986; Sameroff, 2009). Conceptualising the two studies according to these frameworks helped guide the exploration of the influence of the preschooler with an ASD on others in their environment, and to understand the ways in which parents shape their home environments to support a child with an ASD.
Hastings (2002) outlined relationships between behaviour problems, parent stress, and parenting practices, and suggested further research was needed to explore other salient factors affected by raising a child with a disability. The current findings suggested that there are additional parent and family wellbeing variables that are also important to consider in these families. This includes extending beyond individual-level characteristics, and looking at the way in which the family operates as a system. Additionally, parental depressive symptoms also warrant particular attention in families of children with ASDs. Similarly to stress, parental depressive symptoms are associated with child behaviour problems. In the case of depression there are implications for family functioning. As such, considering only stress oversimplifies these intra-familial processes (Osborne & Reed, 2010).

Transactions, or proximal processes, between children with ASDs and their families are apparent throughout the treatment literature. Parents make treatment choices based on their perceptions of what their child needs, meaning characteristics of the child influence which treatment they receive (Carlon et al., 2014). Ecological factors also affect the type and intensity of services available to parents (Maloney et al., 2012). From a transactional perspective, Sameroff and Fiese (2000) suggested that there are three potential avenues for intervention: remediation, redefinition, and re-education. The main components of interventions used for preschoolers with an ASD are focused on remediation, that is, teaching children new skills or abilities to improve their functioning (Prior & Roberts, 2012).

From a transactional approach, intervention aimed at redefinition (working on reframing parental interpretations) or re-education (intervening at the level of the parent-child relationship) would also have positive influences within a family system, which represents family-centered care (Sameroff & Fiese, 2000). Redefinition could also be an important intervention target, particularly when the parent is experiencing depression. Redefinition could involve helping parents reappraise some of the difficult behaviours and symptoms they are managing as well as their role as a parent. Furthermore, within Study 2, some parents explained that they felt unable to begin learning about ASDs and supporting their child until they had come to terms with the diagnosis. Redefinition might have assisted these parents with their acceptance of the diagnosis, which might then positively influence the family system and their ability to engage with their child. Indeed Jones and colleagues (Jones, Hastings, Totsika, Keane,
& Rhule, 2014) recently found that psychological acceptance mediated the relationships between children’s behaviour problems and parental wellbeing, suggesting these psychological processes are potentially protective for parents. Both bioecological and transactional theories view child-parent-familial interactions as being inextricable, influencing child development. Such interactions can be maintained or even exacerbated over time, highlighting the importance of developing positive and beneficial ways of relating in the family home.

**Limitations and Directions for Future Research**

The results of the current study need to be interpreted in the context of the methodological limitations. Issues relating to the nature of cross-sectional data, the sampling methods, and data collection procedures will be discussed in turn, incorporating considerations for future research.

Across both stages of this research, child, parent, and family functioning were examined at one time-point. The cross-sectional design did not allow family processes to be examined over time, which meant inferences about causality could not be made. Testing the models in Study 1 longitudinally would assist in establishing temporal precedence of children’s behaviour problems and would enable bidirectional pathways within families to be examined. A longitudinal design would also enable a more complete exploration of the transactional approach (Sameroff, 2009).

Most data used in the current study were generated using parental self-report measures. This introduced the possibility of reporter bias, where parents’ views of their parenting, children’s behaviour problems, and family functioning might have been influenced by other factors such as their wellbeing (Bennett, et al., 2012; Zablotsky et al., 2015). Parents’ views have been shown to differ to clinicians’ perceptions when looking at the severity of ASD, or the nature of the parent-child relationship (Bennett et al., 2012; Beurkens et al., 2013). In addition, perceptions of family functioning tend to be different depending on the informant (Georgiades et al., 2008). Therefore, it is important that the current findings are interpreted as parents’ subjective descriptions of their parenting and family environment.

When parents are asked to report on their wellbeing, family life, and parenting, they might be motivated to present themselves favourably. Social desirability is likely to have been more apparent in Study 2, where the researchers and participants interacted
directly, whereas the Study 1 participants remained anonymous. Additionally, parents might under-report some of the experiences associated with raising a child with an ASD. Indeed, findings from a study by Benson and colleagues (2009) showed that parents of children with ASDs did not recognise that they had incorporated educational opportunities into their daily routines, but rather viewed these as “just the way things are” (p. 61). Similarly, in the current study Toni and Emily implied that it took an outside perspective for them to realise the severity of their child’s behaviour problems. Toni stated, “his behaviour is kind of, it’s hard to describe because it’s so normal to us” and Emily recounted an experience where her mother had been taken aback by her child’s meltdown, helping her realise that this behaviour was extreme. Independent observations might overcome these potential biases, or help to reveal aspects of family life that are taken for granted by parents. However, for the current research, parents’ perspectives provided valuable information on family processes and were central to understanding their lived experiences. This was pragmatic and in line with the aims of the research.

Findings from Study 1 suggest that in addition to being related to wellbeing at the individual level, depressive symptoms might also limit the capacity of parents of preschoolers with ASDs to maintain a well-functioning family, and to implement positive parenting practices. Although children’s behaviour problems are one risk factor for parental depression, further research is needed to identify both risk and protective factors for depressive symptoms in this population. Elevated depressive symptoms soon after the diagnosis are a risk factor for ongoing depressive symptoms in the preschool years (Carter et al., 2009). There might be procedures, such as providing parents with counselling during and after the diagnostic assessment process, and providing strengths-based psychoeducation about ASDs, that could be protective of depression, which requires further investigation. Services that focus solely on the child with ASDs might overlook depression in parents (Wachtel & Carter, 2008). Depression might be exacerbated if too many demands are placed on parents when they are distressed and vulnerable.

A larger sample size was desired for both phases of this research program. Efforts were made to recruit a larger sample by extending the period of time used for data collection, advertising the study multiple times between 2011 and 2013, and contacting more than 250 groups, services, or organisations to help advertise the study.
For Study 1, the sample size was reasonable and acceptable for the first model tested, however, a larger sample size would make the findings more robust. Models 2 and 3 were affected by the limitations of a small sample size, due to the increased number of parameters involved in testing these models.

A larger sample size for Study 2 might have enabled more comprehensive statistical analyses to be conducted. For example, it remains unclear whether parents’ efforts to incorporate intervention into the home environment are associated with the children’s developmental abilities, parental wellbeing, or family functioning. Such information would have important clinical implications, and would be a beneficial direction for future research. For example, if home-based support is associated with substantial developmental gains in children, yet difficult to implement when parents and families are distressed, more targeted support might be offered by professionals. This could involve counselling to bolster parental wellbeing. Parents might be offered more guidance on the type and intensity of activities to incorporate into the home learning environment, and be assisted to balance this with family life.

In order to truly appreciate the impact raising a preschooler with an ASD has on families, and the support parents provide in the home, a more representative sample is needed. The demographic characteristics of the participants suggest that the experiences of some groups of parents were poorly represented across both phases of the study. Fathers, single parents, those who had not completed tertiary studies, and those with SEIFA scores below four suggesting socio-economic disadvantage, were not well represented in the current study, limiting confidence in the generalisation of the findings to a diverse range of parents and families. This is a commonly identified difficulty in parenting and family research. In the current study, the recruitment procedures and methodology might have introduced bias. Parents were more likely to be informed of the study if they used the internet to find information about ASDs and/or were connected to services. Parents feeling overwhelmed about receiving a diagnosis of an ASD or parents with less access to services such as those living in rural or remote areas might be systematically excluded from research (Maloney et al., 2012; Valentine, 2010).

For Study 2, the self-selected sample were parents who were managing unusually well in difficult circumstances. These families welcomed researchers in to their homes to discuss ASDs and parenting. Families having difficulties managing
raising a child with an ASD might have been disinclined to participate in Study 2, perhaps due to the demands on their time and energy. Furthermore, the behaviour problems shown by children with ASDs can be extreme, and parents often feel stigmatised and blamed for these problems (Neely-Barnes et al., 2011). This might have contributed to a reluctance to be observed with their children, and to discuss their family experiences.

Evidence from the current study suggests that parents having difficulties are more likely to participate in online surveys, and will not readily volunteer for home visits. This is unfortunate, as learning more about the experiences of parents facing adversity, and their capacity to support a child with an ASD is critical. In future research, targeted recruitment strategies are needed to ensure a more diverse sample is obtained. This might be achieved offering incentives such as financial compensation for the time involved in participating in research, or embedding research within a free or low-cost treatment program. Currently individuals from rural or remote areas, from lower socio-economic backgrounds, or those with Aboriginal or Torres Strait Islander backgrounds are benefitting the least from the HCWA package (Maloney et al., 2012). Parents having difficulties might be more willing to be involved in a time intensive study that offers them practical or material benefits in return.

Alternatively, Myers and colleagues (2009) recruited a large ($N = 493$) and diverse sample of participants who were parents of children with ASDs. They included open-ended questions within an online questionnaire, and participants responded with free-text. This methodology meant participants could participate at any time of day or night without needing an appointment, and they remained completely anonymous. However, the risk of conducting qualitative research online is that it removes some of the richness achieved by observing and conversing with parents within their homes. Salient ideas cannot be discussed and expanded on, and participants are not supported in telling their story. In the current study, the opportunity to enter homes and see different learning materials, watch parents respond to their children’s wants and needs, and also interact with their partner or sibling, allowed these impressions to become a part of the overall interpretations. Therefore, although an online survey approach might be accessible to a larger and more diverse sample, this is at the cost of reduced depth and insight into family life.
Procedures were implemented to recruit participants from Study 1 into Study 2, which would have generated data at two time points, enabling these participants to be considered as a sub-set of the Study 1 sample. However, this procedure was unsuccessful, recruiting just one family. This is likely to be due to the more intensive nature of the second phase of the study, which placed demands on parents’ time, and also involved the researchers entering family homes. As a result, the majority of participants in Study 2 formed a new and separate sample, and there was no opportunity for exploration of change over time. There were also areas of difference between the two samples, suggesting the online questionnaire might have been more accessible for those experiencing poor wellbeing or family difficulties. These factors highlight the heterogeneity among parents raising preschoolers with ASDs, as well as the ways in which different methodologies used might influence participation.

The convergent mixed-methods research design in Study 2 was highly time intensive. It was anticipated that the quantitative data would not only describe the sample, but also elucidate relationships between child and family factors, and the facilitation of a home learning environment. This was not achieved in the current study due to the small sample size, and might not be feasible in future research because it is difficult to recruit participants when the time demands are so high. Future studies wishing to employ a convergent mixed-methods design in this population might consider having a reduced scope, with fewer variables to measure. It might be also beneficial to complete in-depth interviews with participants and follow up with questionnaire measures at a later point or using an online questionnaire. An optimal balance might be to focus on the in-depth interviews while minimising the quantitative component given that the interview responses in the current study provided the greatest insights in to the experiences of these families.

Across both stages of the study, the child’s diagnosis of ASD was not independently verified. Parent report was used as evidence of a diagnosis, which has some empirical support as a valid method (Daniels et al., 2012). Daniels et al. (2012) reviewed medical records from families where parents had reported that their child was diagnosed with an ASD. For 98% of cases the diagnosis was clearly verified, and for the remaining participants, a developmental delay, or use of an individualised education plan, had been reported in the child’s medical history. These findings instil confidence in the validity of parent reported diagnosis. In Study 2, a diagnostic assessment report
from a psychologist, psychiatrist, or paediatrician, was the method used to verify diagnosis, and all families also reported receiving funding through the HCWA package, which is only available to families of diagnosed children. Thus, despite not conducting a diagnostic assessment as part of the procedure for Study 2, these measures support the validity of the diagnoses of an ASD for these children.

Closely matched control group data was not collected and the normative data used as a basis for comparison was gathered from diverse samples. The fatigue and warmth comparisons were drawn from Australian parents of preschoolers. However, comparisons of measures of stress and depression were compared with adults in the general Australia population, which does not necessarily take into account any symptoms that could be associated with parenting a preschooler regardless of having an ASD. The FAD (Epstein et al., 1983), Vineland-II (Sparrow et al., 2005), and PEP-3 (Schopler et al., 2005) norms were based on data from the United States, which might also introduce cultural differences. For example, for a different measure of child development, the Bayley Scales of Infant and Toddler Development (Third Edition; Bayley, 2005), Australian children were found to systematically score higher than the normative data from the United States (Chinta, Walker, Halliday, Loughran-Fowlds, & Badawi, 2014). The meaning and interpretation of scores on the PEP-3 (Schopler et al., 2005) and Vineland-II (Sparrow et al., 2005) might differ in Australian samples.

Given the modest amount of variance explained in family functioning, parental wellbeing, and parenting practices in the models proposed in Study 1, there are additional factors that are likely to be important in this group. Factors such as the quality of the couple relationship, social support, parenting self-efficacy, parental anxiety, acceptance of the diagnosis, and physical health are also likely to influence family functioning and elements of parenting, and warrant further investigation. From a bioecological perspective (Bronfenbrenner, 1986) the current study focused on the family microsystem. However, expanding this field by nesting this information amongst community level factors would be of theoretical and practical relevance. Being able to explain more of the variance in these parent and family factors would also help to target intervention.

Adding structure to the interview procedure used with the HOME Inventory (Bradley & Caldwell, 2003) was useful in that it guided questions toward finding out about a number of factors in the home learning environment. However, as a
quantitative measure, this inventory showed low internal consistency. There was limited variability in the patterns of HOME Inventory scores in this sample. The parents in this study achieved high scores or reached the ceiling on the HOME Inventory scales, suggesting this measure was not sensitive enough to establish differences in the facilitation of a home learning environment. This might have been due to the general, rather than specialised, learning materials and teaching methods incorporated in this measure. More detailed questions about how the environment is structured, the ways in which social and communication skills are taught, and whether efforts are made to generalise learning could be more appropriate for families of children with ASDs. Given the importance of this topic, and the possibility that the level of intervention provided to children in the home could contribute to treatment response heterogeneity, developing a measure of the home learning environment specific to this group would be a beneficial area of future study. The involvement subscale (Sanson et al., 2002) also had low internal consistency in this research. These findings indicate that measures traditionally designed for TD children might not give a good indication of home learning activities when there is a preschooler with an ASD.

A semi-structured interview was selected as the most effective way of gathering diverse information about the family environment. However, structuring the interview can limit participants’ opportunity to provide an open-ended narrative of their experiences, which might be gleaned using a broader line of enquiry. The nature of the interview procedure could have influenced the themes that were constructed from the data. By framing questions to highlight areas of difference, the participants could have been compelled to focus on particular aspects of the experience, meaning other significant ideas were not included. This investigation of a new area of study offered information about the home learning environment in these families. Based on this information, future studies could examine some of the salient ideas more broadly. For example, the idea that parents considered everything they did with their child to be a form of treatment or intervention, and parents’ adoption of the role of therapist within the families could be explored in more depth.

Steps were taken to counter some of the bias inherent in qualitative research, particularly the influence of the perspective of the primary researcher. By engaging other members of the research team (Creswell, 2013), some rigor was applied to the thematic analysis. However, it is not possible to remove one’s prior experience, values,
and entwinement from the topic to become a completely objective observer (Angen, 2000; Whittemore et al., 2001). It is therefore acknowledged that the researcher’s perspective is integrated into the current findings.

The findings showed that it is important for researchers to take contextual factors into consideration, particularly when evaluating intervention effectiveness. The accommodations families make to support a child with an ASD are a potential confounding factor in intervention studies, and also warrant consideration as an outcome variable (Bernheimer & Weisner, 2007). When a child with an ASD participates in an intervention study, they continue to be influenced by different home learning environments. It is important to tease out whether gains children make can be attributed to intervention strategies, the way the intervention influenced the family’s capacity to support this child, or some combination of these factors. These factors are not currently estimated or controlled for in studies evaluating treatment efficacy. A necessary first step in this process is identifying an effective measure of accommodations made within the family environment and the provision of a home learning environment. Findings from Study 2 regarding some of the strategies used by these resilient parents could help to inform questionnaire development.

The findings of Study 2 indicated that when there is a child with an ASD, facilitation of a home learning environment is specialised, and includes working with the child across multiple domains. In order to provide a home learning environment, many parents in Study 2 adopted the role of therapist, and incorporated intervention targets into activities across daily life. However, it remains unclear as to whether this process leads to developmental gains for children. It is known that when clinicians involve parents in early intervention programs, it can lead to higher time intensity of the treatment, more opportunities for skill generalisation, and improvements in children with ASDs (Strauss et al., 2013). Parents can be very effective therapy partners in more formalised intervention approaches (Strauss et al., 2013). Therefore, it is plausible that when parents can provide this naturalistic home-based teaching, it contributes to child development. Longitudinal research is necessary to find out more about the influence parents’ efforts have on their child’s development and the possible disadvantage when families are unable to provide this degree of extra support, and perhaps to offer parents more guidance in this process.
Implications for Clinical Practice

This study highlights the importance of understanding a child with an ASD in the context of their family system and home environment. Forward progression in the field of early intervention for children with ASDs would ideally involve interventions becoming better integrated within family life, and including direct support for parents and other family members. The current findings might assist in informing a paradigm shift toward working in partnership with families and building on their existing strengths in early intervention for ASDs. Such a partnership might be based on recognition of parents’ expertise regarding their children and the knowledge allied health professionals have to offer. By working together, parents and professionals might be better able to plan and implement programs and strategies that are sustainable for the family unit.

The current results highlight the need to support parents and families of preschoolers with ASDs in clinical practice. Findings from both phases suggest parents might benefit from practical assistance to alleviate symptoms of stress. It is well known that parents of children with ASDs are at risk for poor wellbeing, and for Study 1 participants, depression and fatigue were also prevalent, and predicted by behaviour problems. Sometimes researchers suggest the main clinical implication of this finding is that targeting behaviour problems in the child with ASD to alleviate parental distress (Estes et al., 2009; Herring et al., 2006). Yet behaviour problems can be severe, multifaceted, and persistent, suggesting change can be a slow process. Although family-centred care is a key principle for best practice in Australia (Prior & Roberts, 2012), family interventions often consist of parent-implemented strategies that target skill development for the child with an ASD (Johnston et al., 2013; Maloney et al., 2012; Prior et al., 2011). Working collaboratively with families, and acknowledging that parents might need direct intervention and support is advisable to improve the capacity for services to meet the needs of these families.

The findings from this research suggest that parent mental health difficulties are a common concern when there is a preschooler with an ASD. Furthermore, as shown in Study 2, questionnaire screening tools might indicate participants are managing well, yet asking parents about their experiences revealed a number of aspects of raising a child with an ASD that were contributing to worry, concern, or a sense of hopelessness. Based on these findings, more specific screening tools would be useful in clinical
practice, as well as asking questions about how parents are managing. It is clearly important to offer the space and invite parents to discuss their experiences to better understand the sometimes subtle as well as more overt impact on their wellbeing.

Although the findings from Study 2 were based on the experience of a small, self-selected sample, the findings revealed the enormous potential of these parents and families to show resilience, and create a specialised home learning environment for their children. Prior research has indicated that resolution of an ASD diagnosis might be an important step toward parents being able to engage in learning about ASDs and becoming actively involved in their child’s treatment (Wachtel & Carter, 2008). Some participants in Study 2 also explained that they needed to process and come to terms with the diagnosis before they could become more engaged in learning about ASDs. Clinicians working in this area might be able to assist parents through this process, so that they can become more available to actively engage in intervention for ASD. In some cases, providing support to parents might be a necessary first step in ASD intervention, because being burdened by mental health and family problems is likely to make it more difficult for parents to engage in strategies to effectively manage their child’s behaviour or work toward improving their skills (Valentine et al., 2010).

The findings from Study 2 highlighted the importance of clinicians and families working in partnership, so that systemic factors are considered in clinical practice. Bernheimer and Weisner (2007) recommended that clinicians ask families raising children with disabilities to describe their daily routines, from the moment they wake up, until they go to bed, to have a better chance of success in intervention. This clinical recommendation is also supported within the current study. Asking about daily routines would give clinicians insight into family life, the level of support being provided by the parents, and possible opportunities for refining or including additional opportunities for learning throughout the day. Placing additional demands on families, without first understanding their daily life, might be detrimental. When strategies are planned to fit within family routines, they might have a better chance of being maintained over time (Bernheimer & Weisner, 2007; Moes & Frea, 2002). Furthermore, when interventions are embedded well within family routines, parents might not even notice all that they are doing with their child, if it fits within family life more naturally (Benson et al., 2008).
Families might need support with some of the practicalities of raising a child with an ASD, such as adhering to routines and navigating a busy therapy schedule. Combining services in a single location is one way to assist parents with this task. Mullan and Higgins (2014) suggested typifying different family environments could help inform interventions for families who are not necessarily functioning as effectively. The findings from this research could be a source of information for parents of newly diagnosed children, parents having difficulty coming to terms with their child’s diagnosis, or those who are unsure about how to manage their children’s behaviour or support their early learning. Other avenues to support parents of preschoolers with ASDs could be related to providing families with opportunities for quality time, or to use Jasmine’s words, “downtime”. Offering parents in-home appointments could also be convenient and save families the time and hassle of travel. The missed opportunities to engage in shared family activities might be to the detriment of the child with an ASD and other family members.

Finally, the results from this study highlight the workload and the expertise of parents raising preschoolers with ASDs. Focussing solely on the child with ASD could potentially overlook the willingness and motivation of parents to work with their children. As indicated by the Study 2 participants, parents who are managing well can provide a very high intensity of home-based involvement and intervention. Overall, the findings suggested that for some children with ASDs, parents and families are doing all that they can to fill the gap between recommended interventions for children with ASDs, and what can feasibly be accessed based on current funding and intervention models.

**Conclusion**

The current study has generated further awareness of parent and family experiences during a critical period for intervention and development for someone with an ASD, and at a time when the family system is arguably most influential. As one of the first in-depth studies of the family environment for preschoolers with ASDs, the findings provide new insights in to home and family life within this population. The wellbeing and family difficulties experienced by some parents, and the resilience described by others, reinforces the critical importance of considering parent and family wellbeing in early intervention. Currently, family-centered care is recommended during
early intervention; however, this approach is not consistently implemented. The results highlight the need to assess and support parent and family wellbeing, rather than taking a purely child-focussed approach to ASD intervention. Improving parental wellbeing could potentially assist parents to feel better equipped to take on the extra demands of raising their child with ASD, and could improve family functioning.

The findings contribute evidence to inform policy development, clinical intervention initiatives, and the provision of services to specifically target parent and family functioning. The information generated from this research is likely to be most useful for clinicians and perhaps other families of children diagnosed with ASDs. Acknowledgement of the expertise of parents, their willingness to integrate intervention approaches in to home life, and the way ASDs are prioritised within families could be facilitative of respectful parent-professional partnerships. Furthermore others parents might find the experiences of the Study 2 participants encouraging, to instil optimism about the efficacy of parents, and the positive qualities of preschoolers with ASDs. Overall, the findings from the current research program suggest learning directly from parents can provide researchers and clinicians with guidance to help work collaboratively towards more positive outcomes for children with ASDs and their families.
References


Appendix A. Study 1 Measures

A.1 Demographic and Family Background Questionnaire

About Your Family

Please indicate YOUR age and gender:  Your age__  □ Male  □ Female

Please indicate your PARTNER’S age and gender:  Partner’s age__  □ Male  □ Female

Which of the following best describes your household?  □ Couple with dependent children
□ Single parent household with dependent children

What is the status of the parental relationship?  □ Married  □ Divorced
□ De facto  □ Widowed
□ Separated  □ Other

Who does your child live with?  □ Both Parents  □ Mother & Step-father
□ Legal Guardians  □ Father & Step-mother
□ Mother Only  □ Other
□ Father Only

In total, how many people live in your house, including yourself, partner, children, and any other adults or relatives? ___

Besides children and a partner (if applicable) how many other adults live in your house? ___

For children living at home please indicate:

<table>
<thead>
<tr>
<th>Child</th>
<th>Age in years (or months if &lt; 1)</th>
<th>Gender</th>
<th>Whether they have sleep, feeding, settling or behaviour problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td>__ Years or __ Months</td>
<td>□ Male □ Female</td>
<td>No/Yes</td>
</tr>
<tr>
<td>Child 2</td>
<td>__ Years or __ Months</td>
<td>□ Male □ Female</td>
<td>No/Yes</td>
</tr>
<tr>
<td>Child 3</td>
<td>__ Years or __ Months</td>
<td>□ Male □ Female</td>
<td>No/Yes</td>
</tr>
<tr>
<td>Child 4</td>
<td>__ Years or __ Months</td>
<td>□ Male □ Female</td>
<td>No/Yes</td>
</tr>
<tr>
<td>Child 5</td>
<td>__ Years or __ Months</td>
<td>□ Male □ Female</td>
<td>No/Yes</td>
</tr>
</tbody>
</table>

If more than five children are living at home, please indicate how many children you have in total ___

What is your country of birth? ______________

Are you of Aboriginal or Torres Strait Islander origin? □ No □ Yes

What is the main language spoken in your home? ______________
What is your postcode? _______

What is the highest level of education you or your partner has achieved?

You:
1. Little or no primary school
2. Completed primary school
3. Some high school
4. Completed high school
5. TAFE, Trade Certificate, Diploma
6. Tertiary (degree or postgraduate degree)

Your partner:
1. Little or no primary school
2. Completed primary school
3. Some high school
4. Completed high school
5. TAFE, Trade Certificate, Diploma
6. Tertiary (degree or postgraduate degree)

Please circle the number that best describes your response.

<table>
<thead>
<tr>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Your health

Your partner’s health

Your focus child’s health

Does anyone in your household have a chronic illness, disability, or ongoing medical condition? □ No □ Yes

If yes, who has the condition?

Please describe the condition ______________

What is your occupation/job title? ______________

Please circle whether your employment is full time, part time, or casual:

□ F/T    □ P/T    □ Casual

What is your partner’s occupation/job title? ______________

Please circle whether your partner’s employment is full time, part time, or casual:

□ F/T    □ P/T    □ Casual

If in paid employment, how many hours on average do you and your partner work each week? You ______  Your partner ______

What is your current annual income?

□ $0 - $30 000  □ $31 000 - $40 000  □ Over $60 000
□ $41 000 - $50 000

What is your partner’s current annual income?

□ $0 - $30 000  □ $31 000 - $40 000  □ Over $60 000
□ $41 000 - $50 000

Do you or your partner do night work or shift work?

<table>
<thead>
<tr>
<th>Never</th>
<th>Shift work with NO night shifts</th>
<th>Shift work with OCCASIONAL night shifts</th>
<th>Permanent night shift</th>
</tr>
</thead>
<tbody>
<tr>
<td>You</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Your partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
On average how many hours do you or your partner spend on housework per day (e.g., washing, preparing meals, cleaning)? You _______ Your partner _______

How closely does your family prefer to follow a regular routine e.g., activities such as bed time, dinner, bath time at the same time each night?

☐ Never  ☐ Occasionally  ☐ Sometimes  ☐ Mostly  ☐ Very closely

How would you rate the quality of your diet?

☐ Poor  ☐ Fair  ☐ Good  ☐ Very good  ☐ Excellent

How would you rate the level of your physical activity?

☐ Poor  ☐ Fair  ☐ Good  ☐ Very good  ☐ Excellent

**About Your Child**

Your child with an Autism Spectrum Disorder is the “focus child” for this survey. If you have more than one child in this age group with an Autism Spectrum Disorder, please select one as the “focus child”. You will need to keep this child in mind when answering the remaining questions.

Please indicate your “focus child’s” birth date and initial of first name __/__/____ __

**dd/mm/yy**  **initial**

*Please note: Providing this code will allow the researcher to match the information given today to your questionnaire data from an earlier phase of this study. If you do not wish for the researchers to access your earlier questionnaire responses, please do not provide the code in the space above.*

Please indicate the age of your focus child  ___ years ___ months

Please indicate the gender of your focus child  ☐ Male  ☐ Female

What is your relationship to your focus child?  ☐ Mother  ☐ Step-mother
☐ Father  ☐ Step-father
☐ Other (please describe)

What diagnosis did your child receive?  ☐ Asperger’s Syndrome
☐ High Functioning Autism
☐ Low Functioning Autism
☐ Pervasive Developmental Disorder – Not Otherwise Specified
☐ Other, please describe: __________________

Who made your child’s diagnosis?

☐ Paediatrician
☐ General Practitioner
☐ Psychologist
☐ Psychiatrist
☐ Other, please describe: __________________
When was your child’s diagnosis made? (please include month and year ___/___ mm/yy)

Please indicate the age of diagnosis of your “focus child” ____ years ____months

Do you have another child with an Autism Spectrum Disorder?

☐ No  ☐ Yes, 1 other  ☐ Yes, more than 1 other

Please list any treatments, interventions, services or therapy your focus child currently receives or has received in the past. This could include behavioural intervention, speech therapy, occupational therapy, psychology, special diets, medication, alternative therapies. A hypothetical example has been provided

<table>
<thead>
<tr>
<th>Type of treatment</th>
<th>Time frame of treatment</th>
<th>No. of hours in a typical week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech Pathology</td>
<td>June 2006 – January 2008</td>
<td>3</td>
</tr>
</tbody>
</table>

Does your “focus child” attend any of the following? (please circle) If yes, how many hours do they typically attend each week?

Childcare  Kinder  Primary School Grade:  ____  Other, please describe ___ hours  ___ hours  ___ hours  ___ hours

Do you access any Government funded/subsidised services? (e.g., FaHCSIA funded early intervention, PlayConnect play groups, Early Days family workshops, Autism Advisors; Medicare, Diagnosis and Treatment planning)

Please describe: ____________________________________________________________
This measure is unable to be reproduced online. Please consult print copy held in the Swinburne Library.
A.3 Measures of Parental Wellbeing

Depression Anxiety and Stress Scales (Lovibond & Lovibond, 1995)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

**Depression Subscale**

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I couldn’t seem to experience any positive feeling at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found it difficult to work up the initiative to do things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I had nothing to look forward to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt down-hearted and blue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was unable to become enthusiastic about anything</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt I wasn’t worth much as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that life was meaningless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Stress Subscale**

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found it hard to wind down</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I tended to over-react to situations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I was using a lot of nerous energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt myself getting agitated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found it difficult to relax</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I was rather touchy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Adapted Fatigue Assessment Scale (a-FAS; Giallo, Wade, & Keinhaus, 2014; Michielsen, De Vries, & Van Heck, 2003)**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Sometimes</th>
<th>Regularly</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am bothered by fatigue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I get tired very quickly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have enough energy for everyday life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Physically, I feel exhausted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Mentally, I feel exhausted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
A.4 Longitudinal Study of Australian Children Parenting Practices Measures
(Sanson et al., 2002)

**Warmth Scale**

Thinking about the last 6 months, how often did you:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never/Almost never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always/Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Show affection to your child by hugging, kissing and holding your child?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Hug or hold your child for no particular reason?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Tell your child how happy he/she makes you?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Have warm, close times together with your child?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Enjoy listening to this child and doing things with him/her?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Feel close to your child, both when he/she is happy and when he/she is upset?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

**Involvement Scale**

In the past week, on how many days have you personally done the following activities with your child?

<table>
<thead>
<tr>
<th>Activity</th>
<th>None</th>
<th>1 or 2 days</th>
<th>3 to 5 days</th>
<th>Everyday (6 - 7 days)</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read from a book?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Told a story, not from a book?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Played with toys/games indoors (e.g., board/card games)?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Involved them in everyday activities at home (e.g., cooking/caring for pets)?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Played a game outdoors / exercise together (e.g., walking, swimming)?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
**Hostility Scale**

Over the past 4 weeks how often have you…

<table>
<thead>
<tr>
<th></th>
<th>Never/Almost never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always/Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Been angry with this child?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Raised your voice or shouted at this child?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Felt that the child’s crying is getting on your nerves?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Lost your temper with this child?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
A.5 Family Assessment device – General Functioning Scale (FAD-GF; Epstein, Baldwin, & Bishop, 1983)

This measure is unable to be reproduced online. Please consult print copy held in the Swinburne Library.
Appendix B. Study 1 Ethics Clearance

To: Dr Catherine Wood FLSS Ms Rachel Jellett (BC)

Dear Dr Wood and Ms Jellett,

SUHREC Project 2010/058 An exploration of family environment factors in Autism Spectrum Disorders
Dr Catherine Wood FLSS Ms Rachel Jellett
Proposed duration: 08/04/10 To 30/12/13

Ethical review of the above project protocol was undertaken by Swinburne's Human Research Ethics Committee (SUHREC) at its Meeting 3/2010 held 23 April 2010, the outcome of which as follows.

This application was assessed in conjunction with SUHREC Project 2010/058. Please note that these applications could have been a single application as they are using the same set of data but for different projects. The project has been approved subject to the following being addressed to the Chair's (or delegate's) satisfaction:

1) Clarify if this study has a control group.

2) Appendix 2 Plain language statement: Needs to be simplified. Two projects listed yet the text refers to only one project. Consider simplifying the form and using a single title. A clearly written introductory paragraph needs to be included (cf text on flyer).

3) Recruitment flyer - Student email address using student number not recommended. (For Interim Procedure and Conditions for Use of Separate Staff Novell Accounts by Research Trainees for Approved Research Activity, see url: http://www.research.swinburne.edu.au/researchers/documents/ResTrnEmailProcedure.pdf)

4) Appendix 4: Some stylistic correction needed, eg, child vs children, 'couple with dependent child' should that read 'child or children'?

To enable further ethical review/finalise clearance, please would you respond to the above items point by point (by direct email reply if preferred). Re your responses:

- please DO NOT submit a full revised ethics clearance application unless specifically required
- queried missing, additional or revised text from the ethics application can be incorporated into your responses (within the body of the email if appropriate and to save
disk space)
- attach proposed or revised consent/publicity/other documentation in light of the above
(if available, converting these documents to pdf before submission will save on disk
space)

If accepted by the SUHREC delegate(s), your responses/attachments will be added to
previous documentation submitted for review, superseding or supplementing as
applicable the existing material/protocol on record. Please also note that human research
activity (including active participant recruitment) cannot commence before proper
ethics clearance is given in writing.

Please contact me if you have any queries about the ethical review process undertaken,
citing the SUHREC project number.

Yours sincerely

Ann Gaeth for
Keith Wilkins
Secretary, SUHREC

*******************************
Ann Gaeth, PhD
Administrative Officer (Research Ethics)
Swinburne Research (H68)
Swinburne University of Technology
P.O. Box 218
HAWTHORN VIC 3122
Tel: +61 3 9214 5935
Fax: +61 3 9214 5267
To: Dr Catherine Wood FLSS; Ms Rachel Jellett (BC)

Dear Dr Wood and Ms Jellett,

**SUHREC Project 2010/058 An exploration of family environment factors in Autism Spectrum Disorders**
Dr Catherine Wood FLSS Ms Rachel Jellett
Approved duration: 14/05/10 To 14/05/14 [Adjusted]

I refer to the ethical review of the above project protocol undertaken by Swinburne's Human Research Ethics Committee (SUHREC). Your responses to the review, as emailed on 12 May 2010 with attachments, were put to and approved by a SUHREC delegate.

I am pleased to advise that, as submitted to date, the project has approval to proceed in line with standard on-going ethics clearance conditions here outlined.

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the National Statement on Ethical Conduct in Human Research and with respect to secure data use, retention and disposal.

- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact me if you have any queries about the ethical review process, citing the SUHREC project number. Copies of clearance emails should be retained as part of project record-keeping.

Best wishes for the project.

Yours sincerely,
Ann Gaeth for
Keith Wilkins
Secretary, SUHREC

******************************
Ann Gaeth, PhD
Administrative Officer (Research Ethics)
Swinburne Research (H68)
Swinburne University of Technology
P.O. Box 218
Appendix C. Study 1 Advertising Flyer

Are you the parent of a young child (aged 2–5 years) with an Autism Spectrum Disorder?

If so, we invite you to participate in a research study about various aspects of parenting a child with an Autism Spectrum Disorder (parent stress, coping strategies, sleep, fatigue, parenting practices and the home environment). This research is being conducted by Rachel Jellett, a Doctor of Psychology student, and Monique Seymour who is completing her Psychology Honours degree at Swinburne University. The supervisor is Dr Katie Wood, a clinical psychologist at Swinburne. The Parenting Research Centre in East Melbourne is supporting this project. To participate, your child must have received a diagnosis of Autism, Asperger’s Disorder or Pervasive Developmental Disorder—not otherwise specified, from a professional.

To participate, all you need to do is complete one of our questionnaires which can be accessed:

- Online: http://opinio.online.swin.edu.au/s?s=8323
- By e-mailing the supervisor, Dr Katie Wood, on: CWood@groupwise.swin.edu.au to receive a paper version of the questionnaire or contacting her by phone on 9214 4627.
- By collecting a questionnaire from the support group or early intervention service you attend or the health professional you and your child see.

If you have any questions or concerns regarding the research please do not hesitate to contact Dr Katie Wood.

Thank you for your interest in this study.

Dr Katie Wood
Clinical Psychologist/Supervisor
Ph: 9214 4627
cwood@groupwise.swin.edu.au

Rachel Jellett
Doctor of Psychology Student
racheljellett@swin.edu.au

Monique Seymour
Honours Student
mseymour@groupwise.swin.edu.au
Appendix D. Study 1 Plain Language Statement

Full Project Title 1: An exploration of family environment factors in Autism Spectrum Disorders.

Researcher: Rachel Jellett, Doctor of Clinical Psychology Student.

Full Project Title 2: Stress, Coping and Fatigue in Mothers and Fathers of children with an Autism Spectrum Disorder.

Researcher: Monique Seymour, Honours Psychology Student

Supervisor of both projects: Dr. Katie Wood

This Participant Information Sheet is 2 pages long. Please make sure you have all the pages.

1. Purpose and Background

Parenting a child with an Autism Spectrum Disorder (ASD) can be stressful because of the extra demands it places on emotional, social and financial resources. Additionally, parents of children with an ASD often report feeling tired, or fatigued. Despite this, there is limited information about the impact of sleep disruption and fatigue in this group of parents, and how this relates to stress and coping for mothers and fathers. This information sheet relates to two projects being conducted at Swinburne University. Rachel Jellett is completing her Doctorate in Clinical Psychology, and her project will explore family functioning and different types of parenting practices. Monique Seymour is completing her Honours degree, and her project will explore the relationship between stress, coping and fatigue in mothers and fathers of children with an ASD, and how this compares to parents of typically developing children. Having a better understanding of these aspects of parenting will provide important information about how to best support families who have a child with an ASD.

The information you provide will be used for both projects. Some of the questions relate specifically to Monique’s project while others relate specifically to Rachel’s project. We invite you to join other parents of children aged between 2 and 5 years to participate in these projects. If you have two children with an ASD in this age bracket, please respond to the questions regarding one child only. You do not have to be the full time carer of your child to participate, but you must be spending regular time with him/her. The Parenting Research Centre (PRC) will be providing resources and support for these projects, including advertising and consultation.

2. Your Consent

You are invited to take part in this research project. Please read this information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Participation involves completing the attached questionnaire and if a paper version, returning it in the reply paid envelope to the researcher. It will take approximately 30-45 minutes to complete the survey. Participation is voluntary and your responses will remain anonymous. No individual can be identified through participation in the study. Completing and returning the anonymous survey implies consent for your involvement in both projects. If you are completing the survey online, then completion implies consent.
3. Possible Benefits and Risks
Some participants may benefit from reflecting on their parenting experience, family functioning, current levels of stress, fatigue, and the coping strategies in which they engage in. Also, it is expected that the information obtained from the survey will guide future interventions aimed at improving parenting well-being and increasing the use of effective parent coping strategies. Whilst not likely to be of direct benefit to all participants, this may benefit some participants who complete the survey and is likely to benefit many parents in future. At the completion of the study, a summary of the major findings will be prepared for participants and those agencies which assisted with the recruitment of families. If you would like a copy of this summary report, please email Dr Katie Wood on CWood@groupwise.swin.edu.au with your contact details, and she will send a copy at the completion of the projects.

There is an option at the end of this questionnaire for participants residing in Victoria (not interstate participants because the researcher is based in Victoria) to contact the research supervisor, Dr Katie Wood, to express interest in participating in a follow-up study related to Rachel's project. Participating in the follow-up study would involve completing additional questions, a home observation and an interview regarding activities you and your child with an ASD engage in together to promote learning. Returning the slip does not mean you are obligated to participate in the follow-up study, but indicates you would be willing to be contacted as a possible future participant. It is important to note that any personal information you provide us with relating to the follow-up study will be separate from your questionnaire response to ensure your anonymity.

We do not anticipate any risks to you if you consent to participate in this project. Some questions may be sensitive and if discomfort is experienced, participation may cease at anytime. Alternatively, if you feel any discomfort or distress, please call Swinburne Psychology Clinic on 9214 8653 (Victorian participants only) which is a low cost clinic or LifeLine on 13 1114 (Interstate and Victorian participants). Alternatively, you can contact the project supervisor, Dr Katie Wood on 9214 4627 who is an experienced clinical psychologist, and would be able to recommend assistance for you. Professionals who are not associated with the project can also provide this assistance. Importantly, you can withdraw from the project if distress occurs, or if you decide that you do not want to continue.

4. Privacy, Confidentiality and Disclosure of Information
As your name, date of birth, and contact details are not collected in the general survey, it is very unlikely that you will be identified from the information that you provide. However, any information obtained in connection with this project that can identify you will remain confidential and will be stored separate to your questionnaire responses. The results of this project will be written up as an Honours thesis for Monique. Rachel's results will form part of her doctoral thesis. The results might also be submitted for publication in an academic journal. If the results are published, there will be no information that will identify you in any way. Only results of groups of participants will be mentioned. All information will be analysed on a group basis and will be stored in a locked area by the researchers. The information will be entered into a secure database and will be stored for a period of five years, after which time it will be securely destroyed. It is possible that the information collected in this study will be used in future research projects for comparison with other groups. Specifically, the PRC will have access to non-identifiable information, which they might use in future publications or reports.
5. Other Issues
Any questions regarding this project can be directed to the Senior Investigator, Dr. Katie Wood of the Faculty of Life and Social Sciences on telephone 9214 4627 or via email CWood@groupwise.swin.edu.au.

6. Participation is Voluntary
Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. Complete and return the survey only after you are certain that you would like to participate. You may have been invited to participate in this survey while attending a community centre or health centre. Please note that whether you choose to complete the survey will not influence the level of services available to you at centres promoting participation in this research project.

7. Ethical Guidelines
This project will be carried out according to the National Statement on Ethical Conduct in Research involving Humans (1999). The Research Ethics Committee of the Faculty of Life and Social Sciences at Swinburne University has given ethics approval for this project.

8. Reimbursement for your costs
You will not be paid for your participation in this project.

This study has been approved by the Human Research Ethics Committee, Swinburne University of Technology. If you have any queries regarding this study, please contact: Dr Katie Wood on 9214 4627 or CWood@groupwise.swin.edu.au.

If you have any queries or concerns about the conduct of the research project, please contact:

Research Ethics Officer
Office of Research and Graduate Studies (H68)
Swinburne University of Technology,
PO Box 218
Hawthorn, Vic 3122

❖ Please retain this page for your own records
Appendix E. Study 2 Measures
The Family Assessment Device

This measure is unable to be reproduced online. Please consult print copy held in the Swinburne Library.
Appendix F. HOME Inventory Interview Guide

This measure is unable to be reproduced online. Please consult print copy held in the Swinburne Library.
Appendix G. Study 2 Ethics Clearance

Wednesday December 22, 2010 5:14PM
From: Ann Gaeth
To: Jellett, Rachel; Wood, Catherine
CC: Resethics; Watson, Robyn
Subject: SUHREC Project 2010/296 Ethical Review

Dear Catherine and Rachel,

**SUHREC Project 2010/296 Autism spectrum disorders and the family environment**  
**Dr Catherine Wood FLSS Ms Rachel Jellett**  
**Proposed duration from 01/12/2010 To 31/12/2013**

Ethical review of the above project protocol was undertaken by Swinburne's Human Research Ethics Committee (SUHREC) at its Meeting 09/2010 held 10 December 2010, the outcome of which as follows.

The project has been approved subject to the following being addressed to the Chair’s or delegate(s) satisfaction:

1) A5: insufficient to say "no risk to the researcher is anticipated" given visit to private locations; some explanation needed as to safety precautions, eg, pre- and post- visit student-supervisor contact.
2) D2(b): specify the location of the data storage and clarify the retention of data following publications.
3) Appendix B PLS: Section 5 contradictory statements regarding length of data storage to be clarified, ie, is it to be destroyed after five yrs or to be used in future projects? clarify in what form the data will be used in future projects; National Statement and ORGS info to be updated.
4) Appendix C Consent Form: Part 2 point 5 consider splitting into two points with some revised text.

To enable further ethical review/finalise clearance, please would you respond to the above item by direct email reply. Re your responses:

- please DO NOT submit a full revised ethics clearance application unless specifically required
- queried missing, additional or revised text from the ethics application can be incorporated into your responses (within the body of the email if appropriate and to save disk space)
- attach proposed or revised consent/publicity/other documentation in light of the above (if available, converting these documents to pdf before submission will save on disk space)

If accepted by the SUHREC delegate(s), your responses/attachments will be added to previous documentation submitted for review, superseding or supplementing as
applicable the existing material/protocol on record. Please also note that human research activity (including active participant recruitment) cannot commence before proper ethics clearance is given in writing.

Please contact me if you have any queries about the ethical review process undertaken, citing the SUHREC project number.

Yours sincerely

Ann Gaeth for
Keith Wilkins
Secretary, SUHREC

Ann Gaeth, PhD
Administrative Officer (Research Ethics)
Swinburne Research (H68)
Swinburne University of Technology
P.O. Box 218
HAWTHORN VIC 3122
Tel: +61 3 9214 5935
Fax: +61 3 9214 5267

2nd February 2011

To: Dr Catherine Wood FLSS Ms Rachel Jellett
CC: Ms Robyn Watson, Research Administration Coordinator FLSS

Dear Catherine and Rachel,

SUHREC Project 2010/296 Autism spectrum disorders and the family environment
Dr Catherine Wood FLSS Ms Rachel Jellett
Approved duration from 2/02/2011 To 2/02/2014 [Adjusted]

I refer to the ethical review of the above project protocol undertaken by Swinburne's Human Research Ethics Committee (SUHREC). Your response to the review, as e-mailed on 1 February 2011, was put to and approved by a SUHREC delegate.

I am pleased to advise that, as submitted to date, the project has approval to proceed in line with standard on-going ethics clearance conditions here outlined.

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the National Statement on Ethical Conduct in Human Research and with respect to secure data use, retention and disposal.
- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact me if you have any queries about the ethical review process, citing the SUHREC project number. Copies of clearance emails should be retained as part of project record-keeping.

Best wishes for the project.

Yours sincerely

Ann Gaeth
for Keith Wilkins
Secretary, SUHREC

Ann Gaeth, PhD
Administrative Officer (Research Ethics)
Swinburne Research (H68)
Swinburne University of Technology
P.O. Box 218
HAWTHORN VIC 3122
Tel: +61 3 9214 5935
Fax: +61 3 9214 5267
Appendix H. Study 2 Advertising Flyer

Are you the parent of a young child with an Autism Spectrum Disorder?

If so, we invite you to participate in a research study about various aspects of parenting a child with an Autism Spectrum Disorder (e.g., the home environment, parenting practices, and family functioning). This research is being conducted by Rachel Jellett, a Doctor of Psychology Student, and Lauren Rawlings who is completing her Postgraduate Diploma in Psychology at Swinburne University. The supervisor is Dr Katie Wood, a clinical psychologist at Swinburne. The Parenting Research Centre in Melbourne is supporting this project.

To participate, your child must have received a diagnosis of Autism, Asperger’s Disorder or Pervasive Developmental Disorder-not otherwise specified, from a professional and is younger than school aged.

Participation involves a home visit where you will be interviewed and observed by the researcher, and you will also complete some questionnaires.

If you are interested in participating, or would like more information please let us know:

- By emailing the researcher on rjellett@groupwise.swin.edu.au
- By e-mailing the supervisor, Dr Katie Wood, on CWood@groupwise.swin.edu.au or contacting her by phone on 9214 4627.

If you have any questions or concerns regarding the research please do not hesitate to contact us.

Thank you for your interest in this study.

Dr Katie Wood  
Clinical Psychologist/Supervisor

Rachel Jellett  
Doctor of Psychology Student

Lauren Rawlings  
Postgraduate Diploma in Psychology Student
Appendix I. Study 2 Plain Language Statement

Autism Spectrum Disorders and the Family Environment
Researcher: Rachel Jellett, Doctor of Clinical Psychology Student.
Assistant: Angelika Radeka

Supervisor of both projects: Dr. Katie Wood

This Participant Information Sheet is 3 pages long. Please make sure you have all the pages.

1. Purpose and Background
The family environment refers to various factors that are important in a child's development, including the physical home environment as well as parenting practices and characteristics of the family. This includes the way educational activities are used in the home and the way parents and their children interact. The family environment is particularly important for young children who are not attending school yet, because this is where they spend most of their time. Many parents find that having a child with an Autism Spectrum Disorder (ASD) necessitates making changes to how they parent, and features of the home environment such as providing special toys, or trying to help manage their child's behaviour. Parents can also feel that there are extra demands placed on them due to their child's individual needs. Some families may receive early intervention or other services to assist their child with an ASD. There are also many informal things that families do to support their child's development that might relate to play, learning and socialisation. In this project, we want to develop a comprehensive picture of the family environment in families where there is a child with an ASD. This will include physical resources like toys and books, parenting knowledge and practices, and other parent, child, and family factors that might influence this environment. We are also interested in whether these family environment factors are related to children's developmental progress. This would involve administering a questionnaire to you and a series of play-based activities to your child to better understand his/her language and motor skills, as well as their behaviour. We anticipate that the information we obtain will help researchers and practitioners gain an understanding of the range of support parents provide their children with an ASD, and factors that are associated with this. By finding out about the kinds of intervention strategies that parents have incorporated into their daily life, we may be able to help encourage, support and promote these for other families.

A second aim of this project is to investigate the relationship between parental fatigue, parenting practices and child behaviour. Parenting a child with an ASD is a uniquely challenging experience. With parents often reporting feeling very tired, or fatigued. However, there is little information regarding the effects of fatigue on parenting practices and child behaviour. Having a better understanding of these aspects of parenting will provide important information about how best to support families who have a young child with an ASD.

We invite you to join other parents of young children with ASDs to participate in this project. To participate you need to be the parent(s)/primary caregiver(s) of the child. Your child with an ASD must not be attending school yet. The Parenting Research Centre
(PRC) will be providing resources and support for this project, including advertising the project and providing consultation.

2. Your Consent
You are invited to take part in this research project. Please read this information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Participation in this project involves the primary researcher and a research assistant visiting your home at a time convenient to you, when your child is at home and awake. During the home visit you will participate in an interview for approximately 1 hour. The interview will involve a discussion about your family, parenting and the home environment. The researchers will also observe interactions between you and your child. The researchers will present your child with a series of play based activities designed to assess language, motor skills and adaptive behaviour. These activities also take approximately 1 hour. The visit is expected to take approximately 2.5 hours in total. You will also be requested to complete pen-and-paper questionnaires. During the interview and when completing questionnaires, you may choose not to answer questions, or decide to withdraw from the study at any point. It is not expected that the questions will be distressing to you. The interview will be recorded by electronic device. Prior to the home visit, the researchers will request a copy of, or to view assessment reports relevant to your child’s diagnosis, learning, speech/language and/or medical/developmental history. If you are comfortable with this, we will ask you to sign a consent form about the release of this information. Your choice to not provide this information will in no way impact on your eligibility for involvement in the study.

3. Possible Benefits
Some participants may benefit from, and enjoy reflecting on their parenting experience and the activities they engage in with their child and family. Also, it is expected that the information obtained from the survey will guide future interventions aimed at supporting parents in their endeavors to provide for their child with an ASD. Whilst this may not be of direct benefit to all participants, this may benefit some participants who complete the interview and is likely to benefit many parents in future. At the completion of the study, a summary of the major findings will be prepared for participants. If you would like a copy of this summary report, please email Dr Katie Wood on CWood@groupwise.swin.edu.au with your contact details, and she will send a copy at the completion of the projects. We can also provide a summary report regarding your child’s results from the Psychoeducational Profile and Vineland Adaptive Behavior Scale results should this be requested.

4. Possible Risks
We do not anticipate any risks to you if you consent to participate in this project. Some questions may be sensitive and if discomfort is experienced, participation may cease at anytime. Alternatively, if you feel any discomfort or distress, please call Swinburne Psychology Clinic on 9214 8653 (Victorian participants only) which is a low cost clinic or LifeLine on 13 1114 (Interstate and Victorian participants).

Alternatively, you can contact the project supervisor, Dr Katie Wood on 9214 4627 who is an experienced clinical psychologist, and would be able to recommend assistance for you. Professionals who are not associated with the project can also provide this assistance. Importantly, you can withdraw from the project if distress occurs, or if you decide that you do not want to continue.
5. Privacy, Confidentiality and Disclosure of Information
The data collected for this project will remain confidential. The results of this project may
be submitted for publication in an academic journal or presented at national/international
conferences. If the results are published, there will be no information that will identify you
in any way. If direct quotes are used they will be unable to be identified through use of a
pseudonym (i.e., fake name).

All information, including electronic recordings, will be stored in a locked area or on a
password protected computer by the researchers. Electronic recordings will be destroyed
once they have been transcribed. Any identifying information such as that in reports
provided to the researcher will be stored separately to the de-identified information. The
information will be entered into a secure database, which will not include yours or your
child’s name. Any reports provided to the researchers as well as questionnaire data will be
stored securely for a period of five years after completion of the study; after which time
they will be securely destroyed. It is possible that the non-identified electronic data file
might be used in future research projects conducted by the Parenting Research Centre
and/or Swinburne University. Such projects would also relate to parenting and Autism
Spectrum Disorders. The Parenting Research Centre might also use the non-identified
information in future publications, reports and/or conference presentations.

6. Other Issues
Any questions regarding this project can be directed to the Senior Investigator, Dr. Katie
Wood of the Faculty of Life and Social Sciences on telephone 9214 4627 or via email
CWood@groupwise.swin.edu.au.

7. Participation is Voluntary
Participation in any research project is voluntary. If you do not wish to take part you are
not obliged to. You may have been invited to participate in this survey while attending a
community center or health center. Please note that whether you choose to complete the
survey will not influence the level of services available to you at centers promoting
participation in this research project.

8. Ethical Guidelines
This project will be carried out according to the National Statement on Ethical Conduct in
Human Research (2007). The Research Ethics Committee of the Faculty of Life and Social
Sciences at Swinburne University has given ethics approval for this project.

9. Reimbursement for your costs
You will not be paid for your participation in this project.

This study has been approved by the Human Research Ethics Committee, Swinburne
University of Technology. If you have any queries regarding this study, please contact: Dr
Katie Wood on 9214 4627 or CWood@groupwise.swin.edu.au.

If you have any queries or concerns about the conduct of the research project, please contact:
Research Ethics Officer
Office of Research and Graduate Studies (H68)
Swinburne University of Technology,
PO Box 218
Hawthorn, Vic 3122

Please retain this page for your own records
Appendix J. Study 2 Consent Forms

Swinburne University of Technology
Autism Spectrum Disorders and the Family Environment
Principal Investigator: Rachel Jellett
Supervisor: Dr Katie Wood

1. I consent to participate in the project named above. I have been provided a copy of the project participant information sheet to which this consent form relates and any questions I have asked have been answered to my satisfaction.

2. In relation to this project, please circle your response to the following:
   - I agree to be interviewed and observed by the researcher and research assistant
   - Yes ☐ No ☐
   - I agree to allow the interview to be recorded by electronic device
   - Yes ☐ No ☐
   - I agree to make myself available for further information if required
   - Yes ☐ No ☐
   - I agree to complete questionnaires asking me about my family, parenting, knowledge of Autism Spectrum Disorders, stress, fatigue, and my child’s behaviour.
   - Yes ☐ No ☐

3. Please select an option from the following by ticking (✓) one box:
   - I agree to provide the researcher with a copy of previous assessment reports regarding my child’s diagnosis, cognitive/academic ability, speech/language skills and/or medical/developmental history.
     This information will be kept confidentially & separate to the questionnaire/interview information that you provide. Any copies of reports will be stored securely for a period of five years after completion of the study; then securely destroyed.
     ☐
   - I agree to allow the researcher to view previous assessment reports regarding my child’s diagnosis, cognitive/academic ability, speech/language skills and/or medical/developmental history.
     ☐
   - I do not wish to provide the researcher with copies or allow the researcher to view assessment reports regarding my child.
     ☐

4. I acknowledge that:
   (a) My participation is voluntary, and that I am free to withdraw from the project at any time without explanation;
   (b) The Swinburne project is for the purpose of research and not for profit;
   (c) Any identifiable information about me which is gathered in the course of, and as the result of, my participation in this project will be (i) collected and retained for the purpose of this project and (ii) accessed and analysed by the researcher(s) for the purpose of conducting this project;
   (d) My anonymity is preserved and I will not be identified in publications or otherwise without my express written consent.

By signing this document I agree to participate in this project.

Name of Participant: ……………………………………………………………………………

Signature & Date: ……………………………………………………………
Swinburne University of Technology

Autism Spectrum Disorders and the Family Environment

Principal Investigator: Rachel Jellett

Supervisor: Dr Katie Wood

Consent Form for Child to Participate in Research Project

1. I/We consent to my/our child/dependent here named to participate in the project named above. I have been provided a copy of the project consent information statement to which this consent form relates and any questions I have asked have been answered to my satisfaction.

   Name of Child/Dependent: ………………………………………………………

2. In relation to this project, please circle your response to the following:

   - I/We agree that my/our child/dependent can be observed by the researcher and a research assistant  Yes  No
   - I/We agree that the interview to be recorded by electronic device  Yes  No
   - I/We agree to make myself /ourselves available for further information if required  Yes  No
   - I/We agree that our child/dependent can interact with the researcher and research assistant  Yes  No
   - I/We agree that my/our child can be administered the Psychoeducational Profile by the researchers to measure his/her language, motor skills and behaviour.  Yes  No

3. I/We acknowledge that:

   (a) My/our child’s/dependent’s participation is voluntary and that s/he is free to withdraw from the project at any time without explanation;
   (b) The Swinburne project is for the purpose of research and not for profit;
   (c) Any identifiable information gathered in the course of and as the result of my/our child/dependent participating in this project will be (i) collected and retained for the purpose of this project and (ii) accessed and analysed by the researcher(s) for the purpose of conducting this project;
   (d) My/our child’s/dependent’s anonymity is preserved and s/he will not be identified in publications or otherwise without my express written consent.

By signing this document I/We agree to your child’s/dependent’s participation in this project.

Name of Parent(s)/Guardian: ………………………………………………………

Signature & Date: ………………………………………………………